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# Social Prescribing for Autistic Adults

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**UNIVERSITY OF  
PLYMOUTH**

**SOCIAL PRESCRIBING FOR AUTISTIC ADULTS**

by

**CHARLOTTE FEATHERSTONE**

A thesis submitted to the University of Plymouth  
in partial fulfilment for the degree of

**DOCTOR OF PHILOSOPHY**

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## **Dedication**

To Vanessa, loving aunt (1964-2022)

## Author's Declaration

At no time during the registration for the degree of Doctor of Philosophy has the author been registered for any other University award without prior agreement of the Doctoral College Quality Sub-Committee.

This thesis has been proofread by a third party; no factual changes or additions or amendments to the argument were made as a result of this process. A copy of the thesis prior to proofreading will be made available to the examiners upon request.

Work submitted for this research degree at the University of Plymouth has not formed part of any other degree either at the University of Plymouth or at another establishment.

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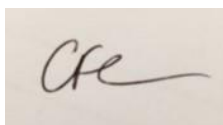
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# **Social Prescribing for Autistic Adults – CHARLOTTE FEATHERSTONE**

## **Abstract**

### **Background**

Autistic adults are affected by health and social disparities that impact life expectancy and quality of life, frequently resulting in escalating wellbeing concerns requiring costly acute care. Evidence suggests barriers to healthcare and a lack of post-diagnostic support may contribute to these inequalities. Social prescribing, a low-intensity personalised care model receiving increasing attention from policymakers and commissioners, offers opportunities to address isolation, build skills and promote health through collaborations between services and communities. However, social prescribing research and provision has overlooked wellbeing and access needs of autistic adults. This PhD project aimed to investigate factors affecting accessibility of social prescribing pathways, which can comprise a variety of models and mechanisms, and their suitability for autistic adults from initial referral through to prescribed activities.

### **Methods**

The research delivered a systematic mapping review and mixed-methods study. The review synthesised previous reviews of literature on outcomes, settings and service pathways within community-based services for autistic adults. An online survey of 128 autistic adults explored barriers to primary healthcare, the point of access to social prescribing, across changing contexts using regression analysis. Semi-structured interviews with 23 autistic participants investigated perspectives on wellbeing, attitudes towards social prescribing as a response to wellbeing barriers, and provision of wider support in the community. Qualitative data were

analysed using reflexive thematic analysis, incorporating critical realism and the candidacy framework, to examine individual, relational and systemic factors.

## **Results**

Findings suggest that access to social prescribing for autistic adults via referral from health and social care services involves patient and provider evaluations, socioeconomic factors and wider contexts. Self-determination was found to link themes relating to meanings of wellbeing for autistic adults. Social prescribing may promote self-determination through its tailored approach. However, pathways require adaptations to maximise engagement, including offering alternative referral routes, novel prescriptions and additional support at key transition points. Providers should work with the autistic community to improve access and acceptability, and bring mutual benefits for individuals and services.

## **Conclusions**

Service commissioners and policymakers should consider supporting a social prescribing pathway embedded in autism diagnostic services or upskilling existing social prescribing pathways to adapt their practice for autistic adults. The research also adds to understandings of peer support and self-determination as important mechanisms in wellbeing for autistic adults.

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# Chapter 1

## Introduction

This research aimed to investigate the potential for social prescribing to respond to unmet wellbeing needs of autistic adults, a group which has received little prior attention in this area despite facing substantial health and social disparities. This chapter will present the background to this research by bringing together relevant literature and policy priorities, to demonstrate the rationale for this study. It will illustrate how preliminary evidence suggests that the social prescribing model could be viewed an acceptable approach by autistic adults and may have the potential to improve wellbeing outcomes. Social prescribing is also a relevant response to policy priorities for increasing provision of services in communities for autistic adults. However, autistic adults experience barriers to the primary care pathway and other health and community spaces, which could affect access to social prescribing. There has also been little investigation of acceptability and outcomes in relation to the entirety of the social prescribing pathway for this population.

### **Background to the Research**

#### *What Is Social Prescribing?*

Social prescribing (SP) is a pathway often based in primary care, which aims to connect patients to non-medical interventions and activities within communities to enhance wellbeing (Polley, Fleming, et al., 2017). Activities provided as part of SP pathways can include exercise referrals, health behaviour interventions, outdoor activity, social groups and clubs, arts therapies, signposting and advice services, counselling, volunteering and peer support (Bickerdike et al., 2017; Chatterjee et al., 2018). These activities are usually led by voluntary, community and social enterprise (VCSE) sector (Davison et al., 2019), thus SP is an “adjunct to primary care services” (Chatterjee et al., 2018, p. 97) involving collaboration between the two sectors. SP is included within the National

Health Service's (NHS) Long Term Plan for improving access to personalised and joined-up care models (National Health Service, 2019).

General practitioners (GPs) working in UK primary care services frequently identify social issues underlying patients' presenting problems and are positive towards making referrals to non-medical services to address these (Popay et al., 2007). SP is therefore targeted most at patients who present with conditions and socioeconomic situations impacting on their wellbeing that are not easily treatable using traditional medical approaches such as prescribing a single intervention, either due to their complexity or ineffectiveness of treatment. These include chronic pain, weight concerns, diabetes, mild to moderate mental health problems, housing issues, dementia and social isolation (Chatterjee et al., 2018; Davison et al., 2019; Pescheny et al., 2018a; Popay et al., 2007).

SP is described as a complex health intervention, because it includes a variety of aims, stakeholders and potential outcomes (Tierney et al., 2020). Unlike traditional medical systems which approach health problems in isolation, a SP referral has the potential to impact many areas of wellbeing (Parkinson et al., 2015). The range of options available to the patient is paramount for SP to fulfil its goal of person-centredness (Polley, Fleming, et al., 2017). The level of personalisation promotes an 'expert patient' approach which combines the patient's expertise on their own condition, with the combined expertise of the health service and third sector (Ogden, 2018). Collaborative approaches are foundational to personalised models of care as they facilitate the exchange of knowledge, provide a shared sense of purpose and improve continuity of services (Lloyd et al., 2017). The more holistic nature of the SP pathway may also lead to a more 'joined-up' approach for patients, with the ability to respond to multiple needs through one referral (Hassan et al., 2020).

The UK has driven a high proportion of clinical and research attention to SP, where in some areas SP has operated as a longstanding model (Morse et al., 2022); this has increased in recent years in line with shifts in policy and practice increasingly recognising the role of co-occurring conditions, the need to manage chronic illness as a feature of an ageing population, and the influence of social

determinants of health as priorities for health service targeting (Brandling & House, 2009; Chatterjee et al., 2018; Ogden, 2018). Attention to SP is also growing internationally, adding to evidence about its application in other socio-political contexts and helping to develop guidelines for its contribution to reducing social determinants of health globally (Morse et al., 2022).

While SP has existed under some UK primary care services previously under a variety of names and models, in other commissioning groups, it may be a more novel concept. A top-down implementation model has recently been incorporated into the NHS Long Term Plan and commissioning for these services is increasing, with the aim to enable an additional 2.5 million people to access SP over five years through adopting a more standardised approach (Dayson, 2017; National Health Service, 2019). The stated rationale for this decision includes cost-saving through a focus on preventative care, better integration of support systems and improving self-management of health (National Health Service, 2019). As well as commissioning, funding for SP can be drawn from personal budgets of patients under Adult Social Care (Chatterjee et al., 2018).

Social prescribing can take myriad forms. At one level, it can comprise a signposting service where GPs are able to recommend services in communities to patients who present with certain issues. Under this model, it is the patients' responsibility to self-refer and seek out the services which are offered, or in some cases GPs are able to refer patients directly to a community-based service or activity (Kimberlee, 2015). In line with its shift towards person-centred care, the NHS Long Term Plan focuses on the link worker model (National Health Service, 2019; NHS England, 2023a; NHS England, 2023b). This involves a referral to a practitioner (the link worker) who will work with a client to establish an understanding of their problems and needs, as well as their strengths and interests, and refer the client onto activities that meet these needs (National Health Service, 2019).

Link worker consultations typically last longer than standard GP consultations, which are usually limited to a short time due to caseload demands (Kilgarriff-Foster & O'Cathain, 2015). Patients may also be able to access follow-up appointments with the link worker (Kilgarriff-Foster & O'Cathain,

2015), representing a substantial investment of time into establishing a rapport and understanding the client. This model is usually provided in a primary care setting such as GP surgery, but can also be delivered in secondary care and other settings. Referrals to the link worker are typically made by a GP but sometimes by other professionals such as practice nurses, social workers or reception staff (Sandhu et al., 2022; C. White et al., 2022).

A link worker may have a clinical, social work or non-medical background and skills required include strong communication and interpersonal skills (Sandhu et al., 2022; Wildman et al., 2019). Link workers are expected to have good knowledge of local services to which they can refer clients developed by building relationships and links with the VCSE sector and statutory services (NHS England, 2023b). They may be employed by the NHS, the third sector, or be self-employed, and can work in a variety of settings, but are often based in the primary care general practice setting (Polley, Fleming, et al., 2017). Link worker roles can vary from referral only, to involvement in setting up and directing an SP programme (Polley, Fleming, et al., 2017).

The most holistic models of SP use external community hubs covering a broad area, which provide a range of internal services or signposting based on a fully coproduced ‘prescription’, with flexibility around methods of referral and engagement for clients (Dayson, 2017; Kimberlee, 2015). These require long-term investment in community assets through strategic collaboration with the VCSE sector to ensure the range of offers remains sustainable, adaptable and relevant to the needs of the community as well as providers (Dayson, 2017).

**What Is The Evidence For Social Prescribing?** There is a growing evidence base for the effectiveness of SP in improving health outcomes; however, research has been criticised for heterogeneous designs of studies and intervention programmes, lack of randomised controlled trials, failure to follow up on outcomes, and omissions of important details of study reporting such as recruitment strategies and intervention characteristics (Bickerdike et al., 2017; Costa et al., 2021). The novelty and complexity of SP also makes it more difficult to make comparisons with other

models of healthcare, as SP operates as a system of components rooted in different contexts (Husk, Elston et al., 2019). It involves multiple stakeholders and aims to achieve outcomes defined by individual patients presenting with a range of issues, in line with its person-centred approach, rather than targeting a single common outcome (Husk, Elston, et al., 2019; Tierney et al., 2020). Even when the same model is used, such as the link worker referral pathway, other features of SP remain heterogeneous, as synthesised in a scoping review of link worker programmes by Sandhu et al. (2022). There has also been a lack of guidance on how best to assess quality of SP (Husk, Elston, et al., 2019). On one hand, some theorists suggest it is premature to have included social prescribing in recent NHS policy due to the lack of evidence meeting established standards (Bickerdike et al., 2017). Others suggest alternative evaluation approaches are needed using methods that diverge from linear standards of efficacy measurement more suited to biomedical approaches (Polley et al., 2020).

Studies and reviews applying realist methods have aimed to extend evidence beyond cause and effect to consider “what works, how, in which conditions and for whom” (Dalkin et al., 2015, p. 1). This can help account for the influence of heterogeneous contexts and mechanisms that may contribute to the observed outcomes of SP programmes. Realist studies and reviews have identified that factors operating at individual, organisational, community and policy levels are involved in the contexts, mechanisms and outcomes demonstrated in SP evaluations. These factors include trust and buy-in of all stakeholders, tailoring, collaborative working, training, healthcare funding and infrastructure, leadership, communication, community features (e.g. transport links), rapport, and individual characteristics including beliefs, expectations and perceptions (Bertotti et al., 2018; Calderón-Larrañaga et al., 2021; Husk, Blockley, et al., 2019; Pescheny et al., 2018b; Thomas et al., 2021; Westlake, Ekman et al., 2022; Wood et al., 2021). Mechanisms, outcomes and contextual issues identified from a range of literature and theoretical standpoints are synthesised below in terms of their impacts on individual patients, organisations and the wider community.

***Patient Outcomes.*** Polley et al. (2016) report that over 40 distinct benefits of SP have been observed. Reviews of studies of SP have shown that many health and wellbeing outcomes are reported for people who receive SP referrals, including improvements in emotional wellbeing such as anxiety and depression, improved self-esteem and empowerment, increased social wellbeing, physical activity and skill acquisition (Chatterjee et al., 2018; Costa et al., 2021). A controlled study showed that, compared to routine care, a link worker programme led to improved quality of life, daily functioning and subjective general health (C. Grant et al., 2000). As well as health and wellbeing outcomes, the person-centred approach of SP may enable patients to feel empowered and develop skills which are of importance to their lives. Skills acquired in SP activities have shown wider impacts beyond health improvement, such as employability (Kimberlee, 2016; Mann et al., 2017; Steadman et al., 2017). SP has been found to promote self-determination, including community connectedness and self-management of health (Bhatti et al., 2021; Hanlon, 2021). However, it is not known if increased patient activation, self-determination or empowerment necessarily leads to better outcomes (Tierney et al., 2020).

There are disparities in research investigating benefits of the types of activities that patients may be connected to through SP. Exercise referral schemes show the most complete evidence base due to being more widely established prior to expansion of SP, with widespread use of objective measures and randomised controlled designs (Chatterjee et al., 2018), while other areas such as arts on prescription programmes have been a focus of qualitative studies that examine subjective experiences but which do not apply replicable methods to measure these interventions' effectiveness (Chatterjee et al., 2018). There is a growing evidence base for the effects of access to nature and green spaces on physical and mental health; reviewers have often noted, however, that observed effects are often small and studies are heterogeneous, leading to a lack of evidence on who these approaches are most suitable for (Clatworthy et al., 2013; Garside et al., 2020; Husk et al., 2018; Wilkie & Davinson, 2021). Volunteering, which can be accessed through SP, has also been shown to promote all aspects of wellbeing described by the Five Ways to Wellbeing model



(Tierney, Mahtani, et al., 2022). There has been less research on outcomes of other types of SP activities, such as information services (Parkinson et al., 2015).

There are also disparities in funding, with exercise programmes receiving more funding than arts-based programmes (Chatterjee et al., 2018). This could be due to exercise having a more established evidence base in terms of health benefits that may make it more readily acceptable to clinicians and researchers grounded in a medical model of health. The evaluation of services has also tended to pay the most attention to the activities resulting from SP referrals, with less attention to how other components within SP pathways may contribute to outcomes (Husk, Blockley et al., 2019; Garside et al., 2020).

Qualitative studies in particular may over-represent positive outcomes but do not provide a representation of baseline levels of wellbeing (Bickerdike et al., 2017). As few as 50% of people referred for SP may attend the initial link worker appointment (Bickerdike et al., 2017) and adherence to SP programmes has been found to range from 30-78% (Costa et al., 2021), yet very few studies have explored the characteristics and attitudes of people who have refused or dropped out of SP services and pathways. This may result in a positive bias in evidence for SP. Small sample sizes may also indicate selectiveness around inclusion of participants and may not fully represent the full range of service users.

Studies suggest positive outcomes of SP may be achieved through increasing individuals' opportunities and capability to exert choice and control over their health (Hassan et al., 2020), which are key components of health behaviour change (Michie et al., 2011). A qualitative study found that the SP model's focus on joint decision-making, non-judgemental space, interest-aligned solutions and supportive staff promoted self-determination for patients, which may increase motivation to achieve personal wellbeing goals (Bhatti et al., 2021). Patients' beliefs and expectations can also affect their likelihood of accepting or benefitting from a social prescription; these can interact with organisational, interpersonal and wider contextual factors. For example, a

patient's expectations about the suitability of social prescribing to meet their needs may be impacted by the way an SP offer is presented and affect their likelihood of progression through the pathway (Husk, Blockley et al., 2019). A written 'prescription' format has been linked to better patient retention (Golubinski et al., 2020), but can also exert a sense of social pressure that has been found to impact negatively on patients with lower intrinsic motivation and higher anxiety (Tester-Jones et al., 2020).

Patients' responses to practitioners can also affect their outcomes; a mixed methods study of personalised care approaches for adults with complex needs found that interacting with voluntary sector staff may have greater acceptability for service users than interacting with traditional clinicians, due to the increased time they were able to spend with individuals as well as levelling of power dynamics (Gradinger et al., 2020). Existing levels of social support, skills in managing health navigation and self-management, and motivations for accepting an SP referral, are further patient factors which may affect engagement and success (Hanlon et al., 2021; C. White et al., 2022). Furthermore, patients' perceptions of the legitimacy of SP can be influenced by their concerns about demand and funding in the context of services that have been cut due to budget limitations (Garside et al., 2020; Khan et al., 2022).

Research has revealed less about barriers and facilitators which may affect certain groups of patients, including those who are currently marginalised or underserved. Reviews have highlighted how underreporting of patient characteristics and underrepresentation of certain backgrounds among those accessing services contribute towards a lack of knowledge about how to better tailor social prescribing to target populations, including those experiencing a greater level of barriers to accessing and engaging with the pathway (Pescheny et al., 2018b; Tierney et al., 2020).

According to a mapping review of the social prescribing pathway, the majority of patients enrolled in SP schemes have been female, aged over 40, from white backgrounds and unemployed (Kilgarriff-Foster & O'Cathain, 2015). One study showed that wellbeing improvements were greater

in younger participants and people who had lower baseline scores, while another found greater effects for female and ethnic minority participants (Costa et al., 2021). On the other hand, younger people have been found to be more likely to disengage or decline a service, which may be because social prescribing provision is more often targeted towards older people (J. Mason et al., 2019). A study by C. White et al. (2022) found that there were difficulties recruiting "socially reticent" clients to their qualitative evaluation of a SP service, and is potentially another source of bias for studies.

Underreporting of disability has been identified in social prescribing studies (Cartwright et al., 2022), which is at odds with a frequently targeted population for social prescribing comprising those with multiple long-term health conditions. A report identified that SP was less effective at identifying support services targeted at specific health conditions or disabilities, as these support models tend to be more widely dispersed, therefore harder to reach, and less prioritised by prescribers (Cole, 2020). On the other hand, the involvement of family, strengths-focused approaches and continuity of care were found to be important mechanisms in the success of community-based approaches for adults with complex needs (Gradinger et al., 2020).

Socioeconomic status and ethnicity are also underreported (Cartwright et al., 2022). This lack of attention to marginalised groups may overlook barriers that may be more prevalent in underserved patient populations, including attitudes towards help-seeking, trust in the medical profession, lack of representation of certain communities in the social prescribing workforce, and practical barriers such as transport (Cartwright et al., 2022). During the Covid-19 pandemic there was an increase in digital provision of services, but this may exclude people without the means or skills to access technology (Cole et al., 2020). However, it is also argued SP has the potential to simplify access to healthcare through its referral process and single point of contact approach (NHS England, 2019). Further research is needed to explore barriers SP may present for underserved groups and how these may be resolved, especially where there is intersectionality between groups which experience greater marginalisation.

***Organisational Factors and Outcomes.*** There have been mixed findings on the impacts of SP on health service usage by patients (Bickerdike et al., 2017), but on average there appears to be a reduction in demand for GP services of 28% (Polley, Bertotti, et al., 2017). Reductions in the use of secondary care services have also been observed (Polley, Bertotti, et al., 2017). While SP has shown to have a higher cost than traditional general practice (Bickerdike et al., 2017; C. Grant et al., 2000), findings from studies also show a positive return on investment with a mean of £2.30 return for every £1 spent (Polley, Bertotti, et al., 2017).

Long-term conditions are often costly to health services, so promoting self-management of health in this way has the potential for cost-saving (Kimberlee, 2016; Ogden, 2018). On the other hand, there is a lack of evidence that personalised care approaches will reduce spending for some populations with complex needs; Gradinger et al. (2020) argue that for some groups, such as those with frailty, the potential for improvements to wellbeing should motivate the use of these approaches more than cost-saving. Economic evaluation of SP is minimal and studies which have used more robust methods such as RCTs have shown more conservative results on the economic outcomes (Polley, Bertotti, et al., 2017). Polley, Bertotti et al. (2017) suggest that improved targeting of populations and more efficient use of resources may increase value for money for health services, while Ogden (2018) suggests that successful SP will require investment in infrastructure, support by commissioning groups and clarity about supply and demand.

From a policy perspective, the SP link worker model may ease the burden of GP caseloads and long wait times, and can offer a more flexible approach for patients in line with recommendations for future NHS service provision (Davison et al., 2019; NHS England, 2019). Case studies have found the working practices of the link worker to be an important contributor to success of SP, such as their level of knowledge of local services (South et al., 2008). The presence of a link worker was found to build GP's trust in the SP approach, and GPs valued having an "extra something" that they could offer patients (South et al., 2008, p. 313). Patients also valued the longer appointments with the link worker and the increased awareness of local supports (South et al., 2008). Studies have

found that individuals who received more time with the link worker had better outcomes (J. Mason et al., 2019) and that engagement with a service can decline when link worker support is withdrawn (Foster et al., 2021). Tierney et al. (2020), however, highlighted gaps in knowledge around the mechanisms of the link worker role, such as how they achieve buy-in from patients and practices, how they are recruited and trained, and how they decide which method of connecting is required.

A review suggested that link workers from healthcare backgrounds can have a tendency to adopt a more medicalised approach than those from the community sector (Cole et al., 2020); this could risk SP becoming another transactional and paternalistic referral system, obscuring the value of person-centredness and coproduction values (Lent et al., 2022). A common theme of many studies investigating link worker experiences is the complexity of the link worker role and inadequacy of training provided, particularly around managing increasing complexity of issues patients are referred with, such as severe mental health problems and domestic abuse (Fixsen et al., 2020; Rhodes & Bell, 2021; Wildman et al., 2019). Referrals do not always make clear the level of complexity of patients referred to a link worker (Hazeldine et al., 2021), as issues may emerge later during longer consultations and other primary care professionals may not have a good understanding of link workers' remit and skill levels (Rhodes & Bell, 2021).

The link worker role may be well-placed, however, to help individuals navigate and overcome certain barriers, such as by fostering confidence and offering tangible support with initial engagement (Husk, Blockley et al., 2019), although the level of support offered may depend on how well link workers' demand and workload are managed. Public views suggest people valued link workers who knew their community well and were relatable for patients; participants had also rarely been engaged in decision-making about SP in their area and felt the community should have more influence over decisions (Khan et al. 2021).

Processes involved in SP models, such as the level of support involved in transition through the referral pathway, and the continuation of opportunities following discharge from services, have

been shown to be mechanisms which may underlie outcomes in users of SP pathways (Dayson et al., 2020), but can vary immensely, demonstrating a need to identify how to best design SP services for success. The ability to refer patients to SP depends on the availability, capacity and funding of services in the community (Wildman et al., 2019), as well as the quality of information about available activities and their target groups (Garside et al., 2020). Link workers' knowledge of their locality may vary between extensive knowledge of local communities, to limited training and use of directories of services (Bickerdike et al., 2017). Although link worker consultations may free up appointment time for GPs once issues are identified, there are risks of workload becoming overwhelming for link workers (Graham-Clarke et al., 2018).

This demand is also passed on to community-based services, leading to long waits, frustration and distrust (Alderwick et al., 2018) and services are necessarily limited by their capacity (Kilgarriff-Foster & O'Cathain, 2015). Features of services such as location and joining fees can create barriers that may limit uptake (Husk, Blockley, et al., 2019; Kilgarriff-Foster & O'Cathain, 2015).

Furthermore, there may be tensions that persist between the health and community sectors. In a mixed methods study Hogg Graham et al. (2020) found community-based organisations perceived services in the health sector as limited, while health providers were often unaware of what was offered by community-based services. In the same study, 83% of health providers perceived collaboration between the sectors to be working well, compared to 23% of community support providers, suggesting more work was needed for community referrals to have a positive impact on the VCSE sector.

***Impacts On Communities.*** NHS England (2019) suggest that the impacts of SP on communities could include greater tolerance, control and resilience due to increased availability, accessibility and sharing of community assets among a wider variety of people. Findings from studies have demonstrated improved control, engagement and empowerment at a community level through the mechanisms of coproduction, reciprocal relationships and reflective learning, although

the quality of research has been assessed as generally low (Thomas et al., 2021) and ‘community’ remains a poorly defined concept due to its subjectivity (Morris et al., 2022).

A sense of self-determination found in a study by Bhatti et al. (2021) was in part achieved by participants perceiving a sense of community connectedness and having a positive influence on others. Being referred to groups in communities may build social connections and access to local assets by creating the contexts that foster social participation for people with fewer social contacts (Esmene et al., 2020). The supported nature of socialisation provided by SP has been found to have positive effects on building social networks, and appears to be more successful for resolving loneliness than social skills interventions, but does not have the robust evidence base of traditional psychological approaches such as cognitive behavioural therapy (CBT) (Mann et al., 2017). A report on the value of social prescribing suggested that commissioners should consider social return on investment (SROI), which can highlight the impact of SP on wider systems and issues in society with associated economic costs, including suicide risk, employability, addiction and abuse (Kimberlee, 2016). A programme evaluation showed an SROI of £2.90 per £1 invested (Kimberlee, 2016).

Scholars have noted how policy and practice in SP often remain tied to an individualised approach to wellbeing (Bell & Foley, 2021; G. Bradley & Scott, 2023; Davison et al., 2019; Gibson et al., 2021; Mackenzie et al., 2020; Morris et al., 2022), whereas the wider social context around a person, such as employment, debt, past trauma and perceptions of powerlessness, can contribute substantially to the likelihood of a successful outcome (Gibson et al., 2021; Mackenzie et al., 2020). Loneliness is often a target for SP but is an individual trait that is an extension of social isolation, a community-level problem (Morris et al., 2022).

There are gaps in understanding of how such an individualised approach may be able to successfully reduce systemic health inequalities (Mackenzie et al., 2020); South et al. (2008) suggest that SP may mitigate health inequalities rather than directly address the cause of them.

Morris et al. (2022) recommend integrating community-focused models into the theory of change for social prescribing and using participatory approaches to bring SP in line with community values and identify informal sources of support active in communities that may strengthen the SP offer.

The prevailing individualistic focus may underlie the increased investment in the primary care sector's role in SP provision, potentially leaving a shortfall in investment in the VCSE sector which provides the prescribed activities, diverting patients away from statutory services they are entitled to and into services which may be ill-equipped to cope with their needs for the sake of cost-saving.

There has been little research including cost-benefit analysis of SP for the voluntary sector. VCSE provision tends to be lower in less affluent areas with fewer assets, despite the fact that deprived areas and their residents may be the most in need of these initiatives and interventions (Cole et al., 2020).

Initiatives may also be limited by the types of activities available; where these cannot first meet patients' basic financial and security needs, such as offering advice with debt and housing, the activities available may be perceived as unsuitable (Cole et al., 2020). If systems increasingly fail to provide for these needs, this may create a demand for SP services that the community supports involved may not have capacity to meet (Hogg-Graham et al., 2020). Conversely, when basic needs are accommodated, this may have a snowballing effect on individual wellbeing; for example receiving financial support in the first instance may allow a person to manage other areas where they have difficulty, such as diet or exercise opportunities (Parkinson et al., 2015). The health service itself is not always well-equipped to manage socially-determined long-term health issues so there may be benefits of exploring community-based solutions, and SP may create cohesiveness between the provision of different sectors (Polley et al., 2020).

Some theorists argue SP may even exacerbate inequalities when it fails to reach the groups who may benefit most (R. C. H. Brown et al., 2021) or exposes a need for services that do not exist or issues which are difficult to address (Garg et al., 2016). Judgements on who SP is appropriate for



can be influenced by changing socio-political contexts and these decisions may be made at multiple levels (Fixsen et al., 2020). Such judgements may be influenced by differing political discourses around the aims of SP ranging from addressing health inequalities, reducing problematic overuse of health services by encouraging health self-management, or increasing personalisation of care delivery (Calderón-Larrañaga et al., 2022). Each of these discourses has led to the application of different goals, delivery models, research designs and perspectives on the roles of services, individuals and communities (Calderón-Larrañaga et al., 2022).

Underlying social inequalities across geographical areas may also affect who is able to access SP activities, as access relies on mechanisms such as availability of transport and safety of a location (Husk, Blockley, et al., 2019). SP has been suggested to be particularly helpful for community cohesion in urban settings with transient populations by facilitating service navigation (Ogden, 2018). On the other hand, rural areas may also benefit from SP initiatives as communities can be impacted by poor public transport systems, reduced services and high rates of social isolation that impact on overall community wellbeing (Fixsen & Barrett, 2022).

There has been little measurement of whether social prescribing delivered in suboptimal circumstances could have a detrimental effect on health (Polley et al., 2020). However, a review of nature-based social prescribing found that inappropriate referrals could risk worsening of issues, injury and alienation from vital health services for individuals (Garside et al., 2020). The same study showed that there has also been a lack of attention to any environmental burden resulting from increased activity in community green spaces which could be detrimental to community wellbeing.

On the other hand, the integration of the VCSE and the primary care sector may help to identify and address areas of need within a community that may not be known to health services (Alderwick et al., 2018). There is an argument that these efforts have existed in other guises before the notion of social 'prescribing', such as occupational therapy (G. Bradley & Scott, 2023), but that the novel

element of ‘prescriptions’ and the primary route of access being primary care health services risks maintaining the power differential in the roles of expert and patient, aligned with the medical model (Mendes, 2021). Models which continue to follow the health service’s transactional model, rather than being relational, and focus on the outcome of service utilisation, may not bring as much empowerment to individuals and communities that requires more focus towards the goal of creating accessible, long-term support systems (Calderón-Larrañaga et al., 2021). This could risk both accessibility and acceptability for patients who experience inaccessibility, disempowerment or stigma in using health services.

Despite these theoretical debates, the evidence that social prescribing may bring benefits to individual health and wellbeing outcomes may make it a worthwhile referral pathway for some patients, with realist research identifying mechanisms which may contribute to success. More research is needed on how to tailor access to social prescribing for those in marginalised groups affected disproportionately by health inequalities without further exacerbating inequalities. Research will also need to establish how to standardise practice and evaluation to improve homogeneity of social prescribing research, yet remain considerate to the need for pathways to be responsive to a wide variety of needs operating in local contexts.

### *Social Prescribing for Autistic Adults*

**Background: Health Inequalities and Autistic Adults.** Autism describes a neurological profile that affects the way a person perceives and interacts with the social and physical world. Medical model definitions of autism, such as diagnostic criteria, focus on observable traits and behaviours, most commonly communication, social interaction and ‘restricted and repetitive’ behaviours (American Psychiatric Association, 2013; World Health, 2018). More recently, self-report methodologies, qualitative, participatory and ethnographic autism research, as well as

informal accounts in press and social media, have given more emphasis to the internal experience of being autistic, to provide a more complete understanding.

Social interaction differences can include body language (e.g. reduced eye contact), having a direct style of communication and difficulty understanding others' behaviour or intentions (Buckley, 2017). Sensory processing differences include heightened reactivity to sound, light, smell, texture and proprioceptive and vestibular sensations (Crane et al., 2009; K. MacLennan, O'Brien et al., 2022). Hyposensitivity can also occur, such as a reduced pain response or seeking sensory input (MacLennan, O'Brien et al., 2022). Overwhelming sensory and social experiences can lead to high stress, so many autistic people have a need for sameness and routine (Buckley, 2017) and many will use repetitive movement to self-soothe or process emotion (termed 'stimming' in the autistic community) (Kapp et al., 2019). Many autistic people have passionate interests and skills related to specific areas, such as music, computers or nature, that can also promote positive affect (Grove et al., 2018; Grove et al., 2016).

Recent estimates suggest between 1-3% of the UK population may be autistic (Hosozawa et al., 2020; O'Nions et al., 2023; Roman-Urrestarazu et al., 2021). Autistic traits are typically noticed in childhood and most autism research has focused on children (Kirby & McDonald, 2021; Michael, 2016), although the majority of autistic people are adults (Royal College of Psychiatrists, 2020), a considerable proportion of whom remain undiagnosed until adulthood (Lai & Baron-Cohen, 2015). While autistic traits are traits that all humans may exhibit to a lesser or greater extent (for example, it is common to feel uncomfortable in an unfamiliar social situation or to exhibit repetitive behaviour when agitated), it is their intensity and impact that leads to the diagnosis or identification of autism (Doherty et al., 2021), and autistic people remain a highly diverse population with each person presenting a different constellation of traits at different intensities.

While autistic people may develop skills and coping strategies throughout the lifespan (Lai & Baron-Cohen, 2015), it is not possible to 'grow out' of being autistic or 'cure' autism, because it is

rooted in innate neurological structures. There is debate over whether or not autism should be construed as a neutral neurological difference that contributes positively to human diversity (a viewpoint that has developed from activism led by autistic self-advocates) (Leadbitter et al., 2021), or as a psychiatric disorder (with the medical profession holding ownership of diagnosis and definitions) (Royal College of Psychiatrists, 2020). There is evidence for autistic traits being strengths in some contexts that suggest advantages to neurodiversity on a collective level (Gernsbacher et al., 2006; G. Russell, Kapp, et al., 2019; Scott et al., 2017; Warren et al., 2021). However, most autistic people will experience some level of disability due to internal differences in processing style combining with demanding social and sensory environments (Lai et al., 2020; Leadbitter et al., 2021), and many autistic adults have uneven profiles such as exceptional abilities in specific areas but more difficulties in others (Buckley, 2017; Doyle, 2020). Autistic people who have co-occurring conditions, such as intellectual disability and motor disorders, can require lifelong, high-intensity support.

Compared to the general population, autistic adults of all profiles have been shown to have a higher risk of many physical and mental health conditions, a finding which has been common to many studies across different regions including Europe and the United States (Croen et al., 2015; Forsyth et al., 2023; Hirvikoski et al., 2016; Woolfenden et al., 2012). The factors that contribute to poor health outcomes for autistic people are complex and cannot easily be attributed to one cause. Although conditions such as epilepsy may have a biological basis, (epilepsy is a common cause of mortality which has a higher prevalence rate among autistic people who also have intellectual disabilities) (Woolfenden et al., 2012), there is a wide range of more preventable yet frequently co-occurring conditions that impact on morbidity and mortality for autistic adults, reducing overall life expectancy (Hirvikoski et al., 2016; Woolfenden et al., 2012). Autism itself is not a degenerative or harmful condition in terms of health outcomes and a recent review showed that a large proportion of mortality recorded is due to externally derived causes, rather than internal illness (Forsyth et al., 2023).

Some conditions seen frequently in autistic people, such as cardiovascular and gastrointestinal problems may result from lifestyle factors, as autistic people frequently experience different eating behaviours, sleep disorders and more barriers to physical activity (Blagrove et al., 2021; Charlton et al., 2023; Kinnaird, Norton, et al., 2019). Autism is sometimes associated with differences in interoception (awareness of internal physical sensations), and alexithymia (difficulty identifying emotions) (Garfinkel et al., 2016; Kinnaird, Stewart, et al., 2019). These may also contribute to problems identifying changes in health. Some autistic people in recent studies have also described being affected by inertia, where it can be difficult to begin an action, including health and wellbeing self-management (Buckle et al., 2021).

Mental health is one of the more prevalent health concerns affecting autistic people across all age groups, who present with high rates of depression, anxiety, post-traumatic stress and other mental health conditions (Hand et al., 2020; Howlin, 2021; Hudson et al., 2019; Rumball et al., 2020). For autistic adults without intellectual disabilities, studies have found one of the leading causes of death is suicide, occurring at a rate up to nine times that of the general population (Hirvikoski et al., 2016). Evidence suggests around 10-40% of those who die by suicide may be previously identified or undiagnosed autistic people, comparing to the lower prevalence of autism in the population (Cassidy et al., 2022).

The scale of these issues and a lack of suitably adapted preventative care at the community level has led to high rates of admission to residential mental health units for this population, with stays often lasting many years due to lack of improvement. For example, there is often a lack of support available following an autism diagnosis to assist autistic people and their families to make sense of the diagnosis and how to support their needs (Crane et al., 2018). Furthermore, without a separate mental health diagnosis, autistic people are often unable to access mental health services for routine support (Sharpe et al., 2019), and there is a lack of high quality evidence on what types of mental health support may be suitable for autistic adults or the best ways to adapt these for autistic people who do experience mental illness (Linden et al., 2023).

Tackling the high rate of mental health admissions through better provision of services in the community has been highlighted as a priority by the Department of Health & Social Care (2022) due to the high stress and poor quality of life associated with these admissions. There is also an issue with overprescribing of antipsychotic medications to manage distress-related behaviour in mental healthcare for autistic adults; these medications can have severe side-effects which cause further health problems (Department of Health & Social Care, 2021).

It is well understood that many long-term health outcomes can be influenced by social determinants of health (Marmot, 2010), with inequalities in these determining factors widening in recent years (Marmot et al., 2020). Autistic adults are less likely to be employed, with the most severe estimates suggesting 29% of autistic adults are in any employment, representing the lowest rate across all disability groups (Office for National Statistics (ONS), 2022), although methodology varies across studies. Despite self- and proxy-reported strengths associated with autism that would be desirable for employment in certain roles (Scott et al., 2017), discriminatory practices and a lack of understanding and implementation of adjustments to work prevent many autistic people from progressing in these areas (Doyle, 2020; Whelpley & May, 2023). Studies have also found that autistic adults and children experience more financial hardship and are more likely to live in social housing (Brugha et al., 2011; Hosozawa et al., 2020). Some studies suggest that autistic adults have poorer educational attainment on average (Brugha et al., 2011); many autistic children miss out on education due to school exclusion (Guldberg et al., 2021).

There are differences in conditions experienced by those with and without accompanying intellectual disability (ID). Those with ID may be more vulnerable to the social determinants of health and require more support with management of health and care. On the other hand, some studies suggest that autistic people in receipt of higher levels of support can have improved outcomes compared to those who manage independently, who are at a higher risk of isolation and having unmet needs (Schott et al., 2021), and ID only weakly predicts overall adaptive functioning (Alvares et al., 2019). Autistic adults without ID can miss out on specialist healthcare pathways

created for those with IDs (Sharpe et al., 2019). There is often no alternative provision for those without ID, despite high levels of health disparities affecting all autistic people. Additionally, inconsistent recording practices in health services may mean that not all people with an autism diagnosis are identifiable by services, which can lead to a lack of appropriate individual accommodations to improve access (Sharpe et al., 2019).

Demographic factors such as gender, sexual orientation and race/ethnicity also interact with health outcomes in the general population and studies show these disparities may intersect with being autistic, leading to different health profiles for autistic people in marginalised groups (DaWalt et al., 2021; Hall et al., 2020; Jadav & Bal, 2022; Rast et al., 2023). Many demographics are underrepresented in autism research (D'Mello et al., 2022; Malone et al., 2022; Maye et al., 2022; Michael, 2016; G. Russell, Mandy, et al., 2019), which may impact on how services are delivered. Receiving a timely diagnosis of autism is associated with better outcomes for autistic people (Atherton et al., 2022; Jadav & Bal, 2022); people who have a less typical presentation of autism or who experience more barriers to diagnosis (particularly older adults, women and some ethnic minority groups) are more likely to be under-identified (Lai & Baron-Cohen, 2015; Perepa, 2014; Perepa et al., 2023; G. Russell et al., 2021). Marginalisation has been found to tie into a higher level of unmet needs and healthcare access barriers for autistic people (Bishop-Fitzpatrick & Kind, 2017; Jeanneret et al., 2022; Perepa et al., 2023).

When health issues are identified, or routine care is required, autistic people as a group experience more barriers to accessing healthcare compared to both non-disabled people and those with disabilities other than autism, especially in the domain of communication with providers (Raymaker et al., 2017). Communication differences are one of the main criteria for autism diagnosis, and can range from differences in processing and interpreting spoken language, to speaking few or no words at all. Where accommodations for this are lacking, it may be difficult for autistic people to describe pain and illness to healthcare professionals.

Furthermore, some studies have found that up to 78% of autistic people experience anxiety and other difficulties using the phone to contact health services (Doherty et al., 2022; Howard & Sedgewick, 2021) and not all GP practices in the UK provide alternative options such as online booking and appointments, or provide this in a limited way; increasing use of remote healthcare since the Covid-19 pandemic may also have exacerbated some of these issues (Shaw et al., 2022). The sensory environment of health services can also be challenging for autistic people, who frequently experience heightened sensitivity to sounds, light and odours (MacLennan, Woolley et al., 2022). There is a lack of training and confidence around treating autistic patients among healthcare professionals (Corden et al., 2022) and a lack of awareness of some common health disparities affecting autistic adults (Micai et al., 2021). Fears that professionals will not understand and support their needs or take them seriously is a major barrier to access to support services for autistic people (Jeanneret et al., 2022; Raymaker et al., 2017).

Some research suggests autistic adults may experience particular barriers around initiating access to wellbeing-enhancing activity and community participation (Cameron et al., 2022), indicating a need for support in this area. Barriers to engaging in physical activity and other community-based pursuits can be complex, comprising a combination of environments, early life experiences, lack of opportunities and resources, and internal processes including anxiety and communication (Blagrove et al., 2021; Cameron et al., 2022; Colombo-Dougovito et al., 2021). However, facilitators have also been identified including social support, a sense of belonging, adjustments to sensory environments, access to structured programmes, and activities taking place outdoors (Colombo-Dougovito et al., 2021; Blagrove et al., 2021; Cameron et al., 2021).

Many interventions which have attempted to improve wellbeing outcomes for autistic people, including pharmacological and psychological interventions, have targeted the individual presentation of autism in line with a medical model of disability (Provenzani et al., 2020; Scott et al., 2019). Such an approach may overlook the complexity of the issues that lead to poor outcomes and fail to understand the adaptive benefits of some autistic traits. For example, social skills



interventions often lack attention to the reciprocal nature of interactions and variable social contexts that occur in reality by focusing on improving individuals' communication (Howlin, 2021); this also overlooks positive aspects of communication typical of autistic people, such as honesty and directness.

There is a lack of attention to social stressors broader than those which can be tackled by targeting perceived individual deficits. These have been found to be associated with poor mental health outcomes for autistic people, and include discrimination, self-stigma and perceptions of burdensomeness and lack of social belonging (Botha & Frost, 2018; Pelton et al., 2020).

Experiences of abuse have also been found to be related to physical and mental health symptoms for autistic people (R. B. Hughes et al., 2019; Rumball et al., 2020). Suppression of autistic traits due to social pressure (known as masking or camouflaging) has shown an association with suicidality (Cassidy et al., 2018), suggesting that interventions aiming to achieve this may harm wellbeing despite the appearance of producing a positive outcome (Jellett & Muggleton, 2022).

These findings highlight a need for autistic community involvement in the development of interventions and decisions on outcomes. Awareness of the importance of service accessibility and the person-environment fit in improving outcomes has also been increasing (Howlin, 2021; Lai et al., 2020). However, the priorities of autism researchers and clinicians are often misaligned with community priorities, such that the majority of funded research continues to focus on biomedical factors and early intervention in autism (Office of Autism Research Coordination et al., 2019), whereas community perspectives demonstrate a need to focus more on issues such as physical and mental health, and services and supports, with a focus on their application across the lifespan to improve daily living and long-term outcomes, such as employment (Roche et al., 2021).

The combination of poor outcomes faced by autistic people and the requirement for intervention at crisis points has led to an estimated cost of £32 billion per year in service provision, lost earnings and other impacts (Buescher et al., 2014; Rothwell, 2020). This highlights the economic argument

for creating more preventative care pathways that address individuals' needs at an earlier stage. Reviews of current knowledge on improving outcomes for autistic adults suggest it would be beneficial to create services which are strengths-based, person-centred, flexible and focused on building skills, social connections and quality of life (Howlin, 2021). Improving quality of life and reducing the burden of poor mental and physical health for autistic people could enable greater social participation that may benefit individuals and society economically, and is also an important goal in itself to allow people to pursue goals that are important to them and lead the lives they deserve.

As part of this approach, it is also important to recognise that not all autistic people will need or desire intervention at all times and that autism is not incompatible with success and thriving (Howlin, 2021). The aims of services should be to ensure support is available when people need it. Autistic individuals and communities also have capabilities, expertise and resources that can be drawn upon to develop support pathways. Those available to individuals will vary depending on external factors and opportunities (Pellicano et al., 2022). In general such resources may include knowledge gained from dedication to intense interests and skill development, mastery of online spaces for sharing information (the internet has enabled connection and self-advocacy to develop in those who have been previously marginalised), and positive experiences of connections in social spaces and to the natural world, that contribute to overall wellbeing (Brownlow & O'Dell, 2006; Gillespie-Lynch et al., 2014; Pellicano et al., 2022). In an early essay (relative to mainstream neurodiversity discourse), autistic self-advocate Jim Sinclair (1993) emphasised the importance of developing shared understandings, applying flexibility to expectations and building the right conditions to improve quality of life for autistic people as positive steps for moving past a focus on deficits linked to distress for autistic people and their families. The COVID-19 pandemic provides another example of being flexible towards harnessing community strengths and resources; much of the advice aimed at reducing stress in the general population reflected day to day behaviour autistic

people apply to manage high baseline stress levels, including maintaining routines, taking advantage of online connections and seeking familiar, sensory input (Heasman et al., 2020).

Overall, it is apparent that a better understanding of autism is needed across services and research, as well as knowledge of service gaps that contribute to unmet needs and an understanding of wellbeing for autistic people so that services are more suitably targeted.

### **Considering Social Prescribing as a Tool for Improving Wellbeing in Autistic Adults.**

The findings of studies evaluating social prescribing as described above suggest that referrals to appropriate community-based support can have positive impacts on areas of wellbeing that would be beneficial to meeting unmet needs affecting many autistic adults, including emotional, social and physical wellbeing (Chatterjee et al., 2018; Costa et al., 2021); these may also interact with social determinants of health to improve other areas of wellbeing. Furthermore, the ability to support others through volunteering and advocacy about autism promotes self-determination for autistic people (Kim, 2019), offering further opportunities for social prescribing in those looking to put these skills to use.

Some small-scale studies have investigated the impact of activities similar to those which often make up the end point of the SP pathway for autistic adults' wellbeing. These include leisure activities, advocacy and information hubs, and nature-based interventions, which have been found individually to improve outcomes for autistic adults such as quality of life, mental health and skill acquisition (García-Villamizar & Dattilo, 2010; Scartazza et al., 2020; Schleien et al., 1991; Southby & Robinson, 2018; Torquati et al., 2019). However, these studies have often relied on small samples and lacked direct measurement of health and wellbeing outcomes, focusing primarily on behaviours and vocational skills identified by researchers.

SP differs from the types of approaches in these studies by being less targeted in terms of population and outcomes, with supports aiming to include a diverse group and target a range of health and wellbeing needs. The intervention studies also reveal little about other key stages of the

SP pathway, such as enrolment into services, uptake and engagement with a service, and adherence to the activities provided (Husk, Blockley et al., 2019).

A recent study by Benevides, Shore, Palmer et al. (2020) used participatory research methods to investigate autism community priorities for improving mental health outcomes. The findings showed that the types of services autistic adults ranked highest as their priorities for supporting mental health reflect those offered by SP, as outlined by Chatterjee et al. (2018), including art therapy as the highest ranking intervention, followed by physical activity/exercise, animal assisted therapies and music therapy. These ranked above disciplines such as occupational therapy and cognitive behavioural therapy. They were defined by the authors of the study not in terms of SP, but as being “self-initiated” and “community-available, and did not require a gatekeeper” (Benevides, Shore, Palmer et al., 2020, p.830), which responds to the aims of SP as being focused on self-management of health using community-available resources and alternative prescription pathways. They also demonstrate a preference for holistic approaches, for example the recognition that physical activity can have benefits for mental health. This suggests that holistic and preventative approaches may be of interest to autistic adults’ health goals, but there has been little research on their current effectiveness and accessibility for this group. The personalised nature of social prescription may enable access to the types of services autistic people have highlighted as priorities for managing wellbeing.

From the perspective of government and public sector policy aiming at improving outcomes for autistic people, SP would support several goals and commitments which have been set out. In 2014, the UK government published the Think Autism Strategy (Department of Health, 2014a) which included aims to increase support, accessibility and inclusion for autistic people at the community level and increase ‘low-level’ support for those who are not eligible for other statutory services. Examples given included buddying schemes and leisure activities. This aimed to prevent escalation of needs to crisis point along with costly inpatient admissions to services ill-equipped to manage the needs of autistic people. Although SP was not offered as an example of a solution, the approach

would fulfil the criteria of developing connections between people and their communities, including helping people to engage with peer groups and low-level support. There is also potential for SP to develop skills that may assist people with finding employment (Kimberlee, 2016; Steadman et al., 2017), another goal of the 2014 strategy.

The Autism Strategy has since been updated, although the 2021 update has focused more on healthcare access and diagnostic pathways for children and adults (Department for Education & Department of Health and Social Care, 2021). Healthcare access is a crucial part of many SP pathways, which frequently include a referral from a primary care practitioner, such as a GP, as the initial stage of the SP process (Husk, Blockley, et al., 2019; Kimberlee, 2015). Furthermore, government funding aims to support link workers to be placed in primary care settings (National Health Service, 2019). If SP can be considered a potential solution to help autistic adults access support in communities, the primary care health pathway needs to be accessible, which will involve tackling the identified barriers to accessing healthcare (Charlton et al., 2021; D. Mason et al., 2019).

In 2022 the Department of Health and Social Care also released the Building the Right Support Action Plan (Department of Health & Social Care, 2022), aimed at reducing inpatient admissions and delayed discharges from mental health settings for autistic people and adults with learning disabilities. The plan reiterates the need for better support in communities, setting out planned investment in crisis support and community discharges. Further recommendations include personalised care, utilising creative and pragmatic solutions, and increased access to sport and physical activity. The government's Core Capabilities Framework for Supporting Autistic People includes personalised support as a core domain intended to increase autonomy for autistic people by taking into account each individual's needs and abilities (Department of Health & Social Care, 2019). These are further aims which could be supported by SP.

Furthermore, NHS policy has explicitly advocated SP as an aspect of the response to the over-prescribing of medications across many groups, and has highlighted autistic people as a priority

group in which to tackle the over-prescribing of psychotropic medications due to the impacts of side effects and the prescription of these medications for uses other than their recommended purpose (NHS England, n.d.(a)). SP is recommended by policymakers to help tackle the underlying causes of health issues, which cannot be addressed through medication (Department of Health & Social Care, 2021). However, the policy does not make the link of recommending SP specifically to reduce medication prescribing in autistic adults and it is not known if increasing access to SP for autistic people would have this effect.

Autistic adults are sometimes defined as a “hard to reach” group; this may be due to having different communication needs, as well as the lack of a unified registry of people with an autism diagnosis in the UK (Sharpe et al., 2019), which can make it more difficult to target healthcare towards this group. However, the European Patients Forum (2016) also highlights aspects of services that contribute to accessibility to groups of patients, showing how a lack of attention to these features makes the services “hard to reach” for some user groups. These include service availability and resourcing, tailoring and choice, affordability, geographical reach and access to non-medical support. This framework was recently applied to assess accessibility of social prescribing for older adults during the Covid-19 pandemic, helping to identify the need to attend to the physical environment, provision of information, digital exclusion and link worker awareness of offers provided by the cultural sector as issues which may impact accessibility (Tierney, Potter, et al., 2022).

The expansion of SP in the NHS means it will be important to ensure its accessibility to the broad population and especially those who are underserved, but services may not be well-prepared to meet the needs of autistic people in the SP pathway given what is known about existing barriers in primary care (Charlton et al., 2021). It is likely autistic people will also need additional support accessing and engaging with SP once services and activities have been identified. Charlton et al. (2021) suggested ways in which the pathway and activities may require adaptation to support this. This included providing enhanced support and detailed information about an offer, such as the

physical location, and details about referral timelines, frequency of sessions and staffing – all aiming to increase predictability and reduce anxiety; making sensory adjustments such as using natural lighting and a quiet break-out room at a venue or encouraging individual adjustments such as the use of noise-cancelling headphones; and a strengths-based approach that allowed people to define success on their own terms (Charlton et al., 2021). Such adjustments do not tend to require a great deal of resource to implement and may benefit service users beyond autistic people (Shaw et al., 2022).

Charlton et al. (2021) suggest that, as SP does not tend to focus on diagnosis to determine eligibility but on the presenting problems, there may be a number of autistic adults who have already accessed SP without this being identified, as autistic people have varying levels of need that can present in diverse ways that may not always be detectable. Autism is also underdiagnosed in certain groups such as older adults and adult women (O'Nions et al., 2023; G. Russell et al., 2021), and so SP referrals involving these groups may include people with undetected autism (C. White et al., 2022). Although the focus of SP is not diagnosis, omitting to mention a diagnosis at the referral stage may create problems for accessibility of services, as people may not be asked about how services can be adapted to meet their needs. A study of a SP service suggested that autistic people may need higher levels of support initiating access to prescribed activity because of the demands this creates for communication and organisation; this sometimes contradicted some referrers' and link workers' attitudes that self-initiation was to be encouraged to promote health self-management (C. White et al., 2022). The authors stressed that not all recipients of social prescribing would have the capability for this at the start of their referral process and that for some it may be a goal to work towards (C. White et al., 2022). This demonstrates ways in which social prescribers may require some education about the needs of autistic adults and others, such as those with social anxiety.

On the other hand, a disclosed diagnosis of autism may create its own problems SP in addition to perceptions of complexity. Tiner et al. (2021) investigated how likely nurses were to recommend physical activity to autistic adults for the purpose of enhancing wellbeing, and found only a

moderate likelihood, which was mediated by their perceptions of the barriers and benefits of exercise for this group. Barriers identified by nurses included a lack of resources for autistic people and lack of access to physical activity. Some barriers were related to being autistic, such as overstimulation and need for routines. Recommendations from the study included increasing training on autism for activity providers and adjustments to avoid sensory overload (e.g. smaller group and venue). Nurses in the study described autism in the same terms as a physical health condition, which additionally suggests there is an attitude towards treating autism as a treatment goal rather than enhancing wellbeing. Therefore, staff understanding and attitudes about autism and how autistic adults relate to concepts of wellbeing may tie into accessibility and acceptability of SP for autistic adults; a key mechanism of SP is the ability to build trust, rapport and a sense of candidacy (the ability for legitimate health needs to be recognised by professionals) through a shared understanding of its approach (Westlake, Ekman et al., 2022).

So far, research has not been able to offer a single intervention or approach that leads to widespread improvement in outcomes for autistic adults (Howlin, 2020); this may be due to the diversity and complexity of needs in this population. There may be some benefits to SP as an option for addressing health inequalities affecting autistic adults as a coproduced and flexible approach to health which could impose fewer norms and expectations around managing wellbeing due to its personalised nature. On the other hand, the top-down, individualised SP model delivered in the primary care sector may continue to subscribe to principles of the medical model, and may be limited in its ability to address the wider social inequalities that exacerbate health disparities for autistic adults.

This research project will investigate the acceptability and accessibility of SP for this population. Through examining first-hand experiences of unmet wellbeing needs and use of community-based supports and services among autistic adults, this research aims to identify potential adaptations that may improve access and adherence to the SP pathway. This may help to address policy gaps, as well as attending to community-led research priorities, focused on how service delivery can be



optimised to improve outcomes for autistic people, such as improving mental health, providing social care and making adaptations to adjust for the specific needs of this population (James Lind Alliance, 2016).

### **Aims and Objectives of this Research**

The research attends to the following research questions:

RQ 1: What are the wellbeing needs of autistic adults and is social prescribing an acceptable response?

RQ 2: What factors may affect access to the social prescribing pathway for autistic adults?

RQ3: What implications do the study findings have for policy and practice?

### ***Structure of This Thesis***

The findings of this research are presented in Chapters 3-7 in the forms of papers which have either been published or prepared for publication. This can lead to some inevitable repetition of the content of the introduction and methods chapters, since each paper includes their own introduction and methods section.

### ***Author's Background and Position to the Research***

In mixed-methods research and particularly that which uses reflexive methods, it is important to contextualise one's own background to the research as part of the process to acknowledge the impossibility of neutrality. Lived experience can influence how data is interrogated and interpreted; reflexive practice aims to make prior assumptions explicit by encouraging the researcher to reflect on their responses to the data as it is analysed and how those responses apply to the process of developing themes (Braun & Clarke, 2022). During coding of qualitative data, Saldaña (2021) encourages reflection on interpretations of participants' roles and relationships, early observations of patterns in the data and data which is more surprising or challenging, any personal or ethical dilemmas that occur during the analytical process, and gaps in the data.

My own prior experience includes an academic and clinical background in Health Psychology with a knowledge of relevant theoretical perspectives, therapeutic approaches and outcome measurement. My undergraduate degree in Psychology covered psychopathology, cognitive processes, neuroscience, sociological concepts and research methods. I undertook a dissertation on stereotypes and stigma about autism from the perspective of people who had an autistic sibling which provided a grounding in qualitative research. Following my undergraduate degree I worked in administrative services for community paediatrics and adult mental health NHS departments, enabling me to experience the organisation and limitations of NHS services, before undertaking a Master's degree in Health Psychology which covered psychological concepts in health behaviour and healthcare, during which I also worked as a research assistant on a trial of technology-based care for people with dementia. This helped to develop techniques around accessible communication in research data collection as well as research governance. I then worked as an assistant psychologist for a clinical health psychology service which developed therapeutic and reflexive skills. I have also volunteered as a therapy assistant for the National Autistic Society's children's services.

In 2016 I sought referral to an NHS autism diagnostic service and was assessed by a multidisciplinary team, subsequently receiving an autism diagnosis. I have personal experience of the autism diagnostic pathway, mental health services and finding ways to manage wellbeing and navigate barriers such as challenging environments. This lived experience combined with my education and employment background enables me to bring different perspectives on autism research and theoretical models by making connections across disciplines, such as how findings of social prescribing research may relate to engaging with the pathway as an autistic person. However, it was important to reflect on differences between my level of social privileges and those of participants and the target population who may have not had the same opportunities, and to examine dynamics of power that prevail between institutions and individuals/communities in the roles I have performed.

Autism is an area of personal interest for me around which I have read extensively around a range of related topics and theoretical perspectives, participated in autism-focused groups and events in the community and sought out discussion about autism in online spaces, which often revolve around areas where research is currently lacking but community expertise may help fill the gaps. My other interests include the role of the natural environment in psychological recovery, which motivated my interest in researching nature-based social prescribing for wellbeing.

During the initial stages of the research I completed a short placement with Cornwall Council's public health department to gain understanding of local public health issues and how social prescribing fits in with health service delivery in the local region. This included meeting with practitioners specialising in autism and public health, and attending public involvement groups aiming to improve services and coproduce adaptations to their delivery to improve the outcomes of autistic people and those with learning disabilities locally. I developed connections to related organisations, such as Healthwatch, who lead similar public involvement activities across regions in the UK. In the NIHR Applied Research Collaboration South West Peninsula, I consulted with staff including information specialists, statisticians and public and patient involvement specialists during the course of data collection and analysis. Throughout the project I developed connections with researchers and practitioners with experience in autism and social prescribing to understand areas of priority within these fields. These have included charities specialising in autism, primarily Autistica and the National Autistic Society; Autism Partnership Boards based in Plymouth and other areas of Devon; autism services based in Plymouth and Bristol which included a built-in a social prescribing pathway; providers of activities available through social prescribing (e.g. horticultural therapy at Thrive and the Eden Project); and peer-led autism services operating in more localised areas.

## Chapter 2

### Methodology

#### **Mixed Methods Study: Introduction**

The thesis presents the results of a mixed-methods study exploring self-management of wellbeing and views on social prescribing from the perspectives of autistic adults. The methods and results should be considered in the context of Covid-19, which emerged during the project timeline. The challenges of the pandemic for both the population (autistic adults) and intervention of interest (social prescribing) are therefore relevant to the rationale, aims and choices of the research methods and procedures. The overall aim of the research is to contribute towards understanding how social prescribing, and other services delivered in communities, may be equipped to support wellbeing for autistic adults within different contexts. The overall aim is operationalised into two specific research questions. While research methods used to achieve the research objectives are described in later results chapters, publishing requirements have often limited the level of detail that could be given on the design and application of methods in those chapters. Therefore, this section aims to present further context and rationale for the methodological choices made to answer the questions and describe all aspects of the methods applied to the original research undertaken for this study.

#### **Research Questions**

***RQ 1: What are the Wellbeing Needs of Autistic Adults and is Social Prescribing an Acceptable Response?***

Inequalities affecting autistic adults have a measurable effect on health and wellbeing, as demonstrated by disparities in morbidity and mortality compared to non-autistic populations (Hirvikoski et al., 2016; Woolfenden et al., 2012), high prevalence of socioeconomic disadvantages (Brugha et al., 2009), and lower scores on standardised quality of life measures (Holmes et al., 2020). However, qualitative studies and critiques of wellbeing measurement have suggested autistic

people may construct wellbeing in ways that differ to established norms and expectations about disability (Welch et al., 2019). This is explored in more depth in [Chapter 6](#). It is therefore important to gather first-hand perspectives on how wellbeing is constructed and managed, areas of unmet need and views on how services, such as social prescribing, may be equipped to respond to these needs. This will enable understanding on how services can be tailored and targeted to address the needs of highest priority for autistic people.

### ***RQ 2: What Factors May Affect Access to the Social Prescribing Pathway for Autistic Adults?***

A growing research literature suggests that the majority of autistic people experience barriers to accessing healthcare (Doherty et al., 2022; D. Mason et al., 2019). Social prescribing is often accessed through referral to primary care, or from aligned services such as adult social care. There is a need for more attention to understanding factors underlying the lack of accessibility to services for autistic adults to begin to address health disparities. Research in social prescribing has paid little attention towards its accessibility for adults with disabilities, including autistic adults, with many studies lacking descriptions of disability in their samples (Cartwright et al., 2022). This may lead to a gap in the literature on mechanisms that act as barriers or facilitators to social prescribing for disabled adults, compared to other models of healthcare. Furthermore, as the involvement of other groups, such as by gender, age and ethnicity, is often skewed or underreported (Cartwright et al., 2022), there may be intersectional inequalities that compound these issues. The context of Covid-19 on access to services is also in need of exploration for this population; although there have been many changes since the start of the pandemic, autistic individuals remain more likely to encounter risk factors associated with Covid-19 infection (Schott et al., 2022), and the pandemic has also led to long-term changes in service delivery that impact accessibility (Liberati et al., 2022).

### ***RQ3 What Implications Do the Study Findings Have for Policy and Practice?***

Social prescribing forms part of the NHS Long-Term Plan (NHS, 2019) for increasing personalised care options available to the public. The Department of Health and Social Care's policy has also

focused on improving health and wellbeing outcomes for autistic adults via resources in communities to reduce harmful mental health admissions (Department of Health & Social Care, 2019; 2022). Policymakers and service commissioners will need ensure social prescribing provision is equitable in order for these policy priorities to be addressed and achieve their aims. This should include producing guidance for service delivery detailing how to support autistic adults to engage with these services, to translate these priorities into practice.

These three research questions led to the development of a mixed-methods study. This methodology allows for the robust testing of hypotheses using validated quantitative approaches, and in-depth exploration of personal experiences in a smaller group, using qualitative methods tailored to the research questions and sample. The components of the study are presented chronologically, as in some cases, the findings of earlier stages influenced the methods used in subsequent stages. Table 2.1 shows the stages of the research completed as part of this study.

### **Summary of Approaches**

The following is a brief overview of the methods applied for this study, presenting a high-level perspective of the methods and how their selection relates to the study aims. The design, methods and procedures involved in the original research (online survey and interviews) is also expanded upon later in this chapter.

#### ***Stage 1: Systematic Mapping Review of Reviews [Chapter 3]***

To understand existing knowledge on social prescribing and other community-based interventions for autistic adults and identify barriers and facilitators to progression through service pathways, I undertook a review of the literature. A systematic mapping review (James et al., 2016; Snilstveit et al., 2016) was selected as the appropriate design to scope existing literature and visualise the types of services that have been studied, their outcomes and the mechanisms that enabled progression through pathways for participants in the included studies.

### ***Stage 2: Online Survey [Chapter 4]***

The literature review suggested that there may be barriers to identifying the needs of autistic adults and accessing a referral to community-based services. The online survey aimed to explore this further by examining barriers to primary healthcare and other community spaces experienced by autistic adults. The survey design would allow for an understanding of a potentially large sample, which could enable investigation into these barriers for different demographic groups within the population of autistic adults. This has been underexplored by previous research on barriers to healthcare, but would allow the study to address recommendations for autism research to consider intersectional inequalities. For example, mortality, morbidity and healthcare utilisation affecting autistic adults show differences by gender, ethnicity and co-occurring disability (Hirvikoski et al., 2016; Hall et al., 2020; DaWalt et al., 2021). Reviews have suggested that there may be disparities in access to social prescribing for different demographic groups (Cartwright et al. 2022).

The survey also used the advantage of a novel context, the Covid-19 pandemic (discussed in more detail below), to explore the impact of the changes in standard service delivery on access to healthcare, which may have relevance to the future of access to social prescribing as service delivery adapts to the challenges posed by the pandemic. Questions on emotional and social wellbeing were also included in the survey, to understand how wellbeing needs may also be affected by this context. This also allowed for exploration of how barriers to healthcare and community spaces may relate to wellbeing; previous studies on access to healthcare for autistic adults have not looked at how these issues may be associated with subjective wellbeing.

### ***Stage 3: Semi-Structured Interviews [Chapters 5-7]***

Interviews aimed to elicit in-depth understandings and rich descriptions of the mechanisms underpinning the main research questions, including the meaning of wellbeing for autistic adults, which may be different from normative standards in the general population (Jones, 2022; Lam et al., 2021; D. Mason, Capp et al., 2021). Interviews asked how individuals may have developed

strategies to self-manage wellbeing, and aimed to identify any areas of unmet wellbeing needs.

Participants were asked about the impact of access to healthcare and different environments on their wellbeing, as features which may be relevant to social prescribing pathways and models of delivery.

They were asked about their impressions of social prescribing as an approach to managing their wellbeing needs. Finally, they were asked about the impact of Covid-19 on their experiences.

Follow-up interviews were designed in response to identification of a topic of interest which had recurred in the initial interviews: that of peer-led support groups and their position in relation to commissioned autism services.



**Table 2.1**

*Study Components*

<b>Methods</b>	<b>Publications</b>	<b>Aims</b>	<b>Research Questions Answered</b>	<b>Components</b>
Literature review: Systematic mapping review of reviews	Featherstone, C., Sharpe, R. A., Axford, N., Asthana, S., & Husk, K. (2022). Health and wellbeing outcomes and social prescribing pathways in community-based support for autistic adults: A systematic mapping review of reviews. <i>Health &amp; Social Care in the Community</i> , 30(3), e621-e635. <a href="https://doi.org/10.1111/hsc.13635">https://doi.org/10.1111/hsc.13635</a>	<ol style="list-style-type: none"> <li>1. “What is the nature and variety of non-medical, community-based support for autistic adults that has been reviewed?”</li> <li>2. Which outcomes are measured for these services and how do they align with the wellbeing priorities of autistic adults?</li> <li>3. What can existing research reveal about the characteristics of referral pathways underlying services and their contributions to the access to and success of services?”</li> </ol>	RQ1, RQ2, RQ3	Data extraction from reviews (N=24) of non-medical, community based services for autistic adults and from UK-based studies identified in reviews (N=19)
Quantitative study: Online survey	Featherstone, C., Sharpe, R. A., Axford, N., Asthana, S., Ball, S., & Husk, K. (2022). Barriers to healthcare and their relationship to well-being and social support for autistic adults during COVID-19. <i>Primary</i>	“We hypothesised (H1) that there would be a significant difference in the number of barriers to healthcare over time in accordance with the progression of the Covid-19 pandemic and (H2) that barriers to healthcare would be significantly associated with emotional and social wellbeing variables.”	RQ1, RQ2, RQ3	Online survey of 128 autistic adults living in the UK, with follow-up survey of 42 participants from the same sample

	<p><i>Health Care Research &amp; Development</i>, 23, e79.  <a href="https://doi.org/10.1017/S1463423622000755">https://doi.org/10.1017/S1463423622000755</a></p>			
Qualitative study: Semi-structured interviews	<p>Featherstone, C., Sharpe, R., Axford, N., Asthana, S., &amp; Husk, K. (2023). Autistic adults' experiences of managing wellbeing and implications for social prescribing. <i>Disability &amp; Society</i>, 0(0), 1–29.  <a href="https://doi.org/10.1080/09687599.2023.2263628">https://doi.org/10.1080/09687599.2023.2263628</a></p>	<p>“We formulated this study to explore the concept of wellbeing for autistic adults and the implications for modifying social prescribing [...] We aimed to understand how individuals defined wellbeing, their strategies for managing wellbeing and experiences of barriers to meeting their wellbeing needs, within the context of Covid-19.”</p>	RQ1, RQ2, RQ3	Semi-structured interviews with 21 autistic adults in the UK and follow-up interviews with two adults from initial sample and two additional adults recruited due to experience of providing peer support
	<p>Featherstone, C., Asthana, S., Axford, N., Sharpe, R. A. &amp; Husk, K. Running the gauntlet, fighting a battle or choosing self-defence: A candidacy framework analysis of autistic adults' experiences of accessing healthcare in the United Kingdom. [In preparation]</p>	<p>“Our study aimed to qualitatively explore the experiences of access and barriers to healthcare for autistic adults, and applied a candidacy framework to the themes identified to embed findings in established theory.”</p>	RQ2, RQ3	
	<p>Featherstone, C., Axford, N., Sharpe, R.</p>	<p>“Through semi-structured interviews exploring autistic adults' views and experiences of social prescriptions</p>	RQ2, RQ3	

	<p>A., Asthana, S. &amp; Husk, K.  A Qualitative Study Exploring Acceptability of Social Prescribing for Addressing Wellbeing in Autistic Adults  [In preparation]</p>	<p>and similar non-medical support in community settings, this study aimed to investigate the acceptability and accessibility of the SP pathway from first-hand perspectives.”</p>		
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## **Target Population**

The target population for this research was autistic adults living in the UK. This was to ensure that findings could be applied to UK policy around both social prescribing and autism. This included those with other co-occurring conditions, with the only specification being that participants had to be able to complete the study procedures either independently or with support from the researchers or an external supporter. Proxy participation was not permitted, as the research aimed to capture first-hand perspectives, and research suggests poor alignment between proxy and self-assessments of relevant concepts such as quality of life in samples of people with intellectual disability (a common co-occurring condition in autistic adults with higher support needs whose experiences may be subject to the use of more proxy reporting in studies) (Koch et al., 2015). Participants were asked if they required any adjustments to study procedures to assist their participation, and we also took steps to make the research more accessible such as providing downloadable content, allowing communication in a range of formats, and providing easy-read information where requested. These measures are expanded and reflected upon further in chapters detailing the stages of the study, as well as in the Discussion ([Chapter 8](#)).

## **Research Context: Social Prescribing for Autistic Adults in the Context of COVID-19**

All of the approaches detailed above were impacted when, in 2020, the COVID-19 pandemic presented a novel situation with implications for the population in question and the context of this research. Early analysis by experts on autism suggested that COVID-19 and the associated restrictions would have far-reaching implications for autistic people, from widening existing inequalities to presenting new problems (Cassidy et al., 2020). For example, areas in which autistic people were already vulnerable include economic instability,

job security, access to healthcare, communication problems and physical and mental health. These vulnerabilities may have been exacerbated by a weakening economic situation, reconfiguring of health services, reduced access to food and other necessities, and social isolation brought about through COVID-19 lockdown measures (Cassidy et al., 2020). Previous research has found that access to tangible social support moderated the association between depression and suicidal ideation in autistic adults (Hedley et al., 2017), and social distancing may have limited access to such support.

A survey by the Office for National Statistics found that those with social and behavioural disabilities, including autism, reported the highest concerns in relation to mental health compared to other disabled populations during the restrictions implemented in Spring 2020 (ONS, 2020a). On the other hand, there was the possibility of some benefits of the situation and a potentially more inclusive future with enhanced accommodation of the needs of disabled adults, such as increased working from home and a levelling of social needs (Heasman et al., 2020).

Some early research involving autistic people and their family members (e.g. National Autistic Society, 2020; Pellicano et al., 2020) supported these discussions, demonstrating the nuances of the situation. Throughout the course of the present project, further findings of surveys and qualitative research were added to the research literature which have described the impact of Covid-19 on autistic adults. Survey-based studies which have focused on mental health have shown increases in anxiety and stress (Bal et al., 2021; Bundy et al., 2022; Hedley et al., 2021), while qualitative and mixed-methods methodologies demonstrated a mixed picture as predicted (Bundy et al., 2022; Hedley et al., 2021; Mosquera et al., 2021), including some improvements in access to services that were attributed to the ability to access them via remote methods. However, for some individuals this was less accessible, provided lower quality care, or limited access to the full range of services or social support needed to

access services (Bundy et al., 2022; Pais & Knapp, 2021). Some studies have also shown autistic people have a higher exposure to risk factors that can increase vulnerability to morbidity and mortality attributable to Covid-19 infection (Schott et al., 2022). This could have implications for long-term health outcomes and the need for more support around managing risk.

It was also speculated that the impact of the economic consequences of the pandemic on wider population health would begin to emerge due to links between unemployment and financial stress with health outcomes, and require intervention (Younan et al., 2020).

Allwood and Bell (2020) suggested that mental health impacts of lockdown and economic instability may be most persistent for people from minority groups, older adults, people at risk of abuse and people with long-term conditions due to existing vulnerability, both to COVID-19 infection and structural inequality. Furthermore, Matias et al. (2020) identified physical and emotional health impacts, including changes to diet, increased stress and loss of social contacts. Long-term effects of COVID-19 infection have also been documented, suggesting the virus can cause chronic ill health such as fatigue and cardiovascular abnormalities (Yelin et al., 2020), adding to the complexity of the illness and the need for long-term health management approaches.

Social prescribing may present some solutions to these varied issues, as the VCSE sector has been able to support the response to COVID-19 through using existing resources to identify vulnerable individuals to health services and provide practical support locally (Cole et al., 2020). Demand for VCSE services increased by up to 700% in some areas as people who had not previously been identified as vulnerable required support during COVID-19 (Cole et al., 2020). This came at a time when Integrated Care Systems (ICS) in the UK health and care sector were being developed, aiming to increase collaboration and integration between sectors and provide place-based partnerships (NHS England, n.d. (c)). Social prescribing was

often called upon to provide support for mental health and social isolation and in many cases this was facilitated by the existing community connections across the sector that may have been absent from traditional medical services (Fixsen et al., 2021; Westlake, Elston et al., 2022). However, there were also challenges for the sector, including resourcing, digital exclusion, service closure and the expectation to respond to needs outside of the social prescribing role remit (Fixsen et al., 2021; Westlake, Elston et al., 2022). Despite the role of the voluntary sector in the COVID-19 response, it continued to be deprioritised in higher level decision-making in ICSs during this time (Miller et al., 2021).

In the longer term, social prescribing may be able to provide access to health-enhancing activities to counteract the widening health disparities resulting from the pandemic. For example, Matias et al. (2020) propose that exercise is an accessible and appropriate solution for both the mental and physical needs associated with these problems, as exercise is known to improve mood, facilitate weight loss and improve cardiac health. Social prescribing may also help to restore social connections and provide continuing tangible support to people who are clinically vulnerable. Access to health-enhancing activities through social prescribing may, therefore, help to readdress disparities in health and wellbeing that have arisen due to COVID-19 for autistic adults.

Accounting for these factors, the aims of this research were reframed to incorporate the context of COVID-19. This included research questions for some stages of the study addressing the impact of Covid-19 and associated restrictions to daily living and service provision. For example we considered it important to understand how the pandemic may impact access to healthcare as the initial point of entry to many social prescribing pathways, and its impact on self-management of wellbeing for autistic adults. Changes to how services are accessed may have impacted candidacy for healthcare (Liberati et al., 2022), the ability for patients to gain recognition as being deserving of care; many changes are likely to persist

beyond the immediate pandemic period through the implementation of more efficient systems (P. Webster, 2020). Through investigating its impact on healthcare access and wellbeing self-management it is possible to make recommendations for future inclusive delivery of care that continues to operate in the way that has been adopted since the pandemic, such as remote healthcare delivery.

COVID-19 also impacted the methods that could be used for operationalising the research questions. From 2020-21, there were several periods of 'lockdown' and restrictions to daily life, sometimes enforced at short notice, where the population was advised to work from home and minimise social contact. These were sometimes implemented at different times across the devolved nations of the UK. At other times there was a tiered system of restrictions in response to local levels of viral transmission, which was adjusted frequently. These measures, as well as community levels of the disease, had an impact on ability to plan in-person research activities, and ethical implications for relying on participants to travel when in place and risking transmission of the disease to participants before vaccines were widely available. The majority of the study was designed during the initial lockdown in March 2020 when the trajectory of the pandemic and restrictive measures was uncertain. To account for this, online research methods were chosen as the most stable option for data collection during this period.

Such methods may be advantageous compared to the originally planned face-to-face methods, given the communication styles of autistic adults, for whom interacting in online environments can be more acceptable than face to face interactions due to differences in processing styles and ways of communicating information (Benford & Standen, 2009; Brownlow & O'Dell, 2006; Gillespie-Lynch et al., 2014). Online interactions can offer flexibility that can improve accessibility, such as asynchronous data collection (Wilkerson et al., 2014), which may accommodate communication difficulties such as processing time.



Online interactions also allow participants to take part in studies within a familiar environment, where travel and unfamiliar locations associated with offline research may have presented challenges including anxiety and sensory discomfort (Gowen et al., 2019). On the other hand, some barriers to digital engagement may persist. These are likely to vary between individuals as the result of complex biopsychosocial interactions including accessibility issues and social factors (Tsatsou, 2020). Therefore, alternative ways of engaging were incorporated, such as being able to participate by telephone or request assistance with completing online forms.

### **Research Ethics**

Study materials, processes and data management plan were approved by the Faculty of Health Research Ethics Committee on 27 August 2020 (ref: 19/20-1311) (Appendix 1). Participants were provided with information sheets outlining the study aims and procedures and their rights as participants, including the ability to withdraw their data and cut-off points for doing so. Data management procedures were outlined in plain language. In the survey study, the information sheet was also reviewed by a small pilot group of autistic adults from a local support group in Plymouth, who gave feedback leading to some improvements such as changes to wording and improved readability. Consent forms were developed for each stage of the study to check that participants understood and agreed with all stages of the procedures. For the online survey, this was hosted on the survey website and participants could not proceed with the study without consenting to each of the procedures. For interviews, consent statements were read out to participants and their verbal agreement with each statement was recorded along with asking them to confirm their name.

Survey and interview data were stored separately to participants' personal data to ensure data were anonymous. During transcription of interviews, names and other references that may identify a participant, such as locations or names of services, were changed to protect their identity. In compiling demographic data from the survey, fields with fewer than five responses were replaced with "<5" to avoid identifying individuals from smaller subgroups.

In all studies, participants were provided with a debrief sheet informing them about the next stages of the research such as how their data would be used, how to withdraw and providing resources for support including autism-related information and mental health helplines, due to the potentially distressing topics addressed within the studies. During the interview process when such topics arose, I remained attentive to participants' wellbeing, making sure to check if a participant was comfortable to continue and recommend a break, if they appeared distressed or spoke about a distressing experience.

At the request of a participant with significant communication barriers, an amendment was approved on 1 September 2021 which allowed interviews to also be carried out by email (Appendix 2). Literature around this subject suggested this was an inclusive and practical solution (Crane, Sesterka et al., 2021; Wilkerson et al., 2014) to maximise participation. The participant consented to the study by typing their response to the consent statements in an email and signing with their full name (this was then stored separately to their interview responses). This adjustment was not requested by other participants, although they were subsequently made aware this offer was available.

In line with APA guidelines (American Psychological Association, 2020), the terminology used throughout the studies – particularly choosing identity-first (“autistic people”) over person-first (“people with autism”) language – aligned with preferences of the wider autistic community (Kenny et al., 2016; Lei et al., 2021; Taboas et al., 2023) and the guidelines set

by health services and autism charities in the UK (National Autistic Society, n.d.; NHS England, n.d.(b)); this required demonstrating these sources to the faculty ethics committee. Although surveys demonstrating these preferences may not be representative of the whole autistic community, they could be considered the ‘best guess’ until further research can be developed to corroborate the findings drawing from more marginalised subpopulations. While some researchers may view language preferences as inconsequential (for example, choosing to alternate between medical model-aligned terminology and identity-first language), following the community preference demonstrates critical engagement with how medicalised terminology can perpetuate stigma for this population which is expressed in both academic and non-academic discourse (Botha et al., 2023; Bottema-Beutel et al., 2020; L. Brown, n.d.; Gernsbacher, 2017; Sinclair, 2013) (in other populations, such as people with cancer, person-first language reduces stigma by distancing the person from their condition). Terms such as Asperger Syndrome and functioning levels (e.g. high-functioning autism) are also avoided except in reference to previous research using these terms or where used by study participants. This decision was made because classifications of ‘forms’ or ‘levels’ of autism are increasingly considered outdated and subject to dubious ethics and utility (Herwig, 2018; Kapp, 2023; Alvares et al., 2019). In line with the values of approaches with high levels of community involvement, I also shared plain language summaries of findings with study participants and published study findings in Open Access journals.

## **Theoretical Framework**

The design of this research is attentive to theoretical debates in both areas of autism research and social prescribing research, particularly the role of the biomedical model of healthcare. These debates are discussed in relation to social prescribing in [Chapter 1](#). The biomedical model situates disability as being due to a medical impairment within the individual, and prioritises treating a condition as the means to improving outcomes (Smart, 2006). Evidence

for the dominance of this paradigm in clinical and academic discourse around autism includes diagnostic criteria that specify deficits, impairments and levels of functioning as characteristics of individuals that lead to a diagnosis decided by a medical expert (American Psychiatric Association, 2013). This is also evident in the allocation of most research funding for studies of biomedical causes, risk factors, treatments and prevention of autism (Cervantes et al., 2021; Office of Autism Research Coordination et al., 2019), with minimal research funding spent on development of services despite this being one of the highest priority areas from the perspective of autistic adults and other community stakeholders (Pellicano et al., 2014).

Recently, autistic scholars have drawn attention to the advantages of critical realism in relation to autism research (Botha, 2021b; Rosqvist et al., 2023). This is the assumption that a material reality exists but that knowledge of the mechanisms of reality is influenced by an interplay of diverse social structures, mechanisms and contexts, resulting in different perspectives and partial understandings of reality, not all of which are measurable (Botha, 2021b). This may give room to accommodate different interpretations and understand the structures of power embedded in them, as well as to acknowledge their limitations. For example, critical realism proponents in autism research argue that findings of empirical studies based on a biomedical perspective may lean too heavily on the role of outsider observation, leading to epistemological injustices such as assumptions that autistic people cannot reliably relate their internal experiences due to their communication and social differences (Botha, 2021b; Legault et al., 2021). This ensures the dominance of the medical discourse through undermining the value of lived perspectives. Critical realism also moderates relativism that may undermine the importance of autism as a diagnostic category, as it acknowledges the measurable nature of social disadvantages observed in the autistic population compared to other groups (Botha, 2021b).

Alternative academic viewpoints on autism have been proposed to counter the limitations of the dominant medical model, including its examination through the lens of the social model of disability and critical disability studies (Woods, 2017; Woods et al., 2018), paradigms for which the inclusion of disabled scholars in academia has driven progress. These models consider disability alongside the contexts and structures of power in which people and their values operate. Thus, disability emerges from loss of opportunity afforded by the social environment rather than existing solely within the person (Oliver, 1990; Shakespeare, 2016). Neurodiversity is a further concept that has been driven by autism self-advocacy and community activism (Leadbitter et al., 2021). Neurodiversity is the notion that there is innate variation in human neurology leading to different ways of processing reality; thus any population of humans can be defined as neuro-diverse. From an ontological perspective, neurodiversity aligns well with critical realism, but is also partly in alignment with the medical model through acceptance of a biological reality of autism as an innate difference in neurology. However, it also adopts social model principles by arguing that disability arises from a lack of acceptance and accommodation for people in neuro-minorities, due to dominant social norms that lack consideration for cognitive diversity (Leadbitter et al., 2021; Stenning & Rosqvist, 2021). Clinical priorities such as diagnosis and intervention are compatible with this paradigm, but place emphasis on fostering wellbeing, reframing individuals' differences as potential strengths and on the importance of the person-environment fit as a focus for intervention rather than attempting to alter individuals' neurology or behaviour (H. M. Brown et al., 2021; Leadbitter et al., 2021).

Qualitative research accounting for lived experience, including grounded theory and interpretative approaches, ethnographic studies and studies that have used novel communication tools to include those whose voices have been historically marginalised (e.g. Lam et al., 2020), has facilitated alternative understandings of autistic traits that are

documented in diagnostic criteria for autism. These include repetitive behaviours (known as “stimming” in autistic community spaces) (Kapp et al., 2019) and the ways in which many autistic people relate to their diagnosis as part of their identity (Botha et al., 2020; Milton & Sims, 2016). Autistic scholarship and the inclusion of autistic people as research partners has given voice to concepts that may be harder to observe, such as autistic people’s experiences of masking or “camouflaging” autistic traits, that can make diagnosis more challenging in minoritised groups yet is an urgent public health matter due to its association with poor quality of life and suicidality (Cassidy et al., 2018; Hull et al., 2017).

Such research has also led to theoretical developments in understanding the mechanisms that may underlie neurodiversity. These include monotropism, the theory that differences in allocation of attention could underlie traits of autism and other neurological conditions such as ADHD (Murray et al., 2005), and the ‘double empathy’ problem, a reframing of communication and theory of mind impairments to account for the reciprocal nature of empathy and its situation in social contexts that also affect non-autistic communication (Crompton, Ropar et al., 2020; Marocchini, 2023; Milton, 2012). As explored in later chapters, these issues can affect interactions with health services and other social environments, impacting wellbeing.

Autistic scholars have also noted how studies which have found evidence of cognitive strengths in autistic people often frame these differences as deficits (Gernsbacher et al., 2006), indicating how a medical model position can be dehumanising and disempowering. Positivist biomedical research also prioritises heterogeneity across how autism is defined and experienced within samples, arguing that enhanced community input may blur established definitions, leading to difficulty targeting interventions at those with higher levels of need (J. A. Hughes, 2021). The critical realist approach to autism argues that too great a focus on heterogeneity may lead to reductionist solutions, avoid examining that which is not yet

known, and perpetuate inequalities by marginalising sectors of the autistic population who are less able to self-advocate or fit less easily into the medical model's paradigm of autism (Botha, 2021b; Pellicano et al., 2022). This includes people whose ethnic background is marginalised in Western science, women and gender minorities, and older adults (Cascio et al., 2020). Within a critical realist perspective, diversity in personal expression and understanding is expected and valued (Shannon-Baker, 2016).

Due to the complexity offered by social prescribing as a cluster of approaches rather than a standard pathway or model, which may vary across contexts, social prescribing research literature has often applied realist methodologies to develop the theoretical knowledge base. These studies have highlighted the importance of the contextual factors underlying the main mechanisms and outcomes observed in studies of social prescribing. Staff training, beliefs and expectations of patients and service staff about the benefits of social prescribing for the presenting issues, trust, level of personalisation, locations of consultations and services and sustainability of funding have all been identified as relevant factors in how social prescribing achieves its outcomes (Bertotti et al., 2018; Calderón-Larrañaga et al., 2021; Husk, Blockley et al., 2019; Tierney et al., 2020). The present research recognises these findings as an important theoretical grounding but also aimed to build and reflect upon previous knowledge through interrogating new perspectives and including other theories from outside social prescribing literature. These include the candidacy model (Dixon-Woods et al., 2006) (see [Chapter 5](#)) that applies a critical interpretative synthesis to studies conceptualising access to healthcare to critique dominant assumptions around equity of access. Attention to knowledge production from within emancipatory and participatory autism research is also centred within this research which may introduce novel contexts and meanings to some of the concepts identified in social prescribing literature. For example, such research has identified the service priorities and healthcare barriers affecting autistic adults (Pellicano et al., 2014;

Raymaker et al., 2017), many of which can be applied to the social prescribing pathway. Importance is also placed on intersectionality, such as how gender, socioeconomic status or age intersect with autism and the wider social context. Social prescribing pathways are examined within these contexts to understand its acceptability and accessibility specifically for autistic adults, an under-researched group in the social prescribing literature, including potential issues for marginalised subpopulations.

The research uses mixed methods, which offer alternate and complementary ways of approaching research questions. From a critical realist perspective, employing a mixed methods approach to examine a research question can give a more complete impression of the relevant concepts, explore contradictions in different perspectives around the same concept and address ontological limitations of different methodologies (Shannon-Baker, 2016). For example, the survey study in [Chapter 4](#) aimed to use empirical methods to examine time-based trends in barriers to healthcare for a sample of autistic adults, determine whether these differ significantly across demographic groups, and explore associations with wellbeing.

To build upon this, [Chapter 5-7](#)'s examinations of experiences of a smaller subset of the survey population through richer qualitative interviews and application of the candidacy framework, attends to dynamic processes and interactions between people and services that may underlie healthcare barriers identified in the survey, and the ways participants understood and assigned meaning to these interactions. While quantifying barriers to healthcare has highlighted types of adjustments to consider within care pathways for autistic adults to increase accessibility of social prescribing, this deeper analysis highlighted the role of autistic masking – a concept that has gained recent attention in autism research but may be less known elsewhere – and how the successful application of reasonable adjustments for autistic adults may interact with hierarchies of access to material and social resources (see [Chapter 5](#)).



## **Methodology Components for Original Research**

Methods for the systematic mapping review, which preceded this stage, are described in depth in [Chapter 3](#). These include the search strategy, inclusion criteria, data extraction and synthesis, and are described there in sufficient detail which does not warrant repeating in this chapter. For clarity and completeness, the following section synthesises and adds additional context towards the method selection and design of the original research (online survey and interviews) which is split between [Chapters 4-7](#).

### ***Online Survey: Aims and Objectives***

The online survey aimed to answer research questions on how access to health services related to emotional wellbeing and demographic characteristics for autistic adults in the UK across three retrospective time periods relating to the impact of COVID-19: Time 1 – in 2019 (or before), Time 2 – during the initial UK lockdown period between 23 March and mid-May 2020, and Time 3 – during the past month. A follow-up survey implemented six months after the final response to the initial survey introduced a Time 4, by asking participants again about their experiences over the previous month.

The survey method was selected for its ability to answer specific hypotheses pertaining to the research questions in a broad sample. An online format was chosen as the most feasible approach for reaching a known hard to reach population with consideration to Covid-19 restrictions. The follow-up survey aimed to compare changes over time as restrictions eased and people adjusted to new ways of living and accessing services. Survey research into this population is scarce (Rubenstein & Furnier, 2020) and this study intended to give insight into which effects of access to healthcare on wellbeing have persisted and for which subpopulations. This may inform tailoring of future social prescribing services for autistic adults in the context of Covid-19 and describe more persistent issues with access that could

be targeted to make healthcare and community spaces more inclusive and lead to improved wellbeing.

Survey results were published in the journal *Primary Healthcare Research and Development* in November 2022. (See [Chapter 4](#))

### ***Survey Design***

The design of the survey (see Appendix 8) was informed by consulting existing literature and professionals' expertise to identify research priorities and appropriate variables for testing the main constructs. Several studies have elicited insights into barriers to healthcare access for autistic adults, which were systematically reviewed by D. Mason et al. (2019). One of the included studies, conducted by Raymaker et al. (2017) used a community-based participatory research approach involving “autistic individuals, family members, health and disability services professionals, and academic scientists” (Raymaker et al., 2017, p. 973) to adapt a measure intended to be used in primary care settings to assess their accessibility for disabled adults. Autistic adults were involved in tailoring the scale through the inclusion of autism-specific items, adapting some of the language to be more accessible to this population and reviewing the content validity of the new measure. Items were selected based on their levels of endorsement across matched groups of autistic, disabled and non-disabled adults. The participatory methods are fitting with the approach of the current research through the centring of first-hand experience and a community-based approach. The constructs were validated by comparing correlations across the different groups. A short form was developed by combining and categorising some items. The short form was selected for the present study to reduce burden on participants, as the inclusion of other methods and demographic questions made the survey questionnaire lengthy. D. Mason et al.'s (2019) review suggests the measure is comprehensive and elicited findings which aligned with other measures.

The short form version of the Barriers to Healthcare Checklist (Raymaker et al., 2017) comprises 17 items measuring constructs such as communication, provider attitudes, sensory and socio-economic factors. For this research, some modifications were made to the questionnaire to improve applicability to a UK setting (e.g. removing a question regarding health insurance and changing “doctor’s office” to “doctor’s surgery” to improve clarity). The tense of questions was also changed so that the scale could relate to multiple time periods, and the “Yes/No” response options were reworded to “Agree/Disagree” to avoid double negatives.

PROMIS outcome measures were used to operationalise the construct of wellbeing, comprising emotional wellbeing, social support and changes to routine. PROMIS is a publicly available bank of patient reported outcome measures, aiming to capture outcomes most important to patients across a range of medical conditions and contexts (Ader, 2007). Scores are standardised based on averages in the general population of the United States; this enables a simple method of comparison with clinical samples. These measures are intended to be completed by the individual and have good consistency across different methods of administration (Wang et al., 2017). Holmes et al. (2020) had successfully used PROMIS measures to assess quality of life across the lifespan in US-based autistic samples. They found high feasibility and acceptability of these measures in autistic adults aged 18-65 years, fitting with the target population of the current research. They also used participatory methods to select those most relevant to autistic adults and develop an autism quality of life battery that could allow for replication of the same methods in future studies. The relatively low quality of life scores found in their sample in comparison to general population means reflects other research that shows similar trends.

The full battery of 18 measures would have been impractical for this study due to the number of scales involved; instead six scales relating to anxiety, depression, sleep impairment,

satisfaction with social roles, and emotional and instrumental social support measures were selected, which were most relevant to the types of challenges that participants might have encountered during lockdown based on the expert discussion by Cassidy et al. (2020).

### *Other Questions*

Screening questions: Participants were asked to indicate whether they had lived in the UK permanently since March 2020, and those who provided negative answers screened out. This ensured that participants' answers related to a similar chronology of the pandemic and associated restrictions in the UK. Participants who self-identified as being autistic without providing details of a formal diagnosis were required additionally to complete the AQ-10 Autism Quotient (Allison et al., 2012) to indicate whether they met the cut-off point of  $\geq 6$  which indicates eligibility for autism assessment. This measure may give some indication that those taking the survey who do not have a clinical diagnosis represent the target population, without needing to exclude this group altogether which could risk a less representative sample (more information on this decision is given in Sampling and Procedures, below). No participants who completed the survey scored below this threshold on the AQ-10.

Demographic questions included: age categories, gender, ethnicity, income, level of education, employment status, social deprivation by local area (as confirmed by postcode) and presence of other disabilities. These were based on knowledge of existing literature and research gaps around intersectional health inequalities experienced by autistic adults, as set out in [Chapter 1](#). Data on participants' usual communication method and level of social camouflaging were also collected to better understand the profile of disability in the sample. Participants were asked about the type of accommodation they lived in before and during lockdown, their habits during lockdown and the support they received in the form of government benefits, adult social care or community support across different time periods.

The survey also included questions about access to outdoor spaces, as I had initially intended to include a research question on nature-based social prescribing and horticultural therapy, but the results pertaining to these questions are not reported as this became less of a focus as the research evolved.

### ***Survey Sampling and Procedures***

An initial survey format was piloted in August 2020 with four adults from a local autism support group based in Plymouth. The pilot survey included feedback questions in the form of scale questions (e.g. “The survey length was acceptable.”) and open questions (e.g. “How could this survey be improved?”). Due to time constraints required by a partner organisation assisting with participant recruitment, only four pilot responses could be gained, but their detailed feedback provided some crucial insights into how to improve the instrument and the information for participants. Adjustments made to the survey after viewing the responses included the question layout and order, to prevent repetition of previous answers; simplifying questions by reducing response options; and improving readability of participant information.

A convenience sampling method was used to obtain responses for this survey, aiming for representation of the target population. This method was chosen as there is no formal medical register of autistic adults in the UK through which to select a random sample, and due to changes in diagnostic criteria, groups such as older autistic adults may also be underrepresented in clinical samples, as evidenced by recent increases in rates of referral and diagnosis amongst older age groups as this disparity begins to be redressed (G. Russell et al., 2021). As the backlog for adult autism assessment in the UK funded by the NHS is currently expected to exceed two years to clear (CHS Healthcare, 2023), allowing people to self-select may be more inclusive of those who had not yet managed to access an autism diagnosis or have been diagnosed through private services, which is more likely to affect women and

older adults (Lewis, 2017; McDonald, 2020), increasing representativeness of the sample. Self-identified autistic adults have been found to experience comparable outcomes as those with formal diagnoses (Doherty et al., 2022; McDonald, 2020).

Other forms of sampling, such as purposive sampling, are challenging with this population, as there remains uncertainty over the prevalence of autism and the configuration of demographic characteristics among this population. Research methods for collecting data to quantify the proportion of autistic people in the general population have varied and often been limited by the clinical criteria used, as in Brugha et al. (2011) whose diagnostic assessment tool, which did not consider existing clinical diagnoses, may have failed to detect autistic women, resulting in a ratio of 9:1 males to females and a conservative figure of 1% prevalence. This was also a time- and resource-intensive method for capturing the sample population. The 1.76% estimate in school children by Roman-Urrestarazu et al. (2021) is limited by identifying autistic children through the presence of a formal Education, Health and Care Plan (EHCP) or Special Educational Needs status, which misses undiagnosed individuals. Meanwhile the use of methods such as unverified parental report seen in studies such as Hosozawa et al. (2020) have resulted in prevalence estimates higher than in previous research. Changes to diagnostic criteria and assessments have contributed to increased prevalence of autism diagnosis in the population in recent years – much of this increase has been due to greater recognition of autistic women, girls, and adults who have previously been missed (G. Russell et al., 2021). This is evidenced by the now much higher prevalence estimates in large studies of paediatric samples (Wallis et al., 2023; O’Nions et al., 2023).

The main recruitment method involved contacting members of a database held by UK autism research charity Autistica via their Network mailing list. The database comprises over 16,000 individuals with a connection to autism, including autistic adults, parents and carers, clinicians and researchers, although primarily those with an interest in research or the work of

Autistica. The highest proportion of responses was gained immediately after the study advert was sent out to Autistica Network members. To widen the pool of participants, I also promoted the study through social media and research hosting websites including Smarten (an organisation focused on student mental health research in the UK) and the National Police Autism Association's research forum. Study details were also circulated to smaller autism charities and support groups operating at a local level in the UK, which were identified through a directory held by the larger National Autistic Society; many of these smaller organisations distributed the survey via their own mailing lists or social media accounts, and I also attended several of these groups' meetings to promote the research via community engagement. I also contacted disability support services, students' unions and disability networks at a selection of UK universities. A detailed recruitment report is included in Appendix 15 and is also part of supplementary material published with the research presented in [Chapter 4](#).

The survey was estimated to take 30-60 minutes to complete, with the option to pause the survey and return later. Participants were required to read the ethical information for the study and agree to consent statements in order to proceed (Appendix 3). Due to the inclusion of questions about emotional wellbeing, a debrief form provided participants with information about charities which provide support and advice around emotional wellbeing and autism (Appendix 4).

The initial survey opened on 9 September 2020 and closed on 31 December 2020. The follow-up survey launched six months after the close of the main survey and repeated questionnaires on barriers to healthcare, outdoor access, wellbeing, social support and changes to routine in relation to the past month. Participants were sent three prompts by email to complete the follow up survey before it closed at the end of July 2021.

### ***Survey Analysis***

Data analysis was carried out using IBM SPSS (version 25). Initial descriptive and graphical analyses were run to examine overall trends in the data. Inferential statistical methods were used to test hypotheses, with t-tests to compare differences in wellbeing scores and barriers to healthcare over time, and regression models to examine the impact of multiple factors on associations between variables, including demographic groupings considered to be relevant based on previous research (e.g. Brugha et al., 2011). These procedures are described in more detail in [Chapter 4](#).

### ***Strengths and Limitations of Survey Methodology and Design***

A strength of the survey design is the use of self-report measures which have been validated previously in similar samples involving collaborative approaches with autistic adults; these also allow participants to identify and report on their own internal states rather than relying on proxy report or outsider observation. A limitation of the design is the use of retrospective questions which rely on memory for different time periods. As participants were unlikely to be able to reliably report their emotional states for the period relating to the previous year, only questions on objective events such as healthcare barriers and time spent in outdoor environments related to this time period. The UK lockdown period was a specific period of time that all participants experienced and the sudden onset and shared experience with other people may have helped it to be memorable. The restrictions in place meant that lockdown would have likely been a relatively consistent time for many people. Therefore, questions relating to the lockdown period (time 2) included both objective and subjective questions.

There are likely to be some limitations of the representativeness of the sample due to difficulties reaching autistic people who face intersectional marginalisation, for example



people who had not completed higher education, who were underrepresented within the sample in this survey. The length of the survey may also have appealed to people with more time, higher literacy and who are not excluded through access to digital technologies. On the other hand, autistic adults considered 'higher functioning' have been observed as being at greater risk of mental health problems and suicides (Hirvikoski et al., 2016); this indicates there are specific wellbeing needs affecting this group that may have been overlooked and warrant attention.

Finally, some participants voluntarily gave feedback via email around aspects of the survey which could be improved in future studies, including layout of questions, length of the survey, limitations of measures used and inclusion of text boxes where they could expand on their answers to closed questions.

### ***Qualitative Study – Semi-structured Interviews: Aims and Objectives***

Following the online survey, I designed an interview-based study informed by results of the survey and gaps in existing literature. This aimed to capture the lived experience and perspectives of autistic adults and to complement the survey results. The study aimed to explore how autistic adults construct meanings of health and wellbeing in relation to autism and to elicit personal narratives underlying observed phenomena such as mortality and morbidity findings and barriers and facilitators to healthcare access. This research was intended to help address gaps in knowledge identified in the literature reviews and to offer opportunities to identify ways of delivering services and measuring outcomes that are relevant to the experiences and health goals of autistic adults. The study also aimed to gauge understandings, attitudes and experiences of social prescribing and how it related to

constructs of wellbeing self-management and healthcare access, to determine its accessibility and acceptability for this group.

### ***Interview Design***

The rationale behind the overarching research questions is set out below, along with how this led on to develop the interview schedules.

**Wellbeing Self-Management and Unmet Needs.** Autistic adults have been found to have lower wellbeing, including mental health and quality of life, than general population samples (Howlin, 2021; D. Mason, Capp et al., 2021); however, qualitative research may elicit perspectives on wellbeing that differ from representations of this construct typical in non-autistic populations. Establishing areas of unmet wellbeing needs for autistic adults will rely on considering autistic adults' understandings of their own needs. Furthermore, personalised and strengths-based approaches to wellbeing interventions for autistic adults, which could include social prescribing, need to centre individuals' abilities and interests and reduce barriers to achieving goals (Huntley et al., 2019). Thus, interview questions in this study aimed to explore how autistic adults self-manage wellbeing, in relation to personal understandings of wellbeing as a concept through asking participants to define what this means to them, and to identify where there are gaps where social prescribing as a personalised care approach could provide further support. This included asking participants about their routines around wellbeing self-management, how these were developed, and what they felt they required from services to support their wellbeing. Furthermore, some specific areas of wellbeing were explored in more depth, including connection to communities and experiences of different environments, as aspects that may be relevant to features of tailored social prescriptions. The context of Covid-19 was also included in these lines of questioning, aiming to attend to gaps in the growing literature on the pandemic's impact on autistic adults

based on expert discussions and statistical findings around areas of daily living that may have affected autistic adults disproportionately, such as social isolation.

**Access to Healthcare.** The majority of studies exploring access and barriers to primary care for autistic adults have been conducted using quantitative measures, resulting in numerical totals of barriers, sometimes across categories, and comparing these across populations (e.g. Raymaker et al., 2017). While important for highlighting inequalities, these studies reveal less on how autistic people understand and experience these barriers from personal and relational perspectives, and how these affect decision-making around healthcare help-seeking. This was considered important to the research topic as primary care is the main route of access to social prescribing in the NHS model. Interview questions asked participants to specify examples of their help-seeking processes, positive and negative experiences of accessing health services, and how their needs have or have not been accommodated. They were also asked to reflect on changes resulting from Covid-19, as an important part of the context surrounding this study, considering its impact on service delivery.

**Attitudes and Experiences of Social Prescribing.** Research findings suggest awareness of social prescribing among the general population may be low at present (Khan et al., 2022). The interview materials in the present study were designed to elicit participants' awareness and opinions on social prescribing in relation to their wellbeing needs and experiences of accessing health services. In cases where participants had no personal experience of social prescribing or of services with any similar features, a hypothetical example of a nature-based social prescription was offered. Where participants described accessing social prescribing or a similar service model, they were asked to reflect on their personal experiences. Questions were based upon previous realist research on the mechanisms of the social prescribing pathway (e.g. Husk, Blockley et al., 2019) and gaps in the social prescribing literature, asking participants to consider their awareness of social

prescribing in their local area, their beliefs and expectations in relation to more medical models of care, interactions with professionals involved in the pathway and reasons for choosing not to engage or lack of success.

**Follow-Up Interviews.** During interviews with autistic adults, it transpired that several participants in the sample had lived experience of providing or facilitating community-based peer support services aiming to support wellbeing needs of the autistic community locally. This area was of interest to the current research and appeared worthy of exploring further. Studies have considered the value and limitations of social prescribing to community-led services focused on specific disabilities, but this area is underexplored as it does not fit into typical categories of social prescription as outlined by Chatterjee et al., 2018. The literature review [[Chapter 3](#)] found that collaborations with autistic people and autism services were a potential facilitator to progression through pathways into community-based support for autistic adults. Working alongside autistic community leaders could be a potential mechanism to tailoring social prescribing offers to better serve the wellbeing needs of this population and so the perspectives of peer support providers was worth exploring further in relation to social prescribing.

Questions were based around the COM-B model of health behaviour, which had been developed to address some psychological processes missing from other health cognition models, such as “impulsivity, habit, self-control, associative learning, and emotional processing” (Michie et al., 2011, p. 2). The COM-B acronym refers to overarching influences of *Capability* (knowledge and skills), *Opportunity* (environmental and social factors) and *Motivation* (decision-making and emotional processes relating to personal goals) on health *Behaviour*. Deconstructing health behaviour and the provision of services in this way can give insight on how interventions can be designed to target these areas in order to promote health. This model could therefore be useful for making inferences about what aspects of the

pathways involved in access and provision of peer support could be targeted to promote accessibility and acceptability for autistic adults to achieve their goals around self-management of health and wellbeing, identified in the initial interviews.

Previous qualitative research has designed interviews around the COM-B model, including in the formulation and structuring of interview questions, and in deductive analysis of responses. For example, Baxter and Fancourt (2020) used the COM-B model to construct a topic guide exploring the barriers and enablers to voluntary sector practitioners working with people with lived experience of mental illness. Questions included asking about factors and skills present in the organisation and the wider environment which facilitated or hindered their work and the analysis mapped themes back onto the components of the model. In a similar vein, topic guides for follow-up interviews in the present research involved asking providers of peer support about: the resources needed to provide their service (opportunity and capability); how the offer of their service compared to other statutory services in their locality in relation to the local community's needs (opportunity); how they accommodated people with different needs (capability and opportunity); and positive and negative experiences of delivering the service, including impacts on their own wellbeing (capability and motivation).

All interview schedules are available in Appendices 9 and 10.

### ***Interview Sampling and Procedures***

All but one of the participants for the qualitative study (total N=21) were recruited through the existing sample from the survey, selected from those who had consented to be re-contacted on a first-come, first-served basis until a feasible sample size was reached. The method of selection was intended to add depth to the survey findings and ensure interviews reflected a similar population, making the research results more internally consistent. The

anonymous nature of the survey limited potential bias in drawing from the survey sample to recruit participants for interviews, as the survey responses of individuals applying to take part in interviews were not known to the research team. A further participant who took part in initial interviews was referred to the study by a contact who led an outdoor activity group for autistic adults and had expressed an interest in taking part in the study. Interviews took place between July and September 2021. Follow-up interviews involved two participants from the initial interviews (out of four who had been contacted for this stage). I then reached out to other peer support services that were available to try to increase the follow-up sample's size and diversity. This resulted in a final sample of four participants taking part in follow-up interviews between October to November 2021.

Semi-structured interviews were carried out online using Zoom, which has been assessed to be suitable for qualitative research (Archibald et al., 2019) and also included features which may enhance accessibility of the interview experience, through offering a range of communication options, screen sharing, telephone access, and virtual reactions. This aimed to help increase reach to under-researched subgroups within the population such as minimally verbal people, and several participants requested use of some of these features to enhance communication and processing. I had past experience of conducting semi-structured interviews in previous research roles. Techniques included the use of pauses, prompts, and open, non-leading questions to elicit more information from participants in their own words. Most interviews lasted between 45-90 minutes. Participant information for the interviews is available in Appendices 5-7.

### *Qualitative Analysis*

The overall method for analysis of qualitative data was reflexive thematic analysis. This methodology can be used flexibly, making it appropriate for both inductive and deductive

analysis of data, including mixed approaches. The process of thematic analysis followed Braun and Clarke's (2006, 2022) methodology. I familiarised myself with the data through listening back to interviews and correcting transcriptions, reflecting on each interview and considering at this early stage possible themes which I could tentatively identify. As a number of research questions were addressed in interviews, I began using inductive colour coding to highlight which question was best addressed by each extract – this did not always relate to the specific interview question or part of the schedule that prompted responses, as the interviews were analysed as a whole to avoid approaching analysis with preconceptions. Transcripts were coded *in vivo* and descriptive codes were later added to move towards identifying patterns in the data. During the coding process I made further reflections on interviews as advised by Saldaña (2021), including summarising the narrative of each transcript, my relationship to participants' accounts, and making notes on participants' actions and interactions. This enabled me to evaluate the narratives participants aimed to tell within their accounts and explore how my own assumptions, theoretical knowledge and lived experiences of autism and health services affected how I interpreted the data.

The repeated opportunities for reflection also enabled me to be mindful of the common pitfalls of thematic analysis, such as interpreter bias (Richards & Schwartz, 2002; J. Smith & Firth, 2011). Further ethical considerations for qualitative research have been described by Richards and Schwartz (2002). Their criticisms around issues such as transparency, informed consent and reflexivity around power dynamics informed how materials were presented and the procedures around data collection and analysis for this study. I also reflected on the practical issues of remote interviewing using video call technology, how the questions I had asked led to the responses I had elicited, and the effectiveness of semi-structured interviews as a method of capturing participants' experiences across the different research questions. My reflective practice involved evaluating and re-evaluating my position to the research

questions and the relation of the research questions and findings to existing research on autism and social prescribing. These reflections helped shape the development and discussion of themes in the analysis stages and to evaluate the strengths and limitations of the research, explored in detail in [Chapter 8](#): Discussion.

At the next stage, I started to explore themes by assigning preliminary categories to groups of codes using an Excel spreadsheet, which helped to organise data presentation. I then began organising categories into prospective themes according to the research questions using NVivo 12. At this stage it became imperative to discuss potential themes with my supervisory team to sense-check the findings and to examine alternative ways of organising the data and to consider existing theoretical frameworks that related to patterns in our own data. This can strengthen the analysis by ensuring the exploration of a new research question is examined in relation to established theory. For example, themes around access to healthcare included similar concepts to the candidacy framework and we then adopted a framework approach to organise the data around this research question. In this case, the candidacy framework (Dixon-Woods et al., 2006) had been an important development in understanding mechanisms affecting healthcare usage by underprivileged groups but had not been used extensively in neurodivergent or disabled samples. A previous research study by Chinn and Abraham (2016) suggested it had utility in examining access to primary mental health care for people with intellectual disabilities. Their analysis elicited consideration to structural, organisational and hierarchical barriers that suggest multiple complex levels contribute to access to healthcare beyond the role of individuals for groups who experience barriers to communication and navigation of services. In this research, applying the framework method involved familiarising with the candidacy literature and re-examining our existing thematic map through comparison with the literature and the source transcripts until the main themes were accounted for within the new thematic structure. For other research questions, such as



wellbeing needs, we developed themes more inductively but reflected on and discussed findings in relation to existing theory, such as self-determination theory and realist research around social prescribing, which influenced how final themes were organised and discussed in relation to other research findings.

Analysis of follow-up interviews was carried out after analysis of initial interviews; as the sample size was small, and initial reflections on the narratives supported the themes derived from initial interviews around access and acceptability of social prescribing, the coding of the follow-up dataset was incorporated into the existing analysis and themes underwent some restructuring until both initial and follow-up data contributed substantially to all components within the final organisation of themes.

### Chapter 3

#### **Health and Wellbeing Outcomes and Social Prescribing Pathways in Community-Based Support for Autistic Adults: A Systematic Mapping Review of Reviews**

This is the accepted version of the full article, *Featherstone, C., Sharpe, R. A., Axford, N., Asthana, S., & Husk, K. (2022). Health and wellbeing outcomes and social prescribing pathways in community-based support for autistic adults: A systematic mapping review of reviews. Health & Social Care in the Community, 30(3), e621-e635*, which has been published in final form at <https://doi.org/10.1111/hsc.13635>. This article may be used for non-commercial purposes in accordance with the Wiley Self-Archiving Policy [<http://www.wileyauthors.com/self-archiving>].

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### **Author Contributions**

CF led the study, and all authors contributed to the conception and decisions on methodology. CF designed and implemented the search strategy with advice from an information specialist, and screened results with RAS and KH. CF extracted and synthesised data with input from KH, RAS, NA and SA. All authors made critical amendments to draft manuscripts and approved the final manuscript.

### **Conflicts of Interest**

We declare no conflicts of interest.

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### **Data Availability Statement**

The data that support the findings of this study are available from the corresponding author upon reasonable request.

### **Acknowledgements**

We would like to acknowledge the contribution of Lorna Burns, Information Specialist (NIHR PenARC), in development of the systematic search strategy for this study.

# **Health and wellbeing outcomes and social prescribing pathways in community-based support for autistic adults: A systematic mapping review of reviews**

## **Abstract**

Adults on the autism spectrum are affected by health disparities which significantly reduce life expectancy and experience barriers to accessing healthcare. Social prescribing is a holistic approach that diverts patients from primary care to health-enhancing activities in communities. However, there has been a lack of research attention to how autistic people navigate the social prescribing pathway and the ability of these approaches to address existing disparities. This mapping review aimed to synthesise features of non-medical, community-based interventions for autistic adults to assess their suitability for a social prescribing approach. A systematic search and screening process was used to identify literature reviews from medical databases (Embase, Medline, PsycINFO, CINAHL and Cochrane reviews) and grey literature. We extracted data from 26 reviews and 21 studies including types of services, participants, outcomes, settings and procedures. A narrative and visual synthesis is used to map the variety of services and interventions identified, the outcome measures used, and the barriers and facilitators to progression through services in relation to a realist social prescribing framework. The review found that there has been minimal evaluation of holistic, low intensity services for autistic adults, such as those offered in social prescribing approaches. Outcome measures remain focused on features of autism and reveal less about the effects of interventions on health and wellbeing. Aspects of the social prescribing model were identified in the features of service pathways, but findings also suggested how social prescribing could be adapted to improve accessibility for autistic people.

## **Background**

Autistic people represent at least 1% of the UK population (Brugha et al., 2011; note identity-first phrasing is accepted terminology – see Kenny et al., 2016; Bottema-Beutel et al., 2020).

Although the characteristics of autism, which include differences in communication, social interaction and sensory processing (Barber, 2017; World Health Organization, 2018) can be disabling in many contexts, autism is not a pathology that causes degeneration or illness.

Despite this, autistic people experience health disparities including higher mortality and shorter life expectancy than the general population, and a high prevalence of preventable physical and mental health concerns (Hirvikoski et al., 2016; Woolfenden et al., 2012; Hudson et al., 2019; Kinnear et al., 2019).

In the UK, a diagnosis of autism alone does not qualify for input by mental health or learning disabilities (LD) services (Barber, 2017; Department of Health, 2014a). Inconsistencies in recording of autism diagnoses may also impact on how preventative healthcare, such as annual health checks, can be targeted (Sharpe et al., 2019). The UK Government's Autism Strategy (Department of Health, 2014a) has highlighted a need for low-level services for autistic adults delivered within communities to reduce inpatient admissions, promote social inclusion and assist individuals ineligible or unknown to other services in order to improve outcomes for this population.

Social prescribing is a distinct referral pathway which involves linking individuals who present to primary care with socially derived or long-term health problems to local, community-based activities such as art groups, exercise clubs and outdoor activities (Chatterjee et al., 2018). Social prescribing delivery typically involves a referral from a GP directly to a service based in the community, or to a link worker, who connects the patient to

a service or activity that will meet their presenting needs through a process of joint decision-making (Kimberlee, 2015). Social prescribing offers an alternative model to traditional healthcare through its holistic approach (Polley, Fleming et al., 2017), and furthermore is already established within primary care networks in the UK and being increasingly prioritised and funded (NHS, 2019).

It is argued that social prescribing has the potential to attend to multiple health and wellbeing needs and promote long-term health management, with studies finding positive impacts of social prescribing programmes and activities on mental health outcomes, subjective wellbeing, self-esteem, social isolation and physical activity in general population groups (Kimberlee, 2016; Foster et al., 2021; Boyce et al., 2018). Autistic people are also disadvantaged by social factors which underlie health inequalities in society (Marmot, 2010), including lower educational attainment, high rates of un- and under-employment, housing disparities and social isolation (Brugha et al., 2011; National Autistic Society, 2016; Orsmond et al., 2013). Social prescribing may help to mitigate some of these social determinants of health (South et al., 2008; Parkinson et al., 2015; Jani et al., 2020); for example, by addressing financial issues, which can impact on multiple areas of health including emotional wellbeing, stress and social relationships; facilitating the development of skills that lead to employment; and providing opportunities for social inclusion and long-term health maintenance.

Single studies of community-level interventions including recreational activities, low-intensity support services (e.g. advice hubs) and social support groups designed for autistic adults have shown reductions in perceived loneliness and improvements in life satisfaction, stress, communication, coping, skill development, quality of life and physical and emotional

wellbeing in autistic adults (Billstedt et al., 2011; García-Villamizar & Dattilo, 2010; Macleod, 1999; Southby & Robinson, 2018; Spain & Blainey, 2015). However, many studies have been characterised by high heterogeneity, small effect sizes and lack both active control groups and long-term follow-up.

While coproduced research with autistic people has identified mental health and quality of life as priority areas for addressing emotional wellbeing (Benevides, Shore, Palmer et al., 2020), many interventions and services for autistic people typically focus on reducing core traits of autism (Provenzani et al., 2020), suggesting wellbeing outcomes may currently be overlooked. Self-determination, employment, social support, personal development, coping, self-advocacy, and physical and emotional wellbeing are relevant indicators of quality of life for this population (Burgess & Gutstein, 2007; Kim, 2019; Schalock, 2000; Shattuck et al., 2012), however research has been limited by the use of mental health measurement scales that have not been validated in autistic samples and a lack of measurement of quality of life outcomes (Provenzani et al., 2020). Furthermore, the disparities in physical health for this population suggest physical health may also be an important outcome for services for autistic adults.

These types of interventions also represent only the end point of the social prescribing pathway. Alderwick et al. (2018) highlight the need for evaluation into service pathways and referral routes to assess how patients access and navigate between clinical and community services. As autistic adults report barriers accessing healthcare (Christou, 2016; Raymaker et al., 2017; D. Mason et al., 2019), leading to delays in treatment and poorer outcomes (Doherty et al., 2022), exploration of service pathways may be important for evaluating how social prescribing can be optimised for this group. Realist studies suggest that factors such as



the quality of a relationship with a GP, the accessibility and location of services and the quality of staff training can influence the outcomes of social prescribing to community-based advice and activities at stages of enrolment (referral), engagement (initial uptake) and adherence to a social prescribing intervention (Husk, Blockley et al., 2019; Bertotti et al., 2018). However, the influence of such factors on access to services and their outcomes for people on the autism spectrum remains underexplored.

Approaches relevant to social prescribing, such as art therapy, physical activity and music therapy, appear to have high acceptability for autistic people, who have identified a preference for such interventions to be available and accessible at the community level as a means of improving wellbeing (Benevides, Shore, Palmer et al., 2020). As a low-level intervention designed to be accessible and available at the local community level, social prescribing aligns well with the goals of the Autism Strategy and may be worthy of consideration as a route for improving health and wellbeing outcomes.

### ***Objectives***

Due to the scarcity of literature on social prescribing as a specific approach for improving health outcomes of autistic adults, this review will synthesise the results of reviews of similar community-based or non-medical support services for autistic adults. This review aims to identify gaps in knowledge around the provision, evaluation and mechanisms of these services through a mapping approach. It also aims to explore what these gaps reveal about the suitability of a broad range of existing support types for social prescribing approaches, to address community participation, social inclusion and wider determinants of health in autistic people, in line with UK health policy and the Autism Strategy (NHS, 2019; Department of Health, 2014a).

Prior reviews have been carried out on studies of this type of support for autistic adults (e.g. Lorenc et al., 2018; Shattuck et al., 2012) but without the focus on social prescribing. This review will address the following research questions:

1. What is the nature and variety of non-medical, community-based support for autistic adults that has been reviewed?
2. Which outcomes are measured for these services and how do they align with the wellbeing priorities of autistic adults?
3. What can existing research reveal about the characteristics of referral pathways underlying services and their contributions to the access to and success of services?

## **Methods**

We undertook a systematic mapping review of the evidence for non-medical interventions for autistic adults. Mapping reviews do not aim to answer a specific research question or appraise the evidence, but represent an exploratory approach to describe the nature of the evidence base, highlight gaps and identify trends in relation to a broad research question (James et al., 2016; Snilstveit et al., 2016). The process involves rigorous systematic searching and data extraction methods, with a visual and narrative synthesis of the findings. The methodological approach is detailed below.

### ***Scoping and Search Strategy***

We used a comprehensive, systematic search process to identify relevant literature. Search strategies were developed in collaboration with an information specialist and drew from the relevant expertise of the review team. Search terms were informed by scoping the existing literature yielding medical subject headings and free text terms pertaining to autism, community-level interventions (e.g. “community referral”; “third sector”) and typical activities and services offered within social prescribing schemes (e.g. “exercise”;

“gardening”; “advice”) (Chatterjee et al., 2018). Literature on interventions for autism, health-related quality of life and peer support within the Cochrane library of systematic reviews was searched to identify additional search terms, as well as using PubReMiner. The final search strategy was developed using Embase, with changes made to how terms were combined and filtered as a result of the amount of relevant hits and further search terms added as these emerged from literature identified through trial searches. The health-evidence.ca filter recommended by Lee et al. (2012) was used to limit results to previous reviews. Additional terms were added to the search strategy to identify further types of review including scoping reviews and rapid reviews. The finalised search strategy is available in Appendix 11 – Embase Search Strategy. The search strategy was applied to the following databases: Cochrane Database of Systematic Reviews, Embase, Medline, Psycinfo and CINAHL. Searches were run simultaneously on 6 December 2019, and repeated for an update of the review in January 2021.

We manually searched reference lists of accessed literature, personal collections, and websites of interest to identify further relevant literature. Including grey literature in a review can allow for the identification of non-academic sources, increasing the evidence base and reducing publication bias (Adams et al., 2016) and in reviews of complex interventions may obtain more valuable results than medical databases alone (C. Cooper et al., 2018). Therefore, EThOS, ProQuest Dissertations and Theses Global were used to identify academic theses, and Google and OpenGrey were used to identify further grey literature. Google searches comprised a broad web search with combinations of terms of the systematic search strategy, as well as focused searches of web addresses ending “.gov.uk”, “.org.uk”, “.nhs.uk” and “.ac.uk”. At least 20 pages of results for each search were scanned for relevant literature. Searches were also performed on The King’s Fund database (health and social care topics)

(<https://koha.kingsfund.org.uk/>) and Social Care Online (<https://www.scie-socialcareonline.org.uk/>). Searching for grey literature and hand-searching took place over a longer period beginning on 11 December 2019, and again repeated in January 2021. All records were extracted to and organised using EndNote X8.

### ***Inclusion Criteria***

**Types of Studies.** We included:

- Any type of review using recognised methods (systematic, scoping, mapping, rapid and realist reviews) to synthesise quantitative, qualitative and mixed methods studies and service evaluations;
- Policy documents or reports, which used a systematic search process with inclusion and exclusion criteria to identify relevant studies and a set protocol for data extraction.

We included reviews using any recognised type of synthesis (e.g. narrative; meta-analysis). Narrative literature reviews or any review, report or evaluation which did not use a systematic search process were excluded.

**Participants.** We included reviews where at least 50% of participants were adults (aged 16 or over) with a reported diagnosis of autism or suspected autism without learning disability, defined as either “autism”, “Asperger’s syndrome” (a former diagnosis for what is now considered to be autism), “autistic disorder”, “autism spectrum disorder” or “autism spectrum condition”. Where IQ but not LD diagnosis was specified, studies were excluded if over 50% of participants had an IQ lower than 70, which is a commonly used cut-off for learning disability (National Institute for Health and Care Excellence, 2018). Where this was

not reported in reviews, this information was discerned from the studies contained within reviews.

**Interventions and Context.** Included reviews needed to have evaluated at least one non-medical intervention. This could be categorised as any of the social prescribing models described by (Chatterjee et al., 2018) (arts, bibliotherapy, adult education, exercise, ecotherapy, healthy living interventions, information referral (including community hubs), supported referral, and/or time banks). Interventions designed to support social skills, employability (including volunteering), befriending and mentoring were also included if relevant to the population of interest. We also included reviews of psychosocial, mind-body, animal-assisted and occupational therapies if delivered outside of primary or secondary care models as further non-medical services that could potentially be targeted at the population of interest. Reviews from any country could be accepted but only those reported in English.

**Outcomes.** Outcomes could be qualitative or quantitative, and could either be self-reported, parent/caregiver/support worker rated, administrative or observational.

### ***Review Selection***

One reviewer (CF) deduplicated results using EndNote. For literature identified through the databases, titles and abstracts for all records were screened independently by two reviewers (CF & RAS) against inclusion and exclusion criteria using Rayyan (Ouzzani, Hammady, Fedorowicz, & Elmagarmid, 2016). Full text was accessed for studies which were included or where inclusion remained unclear. These were screened by two reviewers (CF & RAS) and disagreements were resolved through consultation with a third reviewer (KH). Studies

identified through grey literature searching were screened at the full text stage by two reviewers (CF & RAS).

### ***Data Extraction***

Meta-data relating to reviews were extracted and organised in tabulated format adapted from the Joanna Briggs Institute data extraction form for umbrella reviews (Aromataris et al., 2017) (see Appendix 12 - Identification of Reviews and Studies). Data were extracted by one reviewer (CF) and verified by another (RAS).

We coded outcomes of studies included in reviews into the domains of: mental health (e.g. anxiety, depression, self-esteem); physical health (e.g. physical activity level, physical disability); quality of life and adaptive functioning (e.g. quality of life, executive functioning, self-efficacy/self-determination); autism-related outcomes (e.g. diagnostic tools, empathy/theory of mind, behavioural, cognitive); wider health correlates as summarised by Marmot (2010) (e.g. employment; social support); intervention characteristics (e.g. satisfaction, cost-effectiveness, maintenance, generalisation); other outcomes (e.g. academic outcomes, social interaction quality/quantity, ADHD symptoms); and qualitative findings.

Some reviews did not summarise the results for all outcomes of their included studies.

Snilstvelt et al. (2016) recommend that evidence mapping approaches synthesise data from previous reviews and original studies to ensure both breadth and depth of the evidence. The extraction and synthesis of primary studies was also essential for extracting sufficient data to address the third research question. We therefore extracted data from primary studies in the included reviews but due to the quantity of previous research contained in reviews, and the relevance of our review to UK policy, limited these to studies evaluating UK-based services. However, the findings may be generalisable to other contexts such as the United States and Europe, where social prescribing is also an emerging form of health provision (Alderwick et

al., 2018; Baska et al., 2021), while health inequalities experienced by autistic people are prevalent across many regions (Hirvikoski et al., 2016; Woolfenden et al., 2012), requiring appropriate service provision and outcome measurement to address these needs. Extracting studies from existing reviews also enables access to previous evaluation of the quality of included studies to maintain rigour in investigating an underexplored area, and the inclusion of pre-synthesised literature across many disciplines ensures relevance to the holistic approach of social prescribing.

### *Data Synthesis*

Data from reviews and the extracted UK studies relating to types of intervention, setting, participants and outcome measures were summarised using charts. Study quality assessment was extracted from previous reviews where available.

The extracted primary studies comprised quantitative and qualitative research articles, reports and policy documents. Quantitative outcome data from primary studies were coded according to the same outcome domains identified in reviews; colour coding was used to signify if outcomes were observed to have a positive, mixed/unclear, or adverse effect (Aromataris et al., 2015) and effect sizes, statistical significance and measures used were noted. Coding was carried out by one reviewer (CF) supervised by a further two (RAS & KH).

For qualitative data, all full text articles of the UK studies were uploaded into NVivo which we used to extract descriptive information on study methods and context and qualitative results. Quotes were coded into themes using an inductive method. We adopted an essentialist philosophy and so data were coded at face value. Initial examples of themes were shared and verified by the other reviewers. Service pathway characteristics were coded into

facilitators and barriers and organised according to the framework described by Husk, Blockley et al. (2019) (Enrolment, Engagement and Adherence) (see Background section).

## **Results**

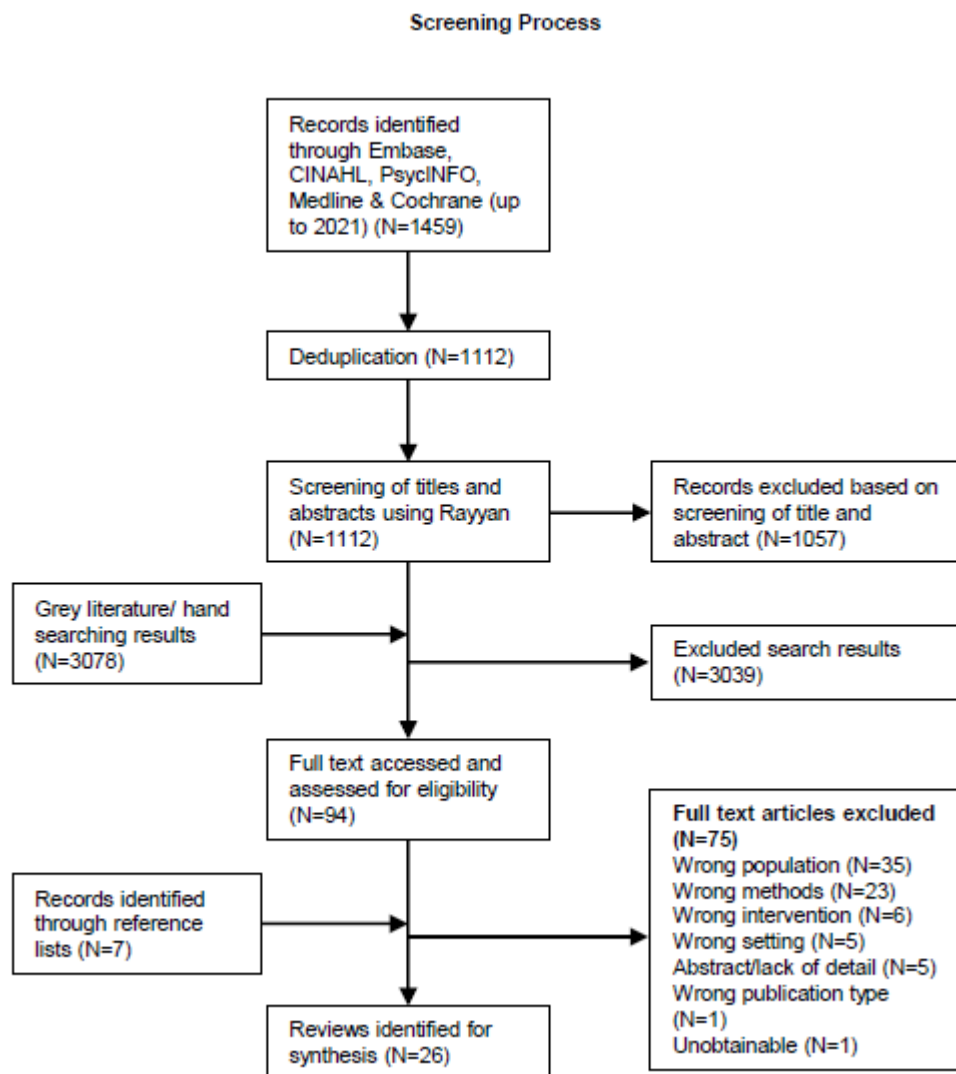
### ***Search Results***

The search strategies identified a total of 4536 hits through database and grey literature searches. 4443 were excluded at title and abstract screening, leaving 93 to be screened at full text. A descriptive summary and flow diagram in Figure 1 details the search process and results and indicates the number of studies identified and excluded at each stage of the process.



**Figure 1**

*Screening Process*

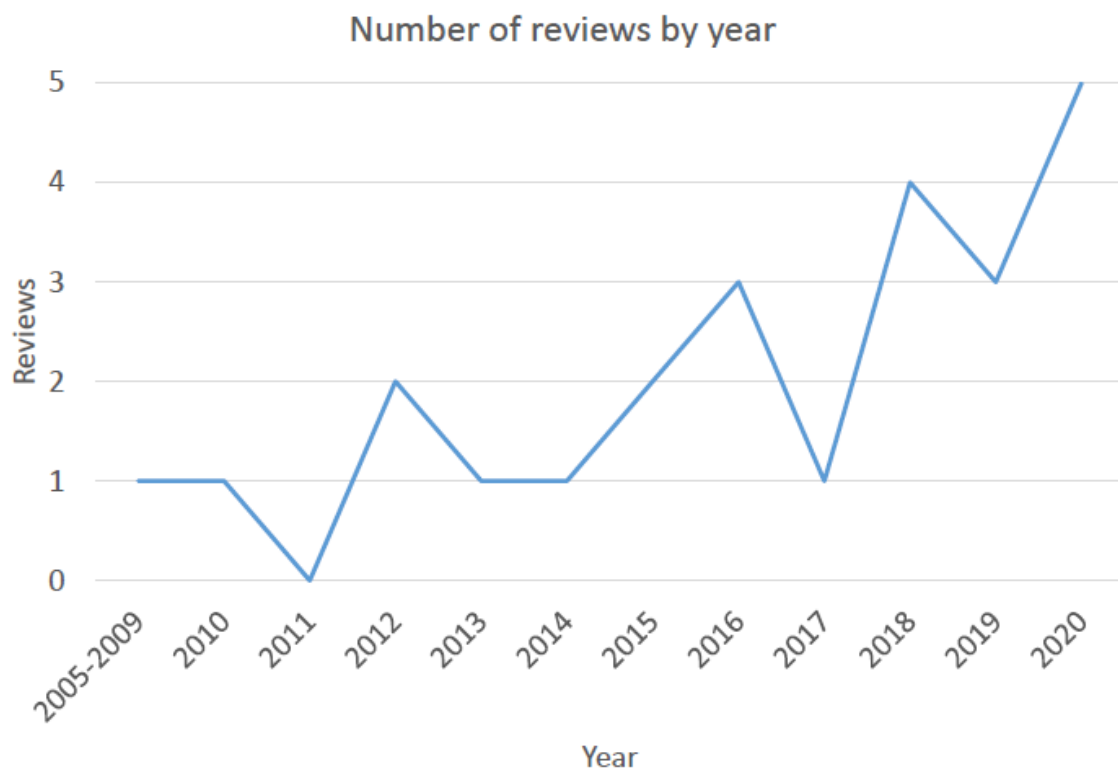


We identified 26 reviews that met the inclusion criteria and data were extracted from 24 of these. The remaining two reviews (Anderson et al., 2017 and Walsh et al., 2017) were items identified later via hand searching. Both concerned vocational interventions, a topic that had been included in ten previous reviews, and neither evaluated any UK studies, so a joint decision was made not to extract further data from these due to saturation and limited benefit from their inclusion. Included reviews comprised systematic, scoping and narrative reviews with a systematic search process. Reviews were published between 2006-2020 (Figure 2) and

included between 5-134 studies (M=22). Appendix 12 summarises the included reviews and the UK-based studies identified therein, including the appraisal ratings assigned to studies by the authors of originating reviews.

**Figure 2**

*Number of Reviews by Year*



***Extraction of Primary Studies***

Twenty-nine studies originating from the UK were identified in reviews and one study was unobtainable. We excluded review articles, studies which did not aim to evaluate outcomes of a specific service or intervention (e.g. cohort surveys) and one study where all participants were under the age of 16. The remaining 19 studies included in the synthesis were published between 1999-2017. One article reported the results of two studies (Golan & Baron-Cohen, 2006). The study included in most reviews was Howlin et al. (2005). Four studies, spanning

1999-2014, evaluated the same service, a supported employment intervention ('Prospects'), delivered by the National Autistic Society (Mawhood & Howlin, 1999; Nesbitt, 2000; Howlin et al., 2005; Mavranouzouli et al., 2014). Quality appraisal by previous reviewers was available for nine studies; of these, two were found to be strong (Mavranouzouli et al., 2014; A. J. Russell et al., 2013), two were of moderate quality (Nesbitt, 2000; Ridout, 2011), three were weak (Howlin & Yates, 1999; Spain et al., 2017; Macleod & Johnston, 2007), and two had inconsistent ratings between reviews (Howlin et al., 2005; Mawhood & Howlin, 1999).

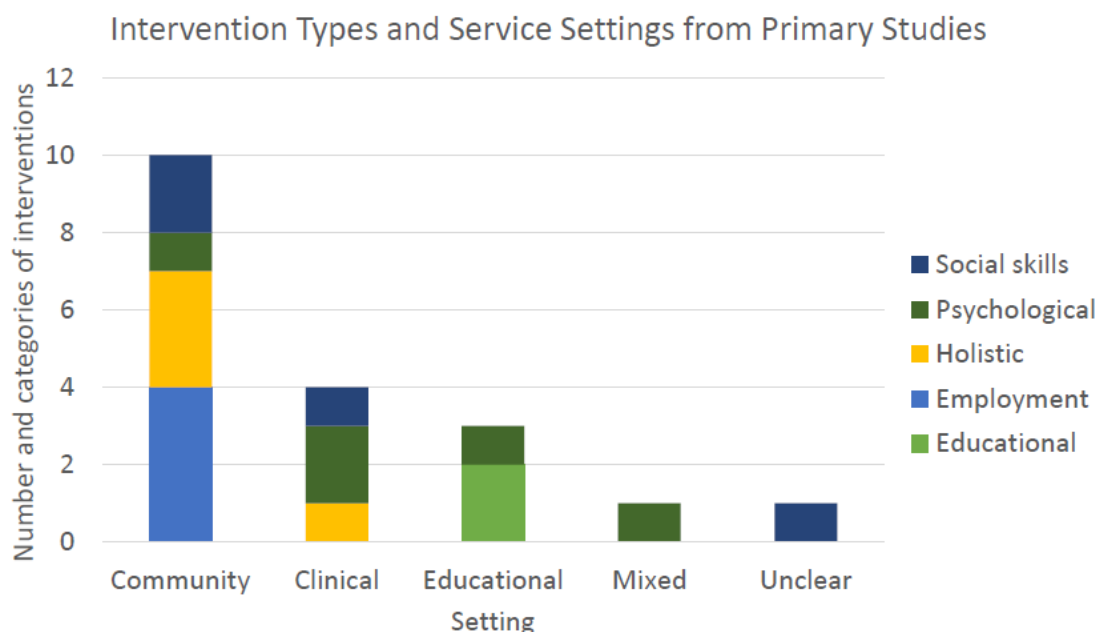
### *Quantitative synthesis*

**Types of Interventions and Services.** Reviews were categorised by topic. Nine reviews were concerned with psychosocial support and interventions, eight with vocational interventions, one with dance-based interventions (categorised as exercise), one with educational interventions for post-secondary students and five were generic reviews of a variety of services. Most studies were conducted in the US, UK, Australia, Canada and Western European countries.

The extracted UK studies evaluated cognitive behavioural therapy (CBT) (Holgate, 2012; Newey, 2002; Spain et al., 2017; A. J. Russell et al., 2013), social skills interventions (Ashman et al., 2017; Howlin & Yates, 1999; Golan & Baron-Cohen, 2006), the Prospects supported employment service (Mawhood & Howlin, 1999; Nesbitt, 2000; Howlin et al., 2005; Mavranouzouli et al., 2014), holistic community approaches (Ridout et al., 2011; National Audit Office, 2009), academic interventions (Lambe, 2015; Macleod & Green, 2009), mentoring (Milton et al., 2017), a peer support group (Macleod & Johnston, 2007) and a stress management intervention (Gracey, 2011). Most services described in the primary studies were delivered in a community setting (Figure 3).

**Figure 3**

*Intervention Types and Service Settings from Primary Studies*



Six UK studies did not describe their processes for obtaining informed consent. All other studies sought consent directly from participating individuals except in individuals aged under 16, where parental consent was sought.

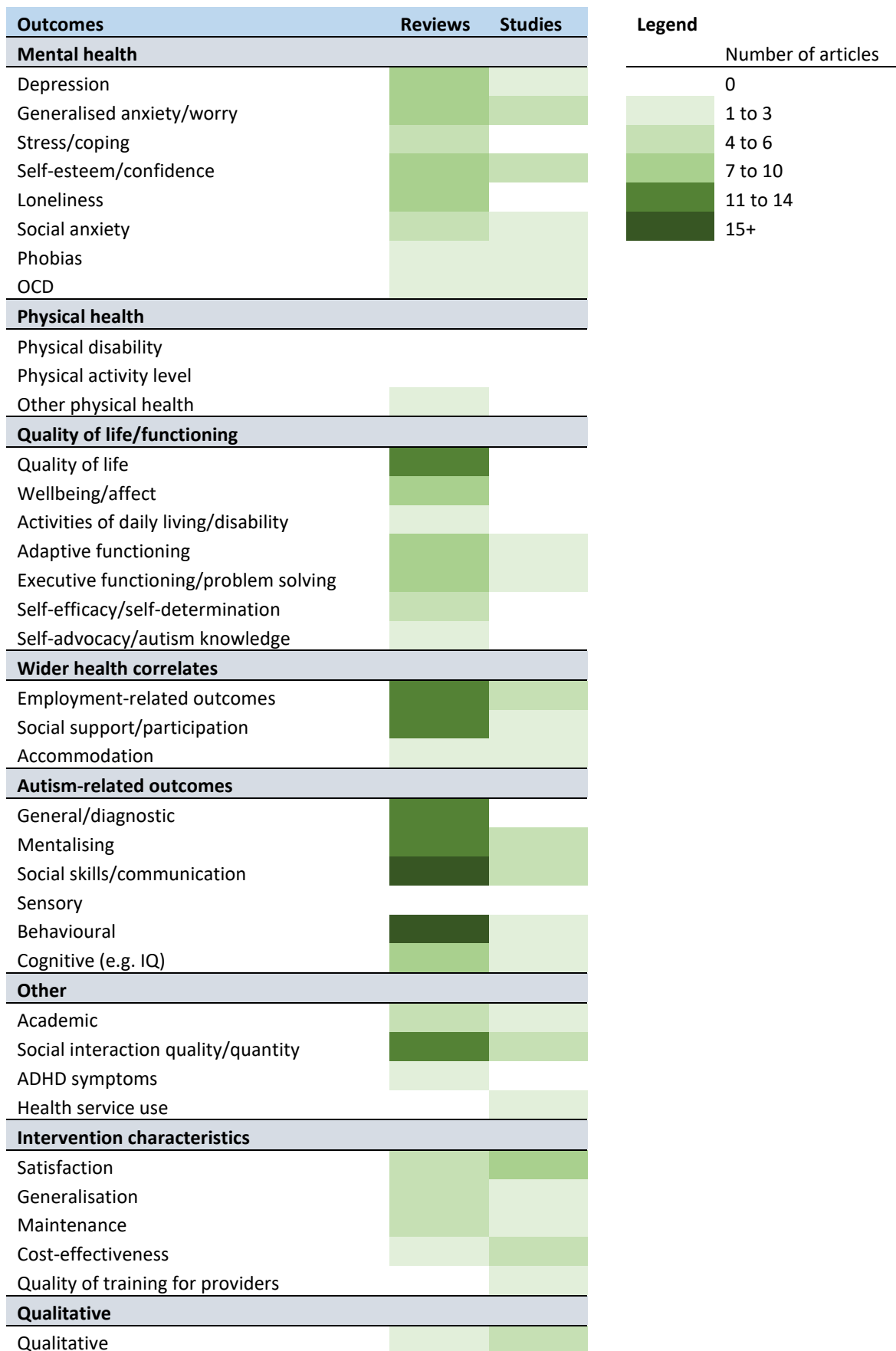
**Participants.** Where reported, participant age range for the reviews was 13-70 with means between 19-30 years for reviews and for UK studies age ranged between 14-61 with means between 18 and 36. Where gender ratios were reported, the proportion of male participants ranged from 56% to 91% for reviews and from 55-100% for UK studies, except for case studies involving single female participants. The majority of participants were of Caucasian ethnicity, though ethnicity was a seldom reported characteristic.

In 18 of the 19 UK studies synthesised, participants comprised autistic adults and in one study, participants were employers (Nesbitt, 2000). No studies reported the socioeconomic status of participants. More participants were unemployed than employed, and this remained the case after excluding students and participants of employment support services. Education level of study participants ranged from no formal education to completion of postgraduate education. All studies required clients to have a diagnosis, or be pre-diagnosis, of autism, Asperger Syndrome or high functioning autism.

**Outcomes.** The outcomes included in reviews and studies are shown in Figure 4. They are categorised according to the domains identified during data extraction.

#### **Figure 4**

*Outcomes Evaluated in Reviews and Studies*



**Service Pathways.** Figure 5 illustrates the synthesis of characteristics of the service pathways at the stages of enrolment, engagement and adherence. Characteristics of interventions that facilitated enrolment of participants into services included the effective and timely identification of needs, matching participants with staff based on goals, and managing expectations of participants and partner organisations. Methods of identification included databases held by existing services, the targeting of gaps in services, and accepting self-referral or referral from a family member or another service. Early identification of problems was important for preventing escalation; where participants did not perceive themselves to require the service, this presented a barrier to timely support. An initial meeting between an individual and the service or intervention provider to clarify expectations and alleviate anxiety was found to lead to greater enrolment in some cases. Some studies reported that participants and partner organisations sometimes had unrealistic expectations for what services would provide and their personal goals.

Collaboration with other services was a mechanism to engagement. This led to a sharing of expertise that extended beyond that of the main provider as well as helping to educate partner organisations, such as employers involved in the Prospects service, about autism. A mentoring service also included autistic adults in the design and delivery of training, which mentors reported as a benefit of the service. Another mechanism for engagement was opportunities for social interaction, which helped to build confidence in social situations and encouraged a sense of belonging to a group. However, some participants found group activities disagreeable, leading to disengagement, so there is a degree of individual preference and a need for flexibility around this. Barriers to accessibility, including transport, anxiety and limited communication options to allow for the rescheduling of appointments, also led to

disengagement. Practical issues around the design or provision of a service or intervention, such as technical difficulties, affected acceptability to participants. Claiming to forget or not have time to complete part of an intervention, which applied to several studies, also suggested a lack of acceptability or practicality. It was also important for measurement tools to be acceptable to participants; participants in one study disengaged where they perceived an outcome measure to be patronising.

The synthesis identified factors facilitating adherence to a service. The skills and qualities of staff delivering services influenced participants' enjoyment of an intervention and the provision of an effective service. These included professional qualifications, level of supervision and reliability. Participants were less satisfied where they perceived a lack of training or expertise. Where there were no standards or a precedent which staff could follow for their service, this created a challenge to providing skilled support. It was also challenging for providers to collaborate with other services in which staff lacked knowledge about autism or the aims of the intervention. Tailoring was a feature of several services at the adherence level; this was achieved through incorporation of participants' interests and goals, titrating the level of support according to participants' changing levels of need and involving family members. Reinforcement included providing homework and materials which could be revisited in a range of accessible formats, such as visual diagrams, and opportunities for spontaneous, unstructured learning. The duration of an intervention may also contribute to opportunities for reinforcement, with one intervention speculated to have been too brief to lead to measurable improvement. Resources utilised by services to deliver support included suitable venues, existing service models, staff training and technology; however, a lack of tangible resources such as staff or funds, long waiting times and systems that were insufficient, led services and staff to become overwhelmed. It was not always possible for

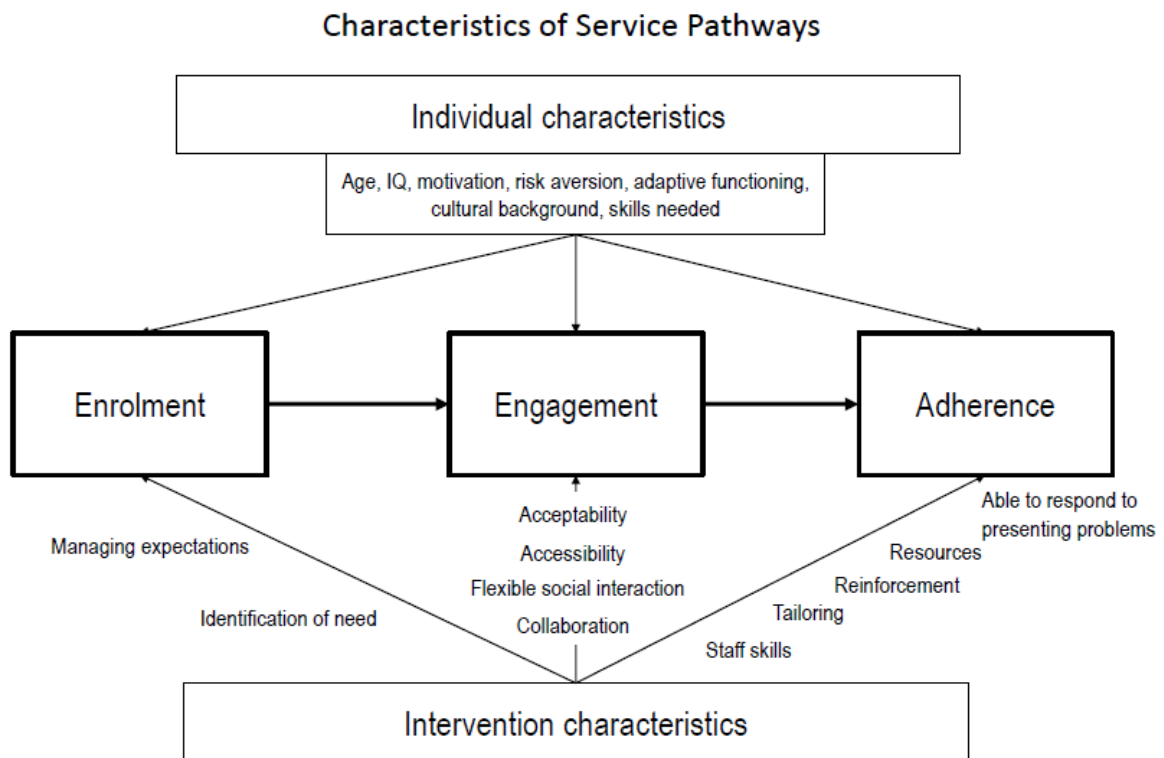


services to address all challenges participants faced in their daily lives, which created a barrier to adherence and achieving a positive outcome. Individual differences identified as affecting levels of enrolment, engagement and retention included age, IQ, motivation, risk aversion, adaptive functioning levels, cultural background and technical skills.

Supporting quotes for the themes outlined above are shown in Appendix 13 - Qualitative Synthesis of Service Pathway Data.

**Figure 5**

*Characteristics of Service Pathways*



## **Discussion**

This review synthesises current research around the variety of non-medical services which have been evaluated for autistic adults, the outcome measures used to assess their effectiveness and the features of service pathways. This discussion will position the synthesis in the context of social prescribing for autistic adults, which has lacked research attention as a distinct model of healthcare for addressing health disparities in this population.

### ***Types of Services and Outcome Measures***

The increasing number of reviews identified by year reflects overall increases in prevalence of autism research relating to adults (Kirby & McDonald, 2021). Our findings demonstrate that studies on employment support and psychosocial interventions have been comprehensively evaluated in reviews. There have been fewer reviews and studies evaluating support services more typical of social prescribing (e.g. information services and holistic approaches, see Chatterjee et al., 2018).

The majority of outcomes identified across all studies and reviews related to autism, including communication, behaviour and mentalising. These measures are selected to demonstrate improvement in a targeted behaviour or reduced autism presentation. Provenzani et al. (2020) have emphasised the importance of including outcome measures beyond those targeting core autistic traits, as there is no evidence that gains in these areas generalise to overall improved health, wellbeing, quality of life or daily functioning (Alvares et al., 2019; Burgess & Gutstein, 2007; Khanna et al., 2014; Lorenc et al., 2018; Marriage et al., 2009; Shattuck et al., 2012). Furthermore, suppression of autistic traits may be damaging to emotional wellbeing (Cassidy et al., 2015; Hull et al., 2017) and sense of identity (Wilkenfield & McCarthy, 2020; Hull et al., 2017), which highlights the importance of

measuring emotional wellbeing concurrently where interventions target autism presentation due to the potential for stigma (Scott et al., 2019) and promoting strengths-based interventions (Huntley et al., 2019). In contrast, social prescribing has been shown to lead to improvements across a range of outcomes and can promote social connections and community participation by facilitating integration within a diverse group of people (Bhatti et al., 2021). This, along with the person-centred and tailored nature of social prescribing, aligns with a more strengths-focused approach, which may help to alleviate the stigma associated with deficits-focused models (Huntley et al., 2019).

Many studies in the present synthesis included primary or secondary outcomes that were categorised as relating to mental health, quality of life, and the wider correlates of health such as employment, although these were less prevalent than autism-related outcomes. While previous reviews showing narrower outcome priorities have been dominated by studies of children (Provenzani et al., 2020), it may be that interventions targeting adults have paid more attention to outcomes identified as important to autistic people including anxiety, depression and quality of life (Benevides, Shore, Palmer et al., 2020). However, the outcomes selected can sometimes have low generalisability; Shattuck et al. (2012) noted that the skills targeted by employment interventions to prepare individuals for working in a prescribed role were often not generalisable to other jobs, suggesting a lack of practical application.

The quality of life dimensions of self-advocacy, community empowerment and human rights set out by Schalock (2000) and Kim (2019) were less evident, which was also observed by Shattuck et al. (2012), suggesting interventions could go further to address these aspects of quality of life which affect autistic people disproportionately (McConachie et al., 2018). Self-determination and self-efficacy were considered in some reviews but none of the identified

service studies. Social prescribing has been found to facilitate many domains of self-determination (Bhatti et al., 2021), so could be an appropriate route to promoting this outcome in autistic adults but this requires evidence.

Only one review (Benevides, Shore, Andresen et al., 2020) and none of the extracted studies considered physical health as an outcome of importance, despite the disparities autistic people experience. This may be because most services did not target physical health, including a review of dance-based interventions which evaluated the impact on differences in eye contact and theory of mind (DeJesus et al., 2020). Further to this, the physical health outcomes extracted were highly specific including skin-picking behaviour and in-hospital recovery from an acute respiratory episode. However, autistic people experience disparities across a range of physical health concerns including cardiac conditions, epilepsy, gastrointestinal problems, hypertension and sleep disorders (Hirvikoski et al. 2016, Croen et al., 2015). It was also notable that no studies or reviews considered the sensory aspects of autism as an important autism-related outcome despite the impact sensory processing can have on emotional wellbeing and quality of life for people on the autism spectrum (MacLennan et al., 2020; McConachie et al., 2018). There is, therefore, a gap in the evidence on the impact of these types of interventions on generalised physical health or managing the challenges of sensory processing.

### ***Pathways Through Services and Implications for Social Prescribing***

Through analysis of the descriptive and qualitative content of studies, we identified barriers and facilitators relevant to progression through service pathways. None of the UK studies described themselves as a social prescribing model, which can include a variety of service models involving direct or mediated referral to community-based activities. All services

identified in this review were designed exclusively for autistic adults rather than an integrated group; however, the factors identified may give an indication of how features of the social prescribing pathway might facilitate or hinder its accessibility for autistic adults as a route to improving health outcomes.

Referral to a service makes up part of an individual's enrolment into social prescribing programmes (Husk, Blockley et al., 2019). In the present review, effective and timely identification of needs was identified as a facilitator to enrolment; the present gap in service provision for autistic adults has been highlighted as a barrier to accessing suitable support for managing wellbeing through failing to identify people who could benefit from support (Sharpe et al., 2019; Brugha et al., 2009). Social prescribing models use referral methods ranging from signposting to link worker referral (Husk, Blockley et al., 2019), which redirect patients from primary care settings to community settings. However, autistic people report barriers to accessing primary care including limitations of telephone booking systems, emotional barriers, communication difficulties and inaccessible environments, causing delays to seeking appropriate healthcare (Raymaker et al., 2017; Christou, 2016; Charlton et al., 2020; D. Mason et al., 2019; Doherty et al., 2022), which could impact on enrolment in social prescribing.

The results of the present review suggest services should use creative methods to overcome this. One method used by studies in the synthesis was the identification through records and databases, although this relies on patients having a diagnosis of autism, which may not be accessible for all those who may benefit from it (Lewis, 2017). It also reveals little about individual differences in needs and preferences (Hudry et al., 2020). It may be that self-referral directly to a link worker or activity could be considered. However, studies reported that individuals were not always able to identify their own needs until these had escalated to

an unmanageable level, so self-referral may be ineffective to address the access barriers. Self-referral can also place additional demand on services, leading to lower efficiency, long wait times, and reduced quality of consultations (Bertotti et al. 2018). Further consideration may be needed as to how to strike a balance between these limitations to best identify those who may benefit from social prescribing.

In contrast to findings by Husk, Blockley et al. (2019), the present review did not identify supported referral, such as a phone call or buddy system, as a facilitator of engagement. Charlton et al. (2020) suggested that support from link workers or family members would help autistic adults to navigate transition points in the pathway and mitigate uncertainty, and previous research on social prescribing generally has found that withdrawal of link worker support may lead to disengagement from services (Foster et al., 2021). While more general samples may benefit from telephone support alone (Husk, Blockley et al., 2019), the reliance on telephone is frequently reported as a barrier to healthcare access in autistic samples (Doherty et al., 2022). Additional forms of communication may need to be considered when supporting autistic people through service pathways, such as service passports that summarise individuals' profiles of needs (Charlton et al., 2020).

Previous research has shown that a barrier to the successful delivery of social prescribing services involves the complexity of patients referred to link workers and activity providers (Wildman et al., 2019), who do not typically receive training on specific conditions. Where patients and referrers involved in social prescribing programmes have perceived both link workers and activity leaders to have good knowledge and interpersonal skills, this facilitated engagement and overall success within services (Husk, Blockley et al., 2019; Tierney et al., 2020; Holding et al., 2020). The present review found that participants had more negative

perceptions of services where staff were inexperienced or untrained, such as students, which impacts on adherence to services. Collaboration utilising the expertise of other organisations and individuals, including autistic adults, enabled engagement and positive attitudes about services. This suggests building strong collaborations may lead to improved accommodations, more effective rapport building and complete gaps in link workers' knowledge about autism (Charlton et al., 2020). The collaborative nature of social prescribing also optimises local, community-relevant resources and a joined-up approach to healthcare (Jani et al., 2020; Kimberlee, 2013), which aligns with some of the Autism Strategy aims (Department of Health, 2014a).

It was important for providers to manage the expectations of clients and third-party collaborators such as employers, to allay anxiety and intervene where expectations were not realistic. In social prescribing, link workers are able to offer longer consultations than standard general practice appointments, which allows patients to discuss their preferences, barriers and beliefs about the ability of the service to meet their presenting needs and to build a trusting relationship (Husk, Blockley et al., 2019; Bertotti et al., 2018; Tierney et al., 2020). However, Charlton et al. (2020) emphasise that definitions of success and goals in social prescribing for autistic adults must meet the preferences of the individual rather than imposing assumptions or norms. Features of tailoring identified in the present review, such as adaptation of intervention content and materials to clients' interests and needs, to facilitate adherence to a service, reflect this person-centred approach. Tailoring a service to both individual and local community needs is a key component of social prescribing, and a barrier when this is lacking (Holding et al., 2020; Foster et al., 2021; Wildman et al., 2019).

Opportunities for social interaction were seen to be important for engagement: these opportunities helped validate clients' experiences and evoke a sense of belonging, but feeling overwhelmed by social demands also led to disengagement by some individuals, suggesting services should be flexible and person-centred around this accessibility need. Charlton et al. (2020) suggest that including adaptations such as a quiet area or breakout room may further enable flexibility allowing social interaction to fit the preferred level of the individual. A further possible mechanism to the success of social interactions identified from previous research is when participants perceive other members to be similar to themselves (Crane, Hearst et al., 2021), which was reflected in these findings.

### ***Strengths and Limitations***

This review achieved its aims of mapping non-medical, community-based support for autistic adults, identifying outcomes used to measure success in these services, and evaluating barriers and facilitators which may occur for autistic adults at stages of the pathway through services. The inclusion of grey literature was an advantage for achieving these aims by allowing for synthesis of results published outside of academic journals, such as policy documentation and small-scale service evaluations. This expanded the number of reviews and studies identified and allowed for a wide range of services and disciplines to be examined, leading to identification of gaps in outcome measurement, and barriers and facilitators to service pathways across disciplines. The findings may therefore be relevant to informing practice across a variety of contexts and interventions beyond social prescribing.

As in previous reviews which have found overrepresentation of males and younger adults (Shattuck et al., 2012; Provenzani et al., 2020), sample limitations mean the present findings may reveal less about what works for autistic older adults, women and individuals from



minority ethnic backgrounds, who will experience compounding health factors and healthcare access issues that intersect with autism (Michael, 2016; Hirvikoski et al., 2016; Bishop-Fitzpatrick & Kind, 2017). It is also important to note that this review synthesised only a small number of services that had been included in previous literature reviews and that many of the primary studies were assessed by reviewers as being of poor quality or had not been subject to quality assessment. Data extraction for the pathways synthesis depended upon the amount of descriptive information included about each service, which was highly varied. There may also be services that have not been reviewed or formally evaluated which could reveal further barriers and facilitators to progression through social prescribing service pathways for autistic adults, but were outside the scope of this review.

### ***Implications for Future Research and Practice***

There is a lack of development and testing of interventions to address physical health in autistic adults. Studies evaluating outcomes of community-based interventions for autistic people should include a wide range of outcome measures beyond autism-related outcomes, including physical and mental health and quality of life. They should also examine how individual differences may affect outcomes so that support can be tailored.

Findings on barriers and facilitators through the referral pathways suggest autistic people may benefit from the link worker appointments and the person-centred and collaborative approach of social prescribing. Ensuring skilled and approachable staff trained in understanding autism, as well as flexible opportunities for social interaction and providing a range of communication options could enable existing social prescribing services to be more accessible to autistic people and increase engagement. It may also be worthwhile to use creative and flexible methods for early identification and referral of autistic people to services, however this needs to be delivered in a way that does not strain service resources.

Making accommodations for people who do not have a formal diagnosis of autism may also help more people to access services in communities.

Further investigation with autistic adults enrolled in self-described social prescribing programmes would be beneficial to examine if these mechanisms are supported in the context of existing social prescribing pathways and activities. These may differ from the services evaluated here as they often serve a diverse population instead of being services designed specifically for autism. This will help to establish the extent to which the UK government's emphasis on social prescribing and community-based service provision addresses identified priorities for this population, including inappropriate inpatient admissions, overprescribing and persistent health inequalities (Department of Health, 2014a; Department of Health & Social Care, 2021).

### ***Conclusion***

In conclusion, this review has demonstrated how a variety of services for autistic adults are delivered and has identified and critiqued the outcome measures used to evaluate these. The review identified a small number of holistic, low intensity and community-based approaches which reflect those offered through social prescribing approaches. Reviews and previous studies focus strongly on outcomes related to autism which is more characteristic of targeted interventions than of the holistic approach of social prescribing, but have also considered outcomes relating to mental health and quality of life. There was a lack of measurement of the impact of services on physical health outcomes relevant to the population. Many of the barriers and facilitators present across the referral pathway had relevance to established social prescribing practice and could be used to identify areas where social prescribing may require adaptation to increase its reach to this population as a potential part of addressing disparities in health and wellbeing.

## Chapter 4

### **Barriers to Healthcare and Their Relationship to Wellbeing and Social Support for Autistic Adults during Covid-19**

This is the accepted version of Featherstone, C., Sharpe, R. A., Axford, N., Asthana, S., Ball, S., & Husk, K. (2022). *Barriers to healthcare and their relationship to well-being and social support for autistic adults during COVID-19*. *Primary Health Care Research & Development*, 23, e79, available at: <https://doi.org/10.1017/S1463423622000755>

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### **Author Contributions**

CF led the study, and KH, RAS, NA and SA contributed to the conception of the study and decisions on methodology. CF managed recruitment, collected results, analysed data and summarised findings. SB advised on selection and reporting of statistical tests. KH, RAS, NA and SA provided supervision over all processes and verification of statistical findings. All authors made critical amendments to draft manuscripts and approved the final manuscript.

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## **Abstract**

**Aim:** The present study aimed to investigate barriers to healthcare and their relationships to social and emotional wellbeing and intersectional inequalities for autistic adults during Covid-19 restrictions in the UK.

**Background:** Autistic adults experience severe health inequalities and report more barriers to accessing health services compared to other both disabled and non-disabled populations. The Covid-19 pandemic has impacted many areas of society that may have increased vulnerability of autistic people to social and health inequalities, including delivery of healthcare from in-person to remote methods.

**Method:** 128 autistic adults who lived in the UK took part in an online survey. Measures included the Barriers to Healthcare Checklist (Short Form) and PROMIS outcome measure bank to assess emotional wellbeing and social support. Participants rated their agreement with items, retrospectively considering three different points of the trajectory of Covid-19 restrictions: before Covid-19, during the first lockdown in spring 2020, and in the month prior to taking the survey during autumn 2020. They completed a follow-up survey six months later to continue to assess change as restrictions in the UK were eased.

**Findings:** The average number of barriers to healthcare showed no significant change between all four time points. However, the nature of barriers to healthcare changed at the point of lockdown and persisted beyond the easing of Covid-19 restrictions. Barriers to healthcare were associated with some social and emotional wellbeing variables and demographic groups including gender, education and presence of additional disabilities. The findings may help to identify areas to target to improve access to both remote and in-person health systems for autistic people as modes of delivery continue to change over time.

## **Background**

The World Health Organisation sets out that access to high standards of health and health resources is a human right (World Health Organization, 2017). Autistic adults have reported more barriers to accessing health services compared to non-autistic populations, including other disabled people without autism (Raymaker et al., 2017). Barriers experienced by autistic adults include communication difficulties (such as problems using telephones), sensory issues in the healthcare environment, lack of provider knowledge about autism that may lead to misinterpretation, and intra-personal factors such as executive dysfunction (D. Mason et al., 2019; Doherty et al., 2022; Raymaker et al., 2017). The impacts of barriers to healthcare for autistic adults include delays to treatment and worsening of illness (Doherty et al., 2022). This is concerning as autistic adults experience disparities in physical and mental health including higher prevalence of physical health conditions such as gastrointestinal problems, diabetes, epilepsy and cardiac illness, and mental health conditions, leading to significantly higher mortality rates than those seen in the general population (Hirvikoski et al., 2016, Croen et al., 2015, Woolfenden et al., 2012). Healthcare access is important for identifying, monitoring and treating these conditions appropriately, as well as providing access to the pathway for autism diagnosis under the National Health Service (NHS) in the UK; accurate and timely autism diagnosis contributes to improved quality of life (Atherton et al., 2022).

Much of the previous research conceptualising barriers to healthcare for autistic adults was conducted prior to the Covid-19 pandemic. Restrictions on face-to-face contact, which began in the UK in late March 2020, introduced changes to health service delivery. This included

services being delivered remotely and virtually (P. Webster, 2020). At the start of the pandemic it was speculated that autistic people may be made more vulnerable to isolation, increased risk of mental health breakdown and reduced support from services (Cassidy et al., 2020). Emerging research with this population has found that lockdown had a negative effect on mental wellbeing for autistic adults, including increasing anxiety and stress (Pais and Knapp, 2021, Bal et al., 2021, Bundy et al., 2022, Hedley et al., 2021). However, qualitative studies revealed mixed impacts including positive experiences of a more stable routine, reduced social demands and increased access to healthcare and services due to remote and virtual delivery (Mosquera et al., 2021, Hedley et al., 2021, Bundy et al., 2022). Challenges in healthcare included loss of contact and continuity from services, barriers to using remote healthcare and Covid-19 related services, and reduced social support in health settings (Pais and Knapp, 2021, Bundy et al., 2022). Mosquera et al (2021) suggested that research should also aim to identify lessons learned from service delivery in lockdown that improved experiences for autistic adults.

### ***Aims and Objectives of the Present Study***

This study aimed to explore how barriers to accessing health services were affected by Covid-19 for autistic adults and their associations with emotional and social wellbeing. Based on prior research on barriers to healthcare, preliminary findings on the potential impact of the Covid-19 pandemic for autistic people (e.g. Pavlopoulou et al., 2020) and an expert roundtable discussion by Cassidy et al. (2020), we hypothesised (H1) that there would be a significant difference in the number of barriers to healthcare over time in accordance with the progression of the Covid-19 pandemic and (H2) that barriers to healthcare would be

significantly associated with emotional and social wellbeing variables. Additionally, Cascio et al. (2020) have highlighted the need for autism research to attend to intersectionality, as some subgroups of the autistic population may have more specific support needs and associations with increased health disparities; for example, women and transgender people in this population have more pronounced disparities in morbidity and healthcare utilisation (Hall et al., 2020; DaWalt et al., 2021); Raymaker et al. (2017) explored the healthcare experiences of autistic people separately from those with disabilities other than autism, but did not assess the impact of co-occurring disabilities on access barriers for autistic people. Furthermore autistic adults experience disparities in education and employment (Brugha et al., 2011; ONS, 2022), but the impact of these on healthcare utilisation is underexplored. Cascio et al. (2020) argue that attending to intersectionality takes account of diversity in the autistic population, making research more applicable to the real world. We therefore aimed to include demographic factors in our analysis of the associations between barriers to healthcare and wellbeing to explore the influence of intersectional inequalities that may require additional attention in priority-setting for adapting health services.



## **Methods**

### *Sample*

Participants could take part if they were over 18 years old and had a formal autism diagnosis or if they suspected themselves to be on the autism spectrum. The research targeted a known hard-to-reach population as there is no record system of autistic people in the UK from which to draw a random sample. There is also a lack of definitive data on autism prevalence in adults as many autistic people do not receive a diagnosis until later life and some demographics such as women may be underrepresented in clinical diagnoses (Lai & Baron-Cohen, 2015). There were no clear sample size recommendations for the measures used when applied to survey methodology. Furthermore, the Covid-19 restrictions limited access to clinical samples. For these reasons, we used a convenience sample for this research.

The sample was limited to the UK to ensure consistency across health services and timings of pandemic control measures such as lockdowns. Participants were recruited primarily by a call for participants from Autistica's Discover Network. In addition, we used filters from the National Autistic Society's autism services directory (<https://www.autism.org.uk/directory>) to contact regional charities and services that supported autistic adults living independently, such as peer support and advocacy groups. We also asked regional branches of Mind, the mental health charity, to share the survey with service users. We contacted local authority Autism Partnership Boards and universities with disability societies or disabled student representatives identifiable using a Google search. The survey was also hosted online by several organisations and on our social media (see Appendix 14 – Survey Recruitment Strategy for further details). The recruitment strategy was targeted at people who could

participate in a survey independently or with minimal assistance, as we did not have the resources to adapt the survey for people with higher support needs without compromising validity of the measures.

### ***Materials***

The following well-established questionnaires and measures were used to operationalise the relevant constructs in the survey:

**Barriers to healthcare checklist (short form).** (Raymaker et al., 2017) - a 17 item checklist coproduced with “autistic individuals, family members, health and disability services professionals, and academic scientists” (Raymaker et al., 2017), assessing barriers to accessing primary healthcare. The checklist was reviewed by D. Mason et al. (2019) and concluded to have high face validity and practical real world applications, strengthened by its use of co-design methods. For the present survey, modifications were made to the questionnaire to improve applicability to a UK setting (removing a question regarding the cost of health insurance and changing “doctor’s office” to “doctor’s surgery” for cultural clarity). The tense of questions was also changed so that the scale could relate to multiple time periods.

**Patient-Reported Outcomes Measurement Information System (PROMIS)  
Measures Relating to Emotional Wellbeing, Social Support and Changes to Routine.**

PROMIS is a publicly available bank of patient reported outcome measures, aiming to

capture outcomes most important to patients across medical conditions and contexts (Ader, 2007). These measures are completed by the individual and have good consistency across different methods of administration (Wang et al., 2017). Holmes et al. (2020) developed the PROMIS Autism Battery – Lifespan (PAB-L), a bank of PROMIS measures chosen to assess quality of life across the lifespan in autistic samples. They found high feasibility and acceptability of these measures in a sample of autistic adults aged 18-65 years. Our questionnaire included scales relating to anxiety, depression, sleep impairment, satisfaction with social roles (e.g. changes to work and home routines), and emotional and instrumental social support measures, which were most relevant to the types of challenges that participants might have encountered during lockdown (Cassidy et al., 2020). Social wellbeing variables (social support and satisfaction with social roles) were measured at all time points as these were more objective, but we anticipated that emotional wellbeing (anxiety, depression and sleep impairment) could not be reliably recalled for the previous year due to their subjective nature and are excluded from pre-pandemic sections. PROMIS measures used a standardised t-score where the mean=50 and SD=10, based on representative samples from clinical and general populations in the United States (Cella et al., 2010). Higher scores indicate better outcomes on measures of social wellbeing and poorer outcomes on emotional wellbeing scales.

**Screening Questions.** Participants indicated whether they had lived in the UK permanently since March 2020. Participants who self-identified as being autistic without providing details of a formal diagnosis completed the AQ-10 Autism Quotient (Allison et al., 2012) to indicate whether they met the cut-off point of  $\geq 6$  indicating eligibility for autism assessment.

**Demographic Questions.** Gender, ethnicity, household income, level of education, employment status, social deprivation by postcode area (as measured by Indices of Multiple Deprivation) (Ministry of Housing, Communities & Local Government, 2019) and presence of other disabilities (categories from the Office for National Statistics Covid-19 impact survey on people with disabilities, (ONS, 2020a)); Attention Deficit Hyperactivity Disorder (ADHD) was also added as another category due to high co-occurrence with autism (Ghirardi et al., 2018) and Covid-19 related disability due to the context of the survey. These categories are self-reported and may not be associated with formal diagnosis.

These questionnaires formed part of a longer survey on wellbeing self-management during the Covid-19 pandemic, within a mixed-methods research project.

### *Procedures*

All research procedures were approved by the University of Plymouth Faculty of Health ethics board on 27/08/2020. The research explored experiences across four time periods (measured across an initial and follow-up survey) to relate findings to stages of Covid-19 restrictions. The initial survey, which was live between August-December 2020, asked participants retrospectively about their experiences in 2019 or before (pre-pandemic), during the initial UK lockdown period between March-May 2020 (hence referred to as spring 2020 reflecting UK seasonality), and during the past month (at point of survey completion between late August-December 2020, hence referred to as autumn 2020). A follow-up survey carried

out six months after the close of the initial survey, in June to July 2021, related again to experiences over the previous month.

The survey was voluntary and took 30-60 minutes to complete, with the option to pause and return later to reduce overwhelm for participants which may encourage retention. Participants were required to read the information sheet for the study and agree to consent statements in order to proceed. Due to the inclusion of questions about emotional wellbeing, a debrief form provided participants with information about organisations which provide support and advice around emotional wellbeing and autism. All participants who had provided contact details (84% of the original sample) were contacted six months later up to three times with a prompt to complete the follow-up survey. The follow-up survey repeated the questions on barriers to healthcare and emotional and social wellbeing.

Due to Covid-19 restrictions, there were no face-to-face options for completing the survey, however participants were informed that they could request support via phone or video call if required or request a printable PDF version of the survey to aid completion of the online form. The survey was piloted with four volunteers from a local adult autism support group, which led to changes including clarity of wording and structure of questions.

### *Analysis*

The data were analysed using IBM SPSS (version 25). Data on continuous variables were screened against normality criteria for linear models. We ran a repeated measures ANOVA to

test hypothesis 1 (change in barriers to healthcare over time), with Greenhouse-Geisser correction. Linear regression modelling was used to test if social and, where applicable, emotional wellbeing variables, and demographic factors (gender, additional disabilities, education and employment), were significantly associated with barriers to healthcare (hypothesis 2). These models only included the responses of participants who had indicated a healthcare requirement for the relevant time point. The analyses was applied to two time points representing pre- and post-pandemic experiences (pre-2019 and autumn 2020) which were also considered to have the highest internal validity for all variables due to sample size and recall accuracy respectively (although follow-up also used a similar recall time frame to autumn 2020, the sample was too small for regression analysis). Demographic categories were recoded into binaries where possible (employed vs. unemployed; university- vs. non-university educated; additional disabilities vs. no additional disabilities) to ensure large enough group sizes for analysis. The PROMIS measures were analysed as continuous variables, as scores represented the sum of multiple Likert scales.

Chi-square tests were used to conduct further analysis of demographic variables that showed a relationship to barriers to healthcare in regression models, by analysing associations between demographics and each barrier in the checklist to identify specific issues affecting each group.

## **Results**

### ***Initial Survey***

**Participants.** 128 participants completed the initial survey. 89.1% of the sample reported having a clinical diagnosis of autism. All of those without a clinical diagnosis scored

above the cut-off of 6 or above on the AQ-10. Of those with an autism diagnosis, 76.6% had received this after the age of 18. The sample was mostly female (50.8% compared to 35.2% male and 13.3% non-binary), white British (81.3%) and educated to university level or equivalent (69.5%), with 56% reporting being in paid employment. 35% of the sample reported having a household income of less than £20,000 p/a (the national median in 2020 was £29,900 - ONS, 2020) and 46% received financial support from the government.

Self-assessed co-occurring disabilities in the predetermined ONS categories (see Methods) included mental health (50.8% of the sample), learning disability or specific learning difficulty (20.3%), stamina, breathing or fatigue (19.5%), dexterity (15.6%), ADHD (15.6%), mobility (12.5%), memory (7.8%), hearing (6.3%), visual (3.9%) and pain (2.3%). Additionally within the 'other' category, 4.7% of participants self-disclosed sensory processing disorder, 2.3% gastrointestinal issues, 0.8% epilepsy, 0.8% Covid-related disability and 6.3% other disabilities. 23% reported no co-occurring disabilities.

42 participants (39% of those re-contacted) completed the follow-up questionnaire. The follow-up sample had closer to equal numbers of males and females (47.6% male, 42.9% female and 9.5% nonbinary) compared to the original sample and was also older on average, with a higher level of disability. Educational level and employment status were proportionally similar to the initial sample. Table 4.1 shows the differences in demographics between the initial and follow-up cohorts.

**Table 4.1***Demographics of initial and follow-up samples*

<b>Variable</b>	<b>N (%) Initial survey</b>	<b>N (%) Follow up</b>
Clinical autism diagnosis	114 (89.1)	36 (85.7)
Non-diagnosis AQ Score >cut-off	14 (100)	6 (100)
Age		
18-25	11 (8.6)	<5
26-35	44 (34.4)	11 (26.2)
36-45	25 (19.5)	9 (21.4)
46-55	24 (18.8)	6 (14.3)
56-65	19 (14.8)	11 (26.2)
66+	5 (3.9)	<5
Approx. age at diagnosis (where applicable & stated)		
<18	26 (23.4)	8 (19.0)
18-25	25 (22.5)	<5
26-35	21 (18.9)	9 (21.4)
36-45	21 (18.9)	9 (21.4)
46-55	14 (12.6)	5 (11.9)
>55	<5	<5
Not stated	3 (2.6)	6 (14.3)
Gender		
Male	45 (35.2)	20 (47.6)
Female	65 (50.8)	18 (42.9)
Non-binary/other	17 (13.3)	<5
Not stated	1 (0.8)	0
Ethnicity		
White British	104 (81.3)	34 (81.0)
White Irish	<5	0
Other White background	10 (7.8)	<5
White & Asian	<5	0
Other mixed background	<5	<5
Bangladeshi	<5	0
Caribbean	<5	0
Any other Black background	<5	0
Other	<5	<5
Not stated	4 (3.1)	0
Education		
No formal education	<5	<5
GCSEs/NVQ Level 1-2	17 (13.3)	6 (14.3)
A Level/NVQ Level 3	19 (14.8)	6 (14.3)
Undergraduate/Diploma/Equiv.	53 (41.4)	16 (38.1)
Postgraduate Degree	36 (28.1)	13 (31.0)
Not stated	1 (0.8)	0
Employment		
FT employment	47 (36.7)	14 (33.3)
PT employment	25 (19.5)	8 (19.0)
Retired	8 (6.3)	<5
Student	5 (3.9)	<5
Volunteer	10 (7.8)	5 (11.9)
Not in employment	30 (23.4)	10 (23.8)



Not stated	3 (2.3)	0
Disability (ONS categories)		
None	30 (23.4)	7 (16.7)
Visual	5 (3.9)	<5
Hearing	8 (6.3)	<5
Mobility	16 (12.5)	7 (16.7)
Dexterity	20 (15.6)	<5
Learning disability/SpLD	26 (20.3)	6 (14.3)
Memory	10 (7.8)	5 (11.9)
Mental health	65 (50.8)	27 (64.3)
Stamina, breathing or fatigue	25 (19.5)	10 (23.8)
ADHD	20 (15.6)	8 (19.0)
Other categories submitted:		
Covid-related disability	<5	0
Sensory processing disorders	6 (4.7)	0
Pain-related disability	<5	<5
Gastrointestinal disorders	<5	0
Epilepsy	<5	0
Others	8 (6.3)	<5
Receives government payments (e.g. PIP, ESA)	59 (46.1)	20 (47.6)
Not stated	6 (4.7)	3 (7.1)
Supported by adult social care	18 (14.1)	9 (24.3)
Not stated	6 (4.7)	5 (11.9)

**Healthcare Use.** Table 4.2 shows how participants in the sample required and used healthcare across the time points of interest. Those who indicated they had required health services were also asked to indicate if they had been offered remote healthcare during each time point. Approximately half of the sample had required healthcare at all time points. Use of remote healthcare increased from the pre-pandemic level of 23.4% of the sample, to over 40% since the onset of Covid-19.

**Table 4.2.**

*Healthcare use by sample*

<b>Time</b>	<b>N(%) of sample who required healthcare during time point</b>	<b>N offered remote healthcare (% of those who required healthcare)</b>
2019 or before	128(100% assumed)	30 (23.4%)
Spring 2020 (lockdown)	71 (55.0%)	56 (78.8 %)
Autumn 2020	65 (50.8%)	45 (69.2%)
Summer 2021 (follow-up)	23 (54.8%)	17 (73.9%)

**Hypothesis 1: Barriers to Healthcare Would Change Over Time.** The data on measures used in statistical analyses showed some skew but were close enough to normality to use robust parametric tests.

Participants in the sample reported experiencing a mean of 9.83 barriers to healthcare prior to the Covid-19 lockdown (asked as “2019 or before”). Those who had accessed healthcare during lockdown and/or in the months prior to completing the initial and follow-up surveys reported 10.0 barriers during lockdown, 9.83 post-lockdown in autumn 2020, and 11.25 in summer 2021. These differences were not significant,  $F(1.88, 20.69)=1.871, p=0.181$ .

[Table 4.3](#) (see end of chapter) shows the rankings of types of barriers experienced as percentages of the sample. The highest ranking barriers at follow-up matched those during and post-lockdown 2020, although a greater proportion of the sample reported them than at previous time points (table 4.2). Notably, table 4.3 shows how the types of barriers experienced differed from pre-pandemic responses and persisted over time.

**Hypothesis 2: Barriers to Healthcare Would Be Predicted by Emotional Wellbeing, Social Support and Demographic Variables.**

**Table 4.4.**

*Scores on PROMIS Emotional and Social Wellbeing Measures Over Time*

Variable	Mean, SD (N=128)				Average score in previous sample of autistic adults aged 18-65 (Graham Holmes et al. 2020)
	2019	Spring 2020	Autumn 2020	Summer 2021	
<b>Emotional social support</b>	46.02, 11.55	45.47, 11.53	46.32, 10.36	44.13 (11.21)	48.1
<b>Instrumental social support</b>	46.47, 12.27	48.29, 13.65	47.21, 11.77	45.47 (10.86)	49.9
<b>Satisfaction with social roles</b>	46.27, 10.40	45.07, 11.01	43.91, 9.57	41.75 (9.09)	44.2*
<b>Anxiety</b>	N/a	64.41, 9.76	63.42, 10.27	65.30 (10.66)	60.9
<b>Depression</b>	N/a	60.98, 11.67	59.96, 11.45	61.49 (12.23)	57.8
<b>Sleep impairment</b>	N/a	56.88, 12.35	60.21, 10.74	60.72 (10.66)	64.4

\*Alternative version of measure selected for present study (may not be directly comparable)

Table 4.4 shows the mean scores for the PROMIS variables against those reported in previous research in a similar sample by Holmes et al. (2020).

The regression model of pre-pandemic associations between demographics, social wellbeing and barriers to healthcare showed that gender, disability and satisfaction with social roles had significant associations with barriers to healthcare (Table 4.5), such that non-males, people with additional disabilities and those with lower satisfaction with social roles experienced more barriers. The regression model for autumn 2020 for associations between demographics, social and emotional wellbeing and barriers to healthcare demonstrated that education and anxiety had significant associations with barriers to healthcare (Table 4.6). People with a lower education level and higher anxiety experienced greater barriers. The

associations between variables and the outcome in regression models were presented as estimated effects with 95% confidence intervals. Some multicollinearity was detected but VIF analysis suggested these were not of concern. Residuals were normally distributed in both models and casewise diagnostics suggested there were no serious outliers or undue influence of individual cases in either model.

**Table 4.5.**

*Associations With Barriers to Healthcare (2019 or Before)*

<b>Variable</b>	<b>Estimated effect (95% CI)</b>	<b>p-value</b>
Gender	1.371 (0.32 to 2.43)	0.011*
Additional disabilities	-1.867 (-3.55 to -0.19)	0.030*
Education	-0.532 (-2.18 to 1.11)	0.523
Employment	0.009 (-1.55 to 1.56)	0.991
Instrumental support	0.013 (-0.06 to 0.09)	0.732
Emotional support	-0.065 (-0.14 to 0.14)	0.104
Satisfaction with social roles	-0.154 (-0.23 to 0.08)	<0.001*

\*Significance (p) <0.05

**Table 4.6.***Associations With Barriers to Healthcare (Autumn 2020)*

<b>Variable</b>	<b>Estimated effect (95% CI)</b>	<b>p-value</b>
Gender	0.647 (-.86 to 2.15)	0.393
Additional disabilities	-1.304 (-4.05 to 1.44)	0.345
Education	-2.244 (-4.42 to -0.06)	0.044*
Employment	0.616 (-1.45 to 2.68)	0.552
Instrumental support	-0.028 (-0.13 to 0.08)	0.590
Emotional support	0.071 (-.05 to .20)	0.254
Satisfaction with social roles	-0.066 (-0.20 to 0.07)	0.320
Anxiety	0.204 (0.02 to 0.39)	0.032*
Depression	0.060 (-0.13 to 0.25)	0.518
Sleep impairment	0.080 (-0.03 to 0.19)	0.137

\*Significance (p) &lt;0.05

Table 4.7 demonstrates analysis expanding upon the identified associations between demographic subgroups (gender, disability and education) and barriers to healthcare affecting this sample. At the pre-2019 time point, female and nonbinary participants experienced significantly more emotional difficulties (fear, anxiety, embarrassment or frustration), problems making appointments and following up on care, misinterpretation of behaviour by staff, feelings of not being taken seriously, difficulty identifying and reporting symptoms, inadequate social support and problems with waiting rooms, compared to males.

People who reported an additional disability experienced a mean score of 11 barriers to healthcare prior to the pandemic, while those without additional disabilities reported 3.5 barriers on average. Having at least one additional disability was significantly associated with reporting difficulty following up on care, translating healthcare recommendations into concrete steps, understanding the healthcare systems, filling out paperwork, accessing accommodations, communicating with providers, identifying and reporting symptoms, getting to a doctor's surgery and sensory discomforts.

Analysis by education level in autumn 2020 showed significant associations between a lower level of education and understanding how to translate healthcare information into everyday steps to improve health, understanding the healthcare system, filling out paper work, difficulties communicating and sensory problems.

**Table 4.7:**

*Results From Exploratory Analysis of Associations Between Barriers to Healthcare Checklist Totals and Items With Sample Demographics*

<b>Barriers</b>	<b>Pre-2019: Female/nonbinary (N=127)</b>	<b>Pre-2019: Additional disability indicated (N=128)</b>	<b>Autumn 2020: Education status</b>
Fear, anxiety, embarrassment or frustration kept me from getting to primary care	$\chi^2(2)=7.56$ , $p=0.023^*$	$\chi^2(1)=1.28$ , $p=0.259$	$\chi^2(1)=0.65$ , $p=0.419$
I had trouble following up on care	$\chi^2(2)=13.73$ , $p=0.001^*$	$\chi^2(1)=7.64$ , $p=0.006^*$	$\chi^2(1)=2.66$ , $p=0.103$
I had difficulty understanding how to translate medical information into concrete steps that I could take to improve my health.	$\chi^2(2)=0.96$ , $p=0.650^{**}$	$\chi^2(1)=4.24$ , $p=0.039^*$	$\chi^2(1)=7.33$ , $p=0.007^*$
I felt that I don't understand the healthcare system	$\chi^2(2)=2.38$ , $p=0.304$	$\chi^2(1)=7.26$ , $p=0.007^*$	$\chi^2(1)=4.00$ , $p=0.046^*$
I found it too difficult to make appointments	$\chi^2(2)=6.12$ , $p=0.047^*$	$\chi^2(1)=0.05$ , $p=0.824$	$\chi^2(1)=3.40$ , $p=0.066$
I had problems filling out paperwork	$\chi^2(2)=4.56$ , $p=0.102$	$\chi^2(1)=12.73$ , $p<0.001^*$	$\chi^2(1)=18.50$ , $p<0.001^*$
My behaviours were misinterpreted by my provider or the staff	$\chi^2(2)=16.08$ , $p<0.001^*$	$\chi^2(1)=2.39$ , $p=0.122$	$\chi^2(1)=1.60$ , $p=0.206$
My providers or the staff did not take my communications seriously.	$\chi^2(2)=10.14$ , $p=0.006^*$	$\chi^2(1)=0.54$ , $p=0.461$	$\chi^2(1)=1.20$ , $p=0.273$
I could not find a healthcare provider who would accommodate my needs	$\chi^2(2)=1.77$ , $p=0.414$	$\chi^2(1)=11.06$ , $p=0.001^*$	$\chi^2(1)=1.56$ , $p=0.212$
My providers or the staff did not include me in discussions about my health.	$\chi^2(2)=0.522$ , $p=0.808^{**}$	$\chi^2(1)=2.53$ , $p=0.112$	$\chi^2(1)=0.51$ , $p=0.475$
Communication with my healthcare provider or the staff was too difficult.	$\chi^2(2)=3.97$ , $p=0.138$	$\chi^2(1)=8.53$ , $p=0.003^*$	$\chi^2(1)=5.68$ , $p=0.017^*$
When I experienced pain and/or other physical symptoms, I had difficulties identifying them and reporting them to my healthcare provider.	$\chi^2(2)=7.13$ , $p=0.028^*$	$\chi^2(1)=4.08$ , $p=0.043^*$	$\chi^2(1)=0.515$ , $p=0.473$
Sensory discomforts (e.g. the lights, smells, or sounds) got in the way of my healthcare.	$\chi^2(2)=5.28$ , $p=0.071$	$\chi^2(1)=8.78$ , $p=0.003^*$	$\chi^2(1)=11.44$ , $p=0.001^*$
I did not have a way to get to my doctor's surgery	$\chi^2(2)=0.90$ , $p=0.670^{**}$	$\chi^2(1)=4.81$ , $p=0.039^*$ ; $**$	$\chi^2(1)=1.15$ , $p=0.284$
I had inadequate social, family or caregiver support	$\chi^2(2)=6.78$ , $p=0.034^*$	$\chi^2(1)=2.40$ , $p=0.121$	$\chi^2(1)=1.01$ , $p=0.316$
I found it hard to handle the waiting room	$\chi^2(2)=8.47$ , $p=0.014^*$	$\chi^2(1)=1.23$ , $p=0.268$	$\chi^2(1)=2.87$ , $p=0.090$

\*Significant difference ( $p<0.05$ ); \*\*Fisher's exact test used due to expected cell counts  $<5$

## Discussion

This study used online survey methods to explore autistic adults' experiences of accessing healthcare during Covid-19 and assess how healthcare barriers were associated both with emotional wellbeing and social support. The sample averages showed poorer emotional and social wellbeing compared to the standardised general population score (M=50) on all wellbeing measures and across all time points, as indicated by lower scores on measures of social support and satisfaction with social roles and higher scores on measures of anxiety, depression and sleep impairment. They also showed poorer scores than those of Holmes et al.'s (2020) previous comparable sample of autistic adults, on all measures except for sleep impairment. The findings reflect previous research suggesting autistic adults experience low health-related quality of life (Holmes et al., 2020, Oakley et al., 2020).

The number of barriers to healthcare reported by this sample did not change significantly across the different stages of Covid-19 restrictions including pre-Covid, during lockdown and post-lockdown in 2020 and 2021. The results therefore did not support the hypothesis that the number of barriers to healthcare experienced would differ significantly across time. However, types of barriers reported during lockdown changed, and these changes persisted post-lockdown into the following year. These results may have implications for the future delivery of healthcare that retains methods of delivery such as remote consultations. The survey also found that after Covid-19, the number of barriers to healthcare experienced was significantly related to increased feelings associated with anxiety. Barriers to healthcare were also compared between differing demographic groups and some findings suggested there may be intersectional inequalities in accessing healthcare for autistic people.



Prior to lockdown, the highest ranking barriers to healthcare access in this sample were waiting rooms, emotional concerns and misinterpretation by providers. Previous research supports the significant difficulty autistic adults experience in these areas compared to non-autistic populations (Raymaker et al., 2017). In all time periods after lockdown, the highest ranking barriers were difficulties following up on care, making appointments and communicating with providers. Previously, follow-up care was not a significant barrier for autistic adults compared to other groups (Raymaker et al., 2017). This suggests lockdown restrictions may have made these aspects of healthcare more difficult for this population and that the easing of lockdown did not improve these experiences. This may be due to service closures, changes to guidance and the persistence of remote healthcare, as 58.6% of the sample who accessed healthcare reported receiving this in 2021 compared to 23.4% prior to the pandemic and 40.6% after the first lockdown in 2020. These findings suggest that more could be done by health services to improve methods of contact and communication with providers within the context of ongoing remote healthcare delivery and any continued restrictions on face-to-face contact, especially as autistic people experience existing disadvantage around communication with healthcare providers. It may also be worth exploring whether observed reductions in service use in the general population during the pandemic (Moynihan et al., 2021) were due in any part to similar barriers around communication.

The direction of the relationship between barriers to healthcare and emotional and social wellbeing is not known due to the cross-sectional nature of the survey, but results suggested there was an association with satisfaction with social roles (e.g. home and work routines) pre-

pandemic and with anxiety post-pandemic. It may be that barriers to healthcare lead to decreased wellbeing or that poorer wellbeing may cause difficulties with access to healthcare, perhaps due to executive dysfunction, emotional regulation issues or communication problems.

Demographic factors including gender, additional disabilities and education were also found to have an association with barriers to healthcare. Prior to the pandemic, female and nonbinary participants were significantly more likely to report being misinterpreted by staff and not being taken seriously compared to males. This is supported by recent studies which also found that autistic adults identifying as women or ‘other’ gender experienced more barriers and unmet healthcare needs (Koffer Miller et al., 2022). Autistic women are also at greater risk of many additional health conditions (DaWalt et al., 2021) and suicide (Hirvikoski et al., 2016), making this finding concerning. Higher level of disability was related to significantly more practical and communication-based problems compared to those with no additional disabilities. A survey by the Office For National Statistics (2020a) found that during Covid-19, people with physical disabilities experienced more problems accessing medicine and other supplies. However, the associations between these variables and barriers to healthcare was not significant post-pandemic, which could indicate a levelling effect of more remote healthcare options for some marginalised groups. In autumn 2020 when there was a greater reliance on remote healthcare delivery, people with a lower level of education showed significantly more barriers around understanding healthcare information and navigating the health system; however, differences in group sizes for this variable mean caution may need to be applied to these findings. These findings suggest that people who experience increased marginalisation may be at a greater disadvantage in healthcare depending on external contexts.

### ***Strengths and Limitations***

This study has expanded on previous research by examining barriers to healthcare for autistic adults from an intersectional perspective, in the context of Covid-19 and in relation to emotional and social wellbeing outcomes. Many of the results were consistent with the findings of previous research. The measures for the main hypotheses had been previously validated in autistic adults (albeit in the United States, so required adaptation for the current sample and study purpose). The external validity and reliability of the study may be affected by the use of a self-selected convenience sample. The sample size achieved is associated with sampling error of between 7-10% (Williams, 2003), however it is also likely the spread of demographics is not representative of autistic adults in general. For example, this group had a high level of female and nonbinary representation, although not at levels atypical for autism studies relying on anonymous self-report (e.g. Doherty et al., 2022; George and Stokes, 2018). Education and employment were also high compared to previous cohort studies aiming to identify a representative sample of autistic adults in the UK population (Brugha et al., 2011). However, although nearly 70% of the sample were educated to university level, only 36.7% were currently in full time employment, over 50% reported having a disabling mental health condition and almost half received financial support from the government. Therefore, although some subgroups of autistic adults in the UK population are less represented by this survey, the results highlight that even those who might be assumed to be more advantaged still experience concerning disadvantages with economic impacts, as appearing “high-functioning” can itself represent a barrier for recognition of support needs in autistic adults (Wolfe, 2022). This is also the first study to our knowledge that has closely examined differences in barriers to healthcare across subgroups of gender, education and additional disabilities, showing where tailoring of services may be needed.

The survey sample was also not large enough overall to make inferences about the intersection of autism and some demographic groups such as ethnic minority status, especially as participants identified across a number of ethnic groups; condensing ethnic diversity into a binary provides a limited understanding of needs (Khunti et al., 2020) and so was not applied to the analysis. Qualitative research and community participatory methods may be better placed to explore the experiences of minority groups' access to healthcare to identify specific issues at this intersection of marginalisation and with specific minority groups in richer detail.

Although the survey aimed for consistency regarding the chronology of the pandemic by limiting responses to the UK, different decisions by devolved governments and the tiered system of restrictions introduced in Autumn 2020 by the UK central government, which changed often, may mean there are some inconsistencies across regions that could be present in the data and may have an unclear effect on results, affecting internal reliability.

### ***Recommendations for Practice***

The findings suggest that where remote delivery is in place, barriers may remain for autistic adults with communicating, understanding healthcare information and booking appointments, which may lead to delays in accessing healthcare and increase severity of health problems, potentially leading to more pressure on acute services. While Shaw et al. (2022) suggest remote delivery of services may have benefits for autistic patients, they also assert that adjustments are needed to overcome the barriers this poses, including offering online booking and a choice of methods for remote appointments to allow people to use their preferred

method. In face to face care, improvements need to be made to the waiting environment. Previous researchers have suggested that enabling autistic patients to wait outside, and to reserve the first and last appointments, may ease anxiety around busy times of day (Shaw et al., 2022, D. Mason, Ingham et al., 2021). The present survey also showed that healthcare interaction difficulties may have had an emotional toll for autistic people since Covid-19 which should be understood and adjusted for in consultations through patience, empathy and clear communication. D. Mason, Ingham et al. (2021) found that an improved understanding of anxiety and compensatory strategies may help providers to be more accommodating of autistic patients. Providing information in advance of procedures may also help to reduce anxiety (D. Mason, Ingham et al., 2021).

Making changes to environments and communication methods will also benefit the wider population of healthcare users. For example, allowing multiple methods of contacting providers would also make using health systems more convenient and efficient for all patients. Furthermore, presentations of disabilities can overlap. As an example, making sensory adjustments and using clearer methods of communication could improve experiences for patients with conditions such as hearing and visual impairments and dementia.

Additionally, undiagnosed autistic people would benefit from adjustments being made at a more universal level rather than implemented individually based on diagnosis. Involving autistic adults in local and central decision-making around accessibility in healthcare may also help to identify additional opportunities for improvement. Finally, the experiences reported disproportionately by women and nonbinary participants of the survey also reflect wider issues in the culture of healthcare around implicit bias in professionals' adjudication of healthcare needs (Annandale et al., 2007), which should continue to be identified and addressed.

## ***Conclusion***

In conclusion, while remote healthcare has increased during the Covid-19 pandemic, the barriers to healthcare access for autistic adults have neither increased nor decreased but have shifted to enhanced issues around contacting and communicating with services. This is a concern for a population already disadvantaged by communication barriers. Barriers to healthcare were found to be related to some areas of emotional and social wellbeing for autistic adults across the lifespan and during Covid-19, and intersectional marginalisation may affect access to healthcare depending on context. This work may help to highlight areas that could require further attention in future research and practice to ensure equitable access to both remote and in-person health systems as modes of delivery continue to change over time.

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## **Conflicts of Interest**

We declare no conflicts of interest.

## **Ethical Standards**

Written informed consent was obtained from all participants.

**Table 4.3: Barriers to Healthcare Checklist (Short Form) Categories With Scores and Ranks From Present Sample**

Category	Items	% Scores				Rank			
		2019 or before N=128	Spring 2020 N=71	Autumn 2020 N=65	Summer 2021 N=23	Time 1	Time 2	Time 3	Time 4
Emotional	Fear, anxiety, embarrassment or frustration kept me from getting to primary care	52.3	54.9	50.8	60.9	2=	4	4=	3=
Executive function	I had trouble following up on care	45.3	67.6	60.0	60.9	8	1	2	3=
	I had difficulty understanding how to translate medical information into concrete steps that I could take to improve my health.	28.1	35.2	36.9	47.8	14	13=	14	11=
Healthcare navigation	I felt that I don't understand the healthcare system	37.5	45.1	49.2	56.5	11	8=	6	5=
	I found it too difficult to make appointments	48.4	63.4	61.5	78.3	6	2	1	1
	I had problems filling out paperwork	33.6	38.0	40.0	39.1	13	12	13	14=
Provider attitudes	My behaviours were misinterpreted by my provider or the staff	52.3	46.5	50.8	39.1	2=	7	4=	14=
	My providers or the staff did not take my communications seriously.	49.2	45.1	44.6	52.2	5	8=	10=	7=
	I could not find a healthcare provider who would accommodate my needs	43.0	53.5	43.1	43.5	9	5	12	13
	My providers or the staff did not include me in discussions about my health.	24.2	23.9	29.2	47.8	15	16	16	11=
Patient-provider communication	Communication with my healthcare provider or the staff was too difficult.	50.0	56.3	56.9	65.2	4	3	3	2
	When I experienced pain and/or other physical symptoms, I had difficulties identifying them and reporting them to my healthcare provider.	46.1	47.9	47.7	52.2	7	6	7=	7=
Sensory	Sensory discomforts (e.g. the lights, smells, or sounds) got in the way of my healthcare.	39.8	35.2	44.6	52.2	10	13=	10=	7=
Socio-economic	I did not have a way to get to my doctor's surgery	10.9	28.2	30.8	21.7	16	15	15	16
Support	I had inadequate social, family or caregiver support	35.2	45.1	46.2	52.2	12	8=	9	7=
Waiting	I found it hard to handle the waiting room	55.5	40.8	47.7	56.5	1	11	7=	5=
	<b>Total barriers (M)</b>	9.83	10.00	9.83	11.25				





## Chapter 5

### **Running the Gauntlet, Fighting a Battle or Choosing Self-Defence: A Candidacy Framework Analysis of Autistic Adults' Experiences of Accessing Healthcare in the United Kingdom**

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## **Abstract**

**Objectives:** Autistic adults experience barriers to accessing healthcare which may contribute to health inequalities. The candidacy framework identifies how claims to healthcare involve repeated processes of negotiation between patients and clinicians in the context of constraints imposed by service operating conditions. This study applied the candidacy framework to autistic adults' first-person accounts of accessing healthcare in the United Kingdom.

**Methods:** We carried out semi-structured interviews with twenty one autistic adults using online methods. Interviews were analysed using reflexive thematic analysis situated in a critical realist philosophy, and the framework approach was applied when concepts of candidacy became apparent in the identified themes.

**Findings:** Barriers to healthcare were consistent with those found in previous research. Participants' accounts demonstrated factors which facilitated or impeded the negotiation of candidacy, including access to social and material resources and the ability to communicate with providers in ways which met expectations.

**Conclusions:** Findings suggested there may be a hierarchy of disadvantage affecting the negotiation of candidacy for autistic adults, which included access to the right to receive reasonable adjustments to care. These barriers may represent an area of health inequality for this population. We discuss recommendations for staff training and service delivery to address these issues.

## Background

Autism describes a neurodevelopmental profile of social, communication and sensory-processing characteristics which are distinct from typical norms and can be disabling in some contexts (Buckley et al., 2017; Lord et al., 2020). Autistic people<sup>1</sup> make up between 1-2 percent of the population (Roman-Urrestarazu et al., 2021; Maenner et al., 2021), but experience a disproportionate level of physical and mental health concerns (Croen et al., 2015). As such, autistic adults will interact with health services beyond specialist autism support, yet healthcare professionals are frequently unaware of their elevated health risks (Micai et al., 2021). Autistic adults experience barriers accessing healthcare which include anxiety, sensory sensitivities, difficulties communicating and interacting with providers, navigating services and processing information (Raymaker et al., 2017; D. Mason, Ingham et al., 2021; Doherty et al., 2022). Self-reported impacts include delays in accessing treatment and exacerbation of medical conditions (Doherty et al., 2022). Mortality trends and suicide rates in autistic people compared to the general population (Hirvikoski et al., 2016; Akobirshoev et al., 2020) suggest that improving access to healthcare for autistic adults should be a public health priority. Survey studies have been helpful for quantifying and categorising barriers to healthcare for autistic adults, but less research has qualitatively explored the constructs and processes underlying autistic adults' personal understandings of the reported barriers in health service interactions.

In response to a need to understand healthcare access in other marginalised groups, Dixon-Woods et al. (2006) developed the candidacy framework using critical interpretive synthesis. This theoretical framework suggests eligibility for healthcare is continuously negotiated between patients and healthcare providers, and impacted by the context and constraints of

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<sup>1</sup> Identity-first terminology ("autistic person") is accepted by APA style guidelines where there is a community preference for this terminology as evidenced in Kenny et al. (2016) and Lei et al. (2021).

service operating conditions, such as resource limitations. Candidacy can be organised into eight constructs (see table 5.1) (Dixon-Woods et al., 2006; Tookey et al., 2018). Relevant factors include an individual's ability to recognise their health problem as eligible for intervention and to access the appropriate services, which may be determined by internal processes such as emotion and motivation, interacting with external limitations including transport and financial costs. Services vary by the level of resources required to access them, which is influenced by referral mechanisms such as levels of gatekeeping. Within healthcare, individuals must demonstrate their needs and be judged as credible by health professionals; this relies on verbal abilities and the perceptions of professionals who adjudicate who is deserving of care. Individuals will also vary in their responses to an offer of care. The local structure of the health service, which determines factors such as resourcing, will influence both patient and professional decisions around adjudication of candidacy. Analysis of healthcare use applying this framework has highlighted factors on multiple levels that can play a role within these processes, including culture, class, social roles, the political landscape, trauma and community structures (Dixon-Woods et al., 2006; McKenzie et al., 2012).

**Table 5.1***Constructs Within the Candidacy Framework.*

<b>Construct</b>	<b>Definition</b>
1. Identification of candidacy	Process in which a person comes to appraise their issue as needing medical help which legitimises them as a candidate for particular health services.
2. Navigation of services	Knowledge of services provided and appraisal of the practicalities involved in making contact with and accessing services. Includes barriers to accessing services such as needing transport, convenience of appointment times and accumulated costs of attending services.
3. Permeability of services	The ease with which a person can use health services. Includes levels of gate-keeping within a service, the complexity of its referral processes, and the ‘cultural alignment’ of services with the person’s needs and values.
4. Appearance at services	The person’s ability to assert their candidacy by presenting at services, articulating their issue and articulating their ‘need’ for care.
5. Adjudication by healthcare professionals	A person’s candidacy is judged by healthcare professionals, subsequently influencing the person’s progression through services and access to care. Adjudication may disadvantage certain people by perceiving them as either ‘deserving’ or ‘undeserving’.
6. Offers of, resistance to services	A person may refuse offers at multiple stages in their journey to treatment including resisting offers for appointments, referral, and treatment.
7. Operating conditions and local production of candidacy	Incorporates factors at societal and macro levels which influence candidacy, such as the availability of local resources for addressing candidacy, and relational aspects which develop between the healthcare provider and patient over multiple visits.

*Reprinted from: Tookey, S., Renzi, C., Waller, J., von Wagner, C., & Whitaker, K. L. (2018). Using the candidacy framework to understand how doctor-patient interactions influence perceived eligibility to seek help for cancer alarm symptoms: a qualitative interview study. BMC Health Services Research, 18(1), 937. <https://doi.org/10.1186/s12913-018-3730-5>. See Acknowledgements for Creative Commons attributions.*

Through emphasising relational interactions between individuals, providers and contexts at multiple levels, the candidacy framework expands upon linear health cognition models that outline health decision-making processes from the perspective of an individual patient or provider (Tookey et al., 2018). The concepts of deservedness and validation of needs as a

power struggle adds further understanding to the experiences of marginalised groups (Mackenzie et al., 2012). Dixon-Woods et al. (2006) focused on groups with lower socio-economic status to illustrate these concepts, but it has since been applied across other marginalised patient groups, such as people with disabilities. In a study of mental health service access for those with intellectual disabilities (ID), this framework highlighted the role of multiple players beyond individual patients and providers to include the influence of service managers and carers in negotiations of candidacy, as well as the constraints perpetuated by operational contexts (Chinn & Abraham, 2016). However, the majority of autistic people do not have ID (Kinnear et al., 2019; Maenner et al., 2021) and healthcare commissioners have noted how generalising knowledge from groups with ID is insufficient to address inequalities and target improvements for autistic adults without ID (Christou, 2016).

The barriers to healthcare reported by autistic adults frequently reflect constructs in the candidacy framework, particularly difficulties navigating service pathways and communicating with providers (Doherty et al., 2022; D. Mason, Ingham et al., 2021; Christou, 2016). For example, autistic adults often report feeling that their problem or behaviour has not been understood by providers (Raymaker et al., 2017). Communication for autistic people is impacted by a complex interaction of innate neurodevelopmental differences, such as processing speed, with social contexts and norms, influencing the interpretations of others (Crompton, Ropar et al., 2020; Milton, 2012; D. Mason et al., 2019). From a candidacy perspective, communication affects access to services, such as booking an appointment, and presenting a problem in a way professionals consider credible. However, research has not yet explored whether the candidacy framework may be helpful for understanding communication-related barriers experienced by autistic people. Autistic people also experience differences in executive function which may impact organisational abilities, are more likely to experience emotional difficulties such as anxiety, and have a stronger need



for sameness and routine, characteristics which can all play a role in healthcare interactions (D. Mason et al., 2019). Mackenzie et al. (2012) noted how characteristics of medical conditions may themselves affect candidacy negotiations.

Autistic people have reported how the attitudes of providers, including their willingness to make adjustments to service delivery, can pose further barriers to healthcare access (D. Mason et al., 2019; Raymaker et al., 2017). Additionally, systemic and societal factors including disability stigma, socioeconomic status, social support and access to practical resources such as transport have been found to affect interactions between autistic service users, providers and barriers (D. Mason et al., 2019). A review of mental health services reported how healthcare barriers could lead to autistic people perceiving themselves unworthy of care (Brede et al., 2022). It may therefore be worthwhile to apply the candidacy framework to further examination of these experiences.

### *Aims*

Our study aimed to qualitatively explore the experiences of access and barriers to healthcare for autistic adults, and applied a candidacy framework to the themes identified to embed findings in established theory.

## **Methods**

### ***Participants.***

We recruited autistic adults aged 18 and over (n=21) for an interview-based study. All but one participant were re-contacted having taken part in an anonymous survey we conducted on access to healthcare and communities during the Covid-19 pandemic. Survey participants had been recruited through the Autistica Discover Network and localised autism and disability support groups and organisations. Participants could take part if they lived in the United Kingdom and had a diagnosis of autism or self-identified, but all participants in our analysis of the survey met the cut-off criteria on the AQ-10 screening tool signifying eligibility for autism assessment (Allison et al., 2012). At the point of consenting to future contact for follow-up studies, participants did not have prior knowledge of the intended interview topics and their survey responses were not known to the researchers. One other participant in the interview study was referred by a contact and had a formal autism diagnosis.

### ***Procedures and Ethics***

Procedures were approved by the University of Plymouth Faculty of Health Ethics Committee. Interview design, data collection and initial analysis were led by a PhD student with an academic background in psychology and lived experience of autism. Remote semi-structured interviews took place between July-September 2021. Twenty interviews were carried out using Zoom and aimed to last approximately one hour. One participant requested to take part by email due to inaccessibility of video call technology for their communication needs – we obtained ethical approval to adjust the interview procedures. Participants received the interview questions in advance to aid communication, and an information sheet explaining the study procedures and their rights as participants to withdraw from the study

without consequences. They were required to give verbal consent to take part at the start of interviews, which was recorded.

We developed an interview schedule guided by our understanding from quantitative studies of barriers to healthcare access, aiming to understand more about their impact on decision-making and meeting of health needs, and their mitigation. The interview schedule asked:

*When you have a health concern (physical or mental health) that you can't manage by yourself, what steps do you typically take to get support?*

- *When do you decide to seek support? Can you give me an example?*
- *What would put you off getting support? What other difficulties might you have?*

*How have you found accessing support for your health?*

- *What types of support do you feel have helped you most?*
- *Do you disclose your autism diagnosis in a healthcare environment? Why/why not?*
- *In what ways have health services adapted for you to support your needs? How did this help?*
- *Have you had any challenges or difficult experiences with getting support for your health or wellbeing?*

As interviews formed part of a broader study on pathways to social prescribing for autistic adults, participants were also asked about their strategies and barriers for managing their general wellbeing, the interactions of wellbeing with environments and their impressions of nature-based social prescribing for improving wellbeing. Participants were also asked to give their initial and concluding thoughts on the research topics at the start and end of interviews respectively. All sections of the interview transcripts were coded for relevant information relating to healthcare access.

### *Analysis and Theoretical Framework*

We initially used thematic analysis to analyse interview findings, situated within a critical realist ontology which is compatible with this methodology and continued to inform our approach throughout analysis (Braun & Clarke, 2022). Critical realism can be useful in autism research by balancing essentialist interpretations of autism as a useful diagnostic and social category with personal experiences and the influence of wider social contexts, giving meaning to the heterogeneity between individuals that can be considered problematic in positivist ontologies (Botha, 2021b; Chapman & Veit, 2021; Woods et al., 2018).

Following guidance of Braun and Clarke's (2022) methods for reflexive thematic analysis, transcripts were coded inductively by one researcher (CF) using descriptive coding and organised into preliminary categories including 'skills navigating services', 'interactions with providers', 'limitations of services' and 'ease of access'. The research team identified that constructs from the candidacy framework resonated with the initial themes, and used an iterative process to examine findings in relation to this framework by referring back to both the data and the candidacy literature, as recommended by MacFarlane & O'Reilley-de Brun (2011). Although the constructs within a framework analysis are predefined, their application ensures a theoretical basis substantiated by acknowledging the contribution of previous research, but remains novel in the context of the research questions of the study regarding population and the unique data supplied by participants (MacFarlane & O'Reilley-de Brun, 2011). Some themes, such as those outlined above, mapped almost directly onto the candidacy framework, while other overarching themes as well as initial codes required re-evaluation, such as becoming subthemes within the candidacy constructs. For instance, an initial theme of 'Communication' became a subtheme within *Appearance and Adjudication*; 'Delaying help-seeking' which had referred to a group of codes within the subtheme 'Making decisions about health', became incorporated into the *Identification of Candidacy*. On

completion of analysis all previous themes and subthemes had been represented within the framework analysis. Table 5.2 shows how the initial themes translated onto the candidacy framework.

**Table 5.2:**

*Translation of Thematic Analysis Onto Candidacy Framework*

<b>Initial Themes</b>	<b>Framework Analysis</b>
Structure of healthcare: Service design, processes and pathways	Operating conditions; permeability; navigation; offers and resistance
Structure of healthcare: Staff training and understanding	Operating conditions
Structure of healthcare: Culture of care	Operating conditions
Help-seeking: Skills navigating services	Navigation
Help-seeking: Personal factors	Identification of candidacy; navigation; offers and resistance
Help-seeking: Making decisions about health	Identification of candidacy; offers and resistance
Interactions: Communication	Appearance; adjudication
Interactions: Adapting services	Permeability; adjudication
Interactions: Decisions around disclosing autism diagnosis	Appearance; adjudication

## Results

### *Sample Characteristics*

We interviewed twenty-one participants (see Table 5.3), ranging in age from 21 to over 70 years old. 11 were male, 7 were female and 3 participants identified as nonbinary or bigender. 15 participants reported additional disabilities including mental health concerns, specific learning difficulties, intellectual disability and physical health conditions. Participants' names have been replaced with pseudonyms in extracts from interviews.

**Table 5.3**

### *Participant Characteristics*

<b>Characteristic</b>	<b>Participants (N)</b>
Gender identity:	
Male	11
Female	8
Nonbinary or bigender	3
Age band:	
18-25	1
26-35	3
36-45	5
46-55	3
56-65	7
66+	2
Ethnicity:	

White British	17
Other white background	1
Black Caribbean	1
Not stated	2
Additional disabilities:	
Mental health (anxiety, depression, social phobia, schizophrenia, bipolar disorder, PTSD)	8
Physical disability or long-term illness (heart, COPD, cerebral palsy, long Covid, neuropathy, diabetes, sleep disorders, ME/CFS)	7
Intellectual disability	2
Specific learning difficulty (dyslexia, dyspraxia, dyscalculia)	5
ADHD	5

### ***Identification of Candidacy***

Participants used a variety of sources of information to help them identify and solve health problems, including online sources and speaking to family members or partners who they perceived to be knowledgeable. Many spoke about exploring all alternative avenues, and trying to manage independently as far as possible, before using medical services.

Reflecting traditional health cognition models such as Protection-Motivation Theory (Prentice-Dunn & Rogers, 1986) participants weighed up factors such as their problem's severity and urgency, and their coping abilities, in deciding whether to seek medical attention, taking this step if a problem began "*getting in the way of daily life*" (P16, M, 56-

65) or “*when I was confident I could not resolve it myself*” (P12, NB, 56-65). However, sometimes participants did not seek help until reaching crisis point and many described needing to be “*desperate*” (P22, F, 56-65) before seeking help. They sometimes had difficulty identifying the severity of their symptoms. In the case of some conditions, symptoms may be difficult for lay people to identify, but autistic people can also experience differences in ‘interoception’ which impacts how bodily states are identified and appraised (Fiene & Brownlow, 2015; Garfinkel et al., 2016); accounts suggested this may have contributed to delays in seeking help.

*“If I think I’ve injured myself, you know, in a bad way, it might take me a while to process that and to actually realise, I am actually injured [...] I didn’t realise I had [chest infection]. I have... I will carry on working and not realise it’s making me tired and things like that, and you know, after a while realise, oh no, everything’s going wrong”* (P22, F, 56-65)

Mental health conditions were sometimes more difficult to appraise than physical health. This may have been affected by wider attitudes about mental health in society, such as “*other people just saying ‘oh, pull yourself together’*” (P16, M, 56-65).

### ***Navigation of Services***

While many participants identified a wide range of publicly available health services they would consider using, others found the health system “*sometimes a bit complicated*” (P22, F, 56-65), with challenges navigating services and negotiating candidacy compared to “*running the gauntlet*” (P10, M, 46-55) or “*fighting a battle*” (P12, NB, 56-65). Service availability varied by area, with some participants describing how the lack of choice in some areas impacted life decisions such as moving home. Experiences of inappropriate referrals had left some participants unsure where to look for help and feeling that they “*need a professional plan of the relevant services*” (P14, F, 56-65). Existing knowledge about health services,



such as through previous employment or relatives who “*knew their way around the health service*” (P15, M, 66+) and could provide signposting, was an advantage for navigation.

Workplace adjustments such as allocated time to attend a therapy appointment enabled access to services. Finding services with adequate autism awareness required additional effort:

*“I’ve had to work so hard to find a private therapist who understands anything to do with autism [...] I’ve had to sort of really, really do a lot of research into that and it feels like it shouldn’t have taken that long”* (P07, F, 36-45)

Initiating contact with services often relied on using the telephone, contributing to feelings of uncertainty and unpredictability for participants due to “*not knowing who will answer the phone*” (P14, F, 56-65) or being put on hold and “*jostling elbows with other people who also want appointments*” (P15, M, 66+). This was considered by some to be “*the worst thing*” (P07, F, 36-45) about navigating services, although for some participants it was less challenging (and even welcome) to receive a scheduled phone call, because it meant bypassing difficult physical environments in order to access care. Contacting services by phone was also challenging for participants with physical disabilities or on pay-as-you-go contracts. Many preferred to contact services using online communication methods, as “*rather than having to think on my feet [...] it wouldn’t matter if it took me an hour to do it [...] I’d know I was getting every last little fact in*” (P07, F, 36-45). The Covid-19 pandemic had increased access to online booking systems. Unfamiliar staff, a lack of continuity of care and having to travel to new locations also contributed to a perception of unpredictability in health service navigation.

Despite the NHS offer meaning healthcare is usually free at the point of access, many participants had sought private healthcare options, feeling “*let down*” (P07, F, 36-45) by NHS services and perceiving a wider choice of services to be available privately with fewer

restrictions, such as being able “*to see my therapist for as long as I want*” (P02, F, 36-45). However, some participants felt that the private sector was not equipped for more complex problems. Many who had pursued private options felt they were fortunate to be able to afford the care they needed. In other cases, low-cost options and care provided by charitable organisations helped those who were less financially advantaged to access services outside of the NHS.

*“[Support group] have counsellors, free counselling sessions which, I was having counselling for an hour once every two weeks, and that was unended, so it went on for about a year and a half. Which you could never ever get on the NHS [...] absolutely life-saving”* (P19, M, 36-45)

### ***Permeability of Services***

Participants reported accessibility problems in services, including “*hectic*” (P13, NB, 36-45) sensory environments, limited communication options and the demand for social interaction, which they found stressful. They had mixed experiences of accessing adjustments to their care. Helpful accommodations included being able to “*see the same doctor every single time*” (P01, M, 56-65) and having an advocate go “*to appointments ahead of me to explain that I'm autistic and some of the things I'll struggle with*” (P05, F, 46-55). Participants emphasised the importance of adjustments to services being individualised, such as explaining how “*I want to know [details] but other people might not*” (P02, F, 36-45). Without accommodations, some participants resorted to “*self-defence*” (P12, NB, 56-65), making their own adjustments in healthcare settings, such as using noise-cancelling headphones to minimise sensory disturbance; however, this relies on having access to adequate resources and these adaptations were not appropriate for all healthcare settings. Some participants described a sense of helplessness, feeling that there was little that health

services could do to accommodate their needs, whereas others suggested changes that implied minimal costs and effort but would have a significant impact on their access to care:

*“They could actually adapt a room you know, and make it autism friendly where they got some low lights and it's a little bit quieter [...] they don't have to adapt the whole hospital [...] with my appointment, a couple of weeks ago that would have made me stay there” (P08, F, 56-65)*

Participants highlighted problems with receptionists acting as gatekeepers, including concerns about their training, and several participants felt receptionists who triaged patients sometimes reacted negatively to certain conditions or problems.

*“Difficulty at mention of word Autism and housebound Disabled, that complexity means often my call is immediately put down or timed out” (P14, F, 56-65, typed response)*

Others had experiences where receptionists did not allow a carer to speak on a patient's behalf or follow the doctor's advice with regards to their treatment.

Participants were not always eligible for services they felt were needed, including when they had no alternative support in place, leaving them with unmet needs or having to pursue private options. They also experienced inappropriate referrals which were deflected by services and a lack of follow-up contact on asking for a call back. Participants described how having the option of regular appointments would make accessing health systems more predictable and *“be like a routine”* (P18, F, 26-35). Annual health checks are currently offered to those with learning disabilities and severe mental illness, but not offered based on an autism diagnosis alone (Sharpe et al., 2019). A participant with a learning disability mentioned having successfully taken up offers of these routine checks.

### *Appearance and Adjudication*

Many participants felt that how they presented at services could affect care outcomes. Some described a struggle to present themselves in the way that they believed healthcare providers expected. For example, some felt that being more matter-of-fact than emotional in discussions about their health had led to perceptions that their problems were “*not that bad*” (P05, F, 46-55). Masking and compensatory strategies used to navigate daily life sometimes negatively affected providers’ adjudications of their needs as “*it seems like I am [understanding], but I realised that actually only some of the words go in and sometimes I misunderstand. So, during those processes, they saw a different person, a person that was presenting how I’ve learned to present to the world*” (P12, NB, 56-65).

Several participants described feeling ignored and disbelieved when seeking help, for example by doctors who “*hijacked the appointment*” (P01, M, 56-65) to talk about other issues or did not appear to listen to concerns. Repeated problems asserting candidacy led to delays in diagnosis and unmet needs. Where participants had experienced misdiagnosis, this was accompanied by stressful experiences including needing to appeal decisions and experiencing treatments that “*weren’t working, because obviously the diagnosis wasn’t right, so they would think I was game-playing*” (P08, F, 56-65). Participants’ distress made communication more difficult, which could lead to further misinterpretation and negative responses, such as being “*shouted at [...] because I also have shutdowns and mutism*” (P05, F, 46-55).

Despite participants’ expectations that their autism diagnosis would be recorded on their medical records, many described experiences of disclosing their diagnosis to try to prevent misunderstandings that might arise if they behaved “*unexpectedly*” (P02, F, 36-45) and reduce the expectations placed upon them by healthcare professionals. In some cases this

helped professionals relate the patient to their own experience, such as a family member, and understand “*how you struggle with that, because my brother or my son or daughter or whatever has autism*” (P13, NB, 36-45). Although this participant appreciated attempts to make these connections and respond accordingly, they highlighted how this could overlook autistic patients’ diverse profiles of needs and abilities. For other participants, disclosure was sometimes described as “*awkward*” (P18, F, 26-35), leading to confusion, silence or applications of stereotypes that “*I cannot speak or [I’m] stupid*” (P14, F, 56-65, typed response). Some participants preferred not to disclose for these reasons; others perceived no change to their care after disclosing. One person noted that “*if I say I have anxiety and not autism, it’s much more clear they’re making adaptations for me*” (P13, NB, 36-45), suggesting that professionals may sometimes be unclear how to accommodate autistic patients.

Participants identified gaps in health professionals’ understanding of autism, including “*any form of understanding adults, female adults with autism*” (P07, F, 36-45). Additionally, some participants felt professionals were resistant to training about autism and had experienced negative responses to attempts to self-advocate, including being accused of “*using autism as a weapon*” (P08, F, 56-65). Participants felt that specialists often failed to understand that an autism diagnosis may be relevant to other health concerns.

“*If you say to a specialist on autoimmune conditions, I’m also autistic he just looks at you blankly [...] he doesn’t see that that there’s any relevance*” (P05, F, 46-55).

Participants appreciated professionals who “*seemed to care*” (P01, M, 56-65) by demonstrating sensitivity, patience, humour and honesty, who validated their concerns and were willing to learn:

*“My cancer Consultant Surgeon asked me what my Autism was to me and what affects[sic] it had, she was the best kind, the collaborative with me. Both educators to each other”.* (P14, F, 56-65, typed response)

However, this experience also highlights additional effort for the patient in having to educate her provider. Not all autistic adults can manage this, particularly when in acute distress.

Participants described sometimes relying on partners or family members to help them process information or preferring less stimulating modes of communication such as telephone appointments where there was reduced interference from visual cues and sensory information. Despite modern technological advances and their widespread use, some participants experienced difficulties requesting alternative modes of communication such as email. Finally, some participants had not *“felt that my autism or whatever has overlapped with or interfered with communicating with a doctor about a particular physical health problem”* (P11, NB, 26-35), reflecting the diversity of communication needs across the autism spectrum.

### ***Offers and Resistance to Services***

For autistic patients, offers of and resistance to treatment related to barriers to navigation and permeability of services such as inaccessible communication systems, the sensory environment and ill-defined waiting times, which prevented participants from attending appointments.

*“I was waiting for two hours. And I knew that my appointment was about to come up, finally, but by that point, it was this room, it was one of those hot days we had [...] hospital windows don't really open, so it was, there was all the fluorescent lights and after about an hour and a half [...] I couldn't wait anymore, so I left. And I knew that I was leaving and I was going to miss my appointment, they would probably think, well, you missed your appointment and*

*we're taking you off, and it was to my detriment, but I- I couldn't actually cope anymore.”*

(P08, F, 56-65)

This experience shows how resistance and delays to treatment may not always be the individual's choice, instead resulting from accessibility barriers faced in earlier stages of the pathway. Some services, particularly for mental health, were described as “*one-size-fits-all*” (P12, NB, 56-65) and were refused because “*the way my mind works - or doesn't - six weeks isn't really enough*” (P09, M, 46-55), showing how resource limitations may disadvantage neurodivergent clients. Furthermore, treatment offers such as hospital admission were not always fully explained, leading to distress and resistance.

### ***Operating Conditions***

Participants' concerns about staff training around autism awareness and reasonable adjustments suggest this may be lacking in parts of the health service. Participants' accounts also suggested that various health service cultures often did not align with their personal values. Many valued a holistic approach to wellbeing, but their accounts indicated a predominance of the medical model. Recently awareness has been raised about the overuse of sedative or antipsychotic medication on autistic adults to manage distress-related behaviours (NHS England, n.d.(a)). One participant described an experience of being medicated in hospital that conveyed a loss of control over his care:

*“When I was in the hospital, when I broke down seven years ago, you had signs all over the wall saying talk to us before we medicate you. But the problem is they never kept to their word [...] I was effectively having to go through a withdrawal of Valium, because all they did was just fill you full of this stuff. I couldn't cope with hospital, so I went through this horrible process.”* (P10, M, 46-55).

Services were also portrayed as fragmented, with little communication between providers, which caused frustration and unidentified needs. Efforts to provide inclusive services for autistic adults were often perceived as tokenistic and failing to translate into improved outcomes. Long waiting times and bureaucracy further complicated access to healthcare and sometimes deterred participants from pursuing services such as diagnosis, including for autism. Many perceived the “*sheer depletion of resources*” (P15, M, 66+) as impacting the quality and availability of services and leading to staff turnover due to burnout. The combination of these problems diminished trust in services and staff. Participants who had had negative experiences also perceived systemic barriers within the complaints systems.

*“You can write to the Care Quality Commission and NHS PALS, they're not going to do anything because it's not just one person, it was the whole, it was the whole city, the whole structure”* (P04, M, 26-35)

These extracts convey autistic adults’ sense of disempowerment about having their concerns properly recognised and addressed in the way that they expected from health services.



## **Discussion**

This study applied the candidacy framework to autistic adults' accounts of accessing and using health services. The findings support previous research showing that barriers including inaccessible communication options and physical environments, difficulty navigating the health system, negative interactions with providers and anxiety about using health services lead to treatment delays and untreated health needs for autistic adults (Doherty et al., 2022; Raymaker et al., 2017). Using the candidacy framework identified possible contributing factors and dynamic processes underlying observed barriers, facilitators and disparities experienced by this population.

One such process may be a negative spiral of communication, misinterpretation and emotional distress. Participants in this study expressed difficulties with processing verbal information and communicating. They perceived that professionals held expectations about appearance that affected adjudication of candidacy. This relates to findings by Chinn and Abraham (2016) who found that appearance could affect providers' perceptions about patients' skills and capabilities and influence their candidacy for services. As a result of these problems, participants shared experiences of being misinterpreted or disbelieved by providers, an issue which has been highlighted in previous research (Raymaker et al., 2017). Although there are two sides to interactions with health providers, studies have shown that autistic people are more likely to be misinterpreted by others, for example being perceived as deceptive when conveying information sincerely (Bagnall et al., 2021). This may be due to a 'double empathy' problem, where people with different ways of thinking and communicating struggle to understand each other (Milton, 2012). Being repeatedly misinterpreted can have negative implications for mental health over time (Mitchell et al., 2019). The present study showed how these struggles served to increase immediate anxiety for patients attempting to negotiate candidacy in an already stressful environment, which stifled communication

further, leading to continued misinterpretation and negative adjudication. In turn, this increased anxiety and distress further and affected decisions around the use of health services that suggested additional effort for individuals.

These negative feedback loops have been identified previously (Saqr et al., 2018). The present study identified additional factors in negotiating candidacy which may contribute to these loops. For example, masking or compensating for autistic traits in order to create a social identity safe from stigma and marginalisation, which can be a conscious or unconscious strategy (Pearson and Rose, 2021), may contribute to misinterpretation. Autistic masking has received limited attention in research on access to healthcare. Although it may have advantages, it sometimes proved inadequate for navigating appearance-related processes of healthcare. Participants sometimes disclosed their autism diagnosis to aid understanding of their needs, but this was not straightforward. It involved weighing up risks and benefits, was sometimes ineffective at resolving issues with adjudication or obtaining reasonable adjustments and in some cases received negative responses.

Accounts suggested that navigating the health service involved high levels of effort and uncertainty for autistic adults. Differences in processing uncertainty can contribute to elevated anxiety in autistic adults (Jenkinson et al., 2020). The resulting stress and frustration may therefore be present from the outset of help-seeking and were found to impact communication. Some participants considered having to use the telephone to make the initial contact with services, which was mired in uncertainty including wait lengths and the anonymity of the receiving service provider, to be “the worst thing” about navigating health services. This is consistent with previous research showing that the telephone as the primary method of communication is a barrier for 62% of autistic adults compared with 16% of non-autistic people and was associated with untreated health needs (Doherty et al., 2022).

Furthermore, gatekeeping and triage processes may add another stage of communication and

uncertainty before reaching healthcare professionals, heightening the effort and stress involved in contacting services for autistic adults. Despite sometimes lacking medical training, participants' accounts suggest gatekeepers such as administration staff make adjudications about candidacy for healthcare. Brede et al. (2022) found that autistic people were likely to be given harmful and inaccurate labels in mental health services; in this study, participants perceived that receptionists were sometimes averse to particular disabilities or conditions being raised and showed a lack of understanding around providing reasonable adjustments, even when requested by a doctor. This may demonstrate why gatekeeping has been found to be a significant barrier to healthcare access for autistic people compared to non-autistic people (Doherty et al., 2022). Cultures and attitudes underlying the structure and delivery of services, combined with a perceived lack of training and understanding about autism, may contribute further to misinterpretation, negative adjudications of candidacy and unmet needs.

Inequalities in access to the health service and to reasonable adjustments to care could sometimes give the appearance of resistance to offers of treatment. Findings suggested that the right to ask for adjustments to care was part of the negotiation of candidacy for autistic people, but there may be a hierarchy of disadvantage affecting these negotiations. Prior knowledge of the health system, access to social support and material resources, and being capable of self-advocacy, appeared to facilitate access to healthcare and the negotiation of candidacy for autistic adults. Those who could access these resources still struggled to use communication methods and have their needs and concerns recognised. These system-level factors not only make it difficult for patients with disabilities to adapt to services, but also pose challenges for individual staff seeking to level these structures to accommodate service provision for those with disabilities (Chinn & Abraham, 2016).

People in the present study who used private services to access psychotherapies and diagnosis of autism and other conditions considered themselves lucky to afford this option and were both aware and concerned that not all their peers were so fortunate. Although issues such as waiting times in NHS services may lead many patients to similar decisions, autistic people may feel forced to seek more specialist services or those with better autism awareness, due to their needs not being accommodated in mainstream healthcare. Brede et al. (2022) found that operating conditions such as withdrawal of mental health services and their funding contributed to use of private healthcare for autistic adults. Low-cost options and services provided by charities enabled access to alternative health systems for autistic adults in this study. Reliance on private and alternative health pathways outside the NHS may signify an invisible struggle faced by autistic people in accessing healthcare, which may contribute to the health inequalities and acute care needs observed in this population.

### ***Strengths and Limitations***

A strength of the study was the diversity of the sample. Participants trended towards the older age groups on average, contrasting with most autism research which focuses on children and younger adults (Michael, 2016). There was also a balance of gender representation (including from those who were gender nonconforming or identified as LGBT), those with other co-occurring disabilities, and life experiences including being employed, unemployed or retired, users of social care, and people who were married, had children or lived alone. These accounts reflect the diversity of autistic adults. However, as the study was not designed with the candidacy framework in mind, we did not collect data on socioeconomic status of participants, which given the frequency of access to private healthcare among our sample, may have provided further insight into how this relates to the ability of the wider autistic population to access the same opportunities.

The findings may be limited by their dependence on first-person accounts, which may present a one-sided narrative, as participants in the study who had fewer problems with accessing health services gave less detailed responses. However, descriptions of the barriers to accessing services were consistent with previous research (D. Mason et al., 2019; Doherty et al., 2022; Saqr et al., 2018). The accounts sometimes made assumptions about providers' intentions. However, participants backed up their opinions with examples from their experiences. Furthermore, participants' accounts also revealed factors they felt facilitated or improved their experiences of healthcare access, providing balance. Future research could explore the processes of adjudication of autistic patients from providers' point-of-view, perhaps using observational or ethnographic methods to identify the processes of negotiating candidacy from both sides in these interactions.

### ***Recommendations for Practice***

While having different neurological processes can make it difficult for many autistic people to adapt their communication styles, healthcare professionals can adjust their communication. Participants in the study appreciated health professionals who demonstrated a patient and empathetic approach. Staff should also have a prior understanding of the types of supports which may assist with communication and reduction of overwhelm for autistic people in healthcare settings. This should also consider the diversity of people on the autism spectrum, so personalised supports (e.g. a health passport) which explain an individual's specific needs may be helpful if implemented at scale, kept up to date and followed through.

The gatekeeping issues described by participants suggest that a possible adaptation for autistic people could be a fast-track system which bypasses standard triage processes.

Participants in this study also suggested that pre-scheduled contact with health services would be more helpful than needing to seek help independently when needs escalated. Research is

investigating the expansion of NHS annual health checks for autistic adults, which are currently offered to people with ID (Department of Education & Department of Health & Social Care, 2021), but this study highlighted how autistic people without ID can still experience challenges with identification of need, service navigation and permeability. Lack of identification of health needs may contribute to autistic adults falling between gaps in services and consequently widen health inequalities (Sharpe et al., 2019), whereas routinely checking for new physical and mental health concerns may overcome problems of fragmented health services described by participants and address this area of public health need. However, services providing routine health checks would need continue to address accessibility of communication methods and environments to ensure success.

Online methods of communication were also identified as reducing the uncertainty and effort of navigating services and negotiating candidacy. While other analyses suggest that service permeability became more restricted during the Covid-19 pandemic due to reduced contact options (Liberati et al., 2022), participants in this study reported online options during the pandemic facilitated their communication needs and reduced uncertainty. Services should retain these options, which may maximise accessibility and convenience not only for autistic patients but also for other patients.

### ***Conclusion***

This study utilised the candidacy framework to expand on research investigating the challenges that autistic adults face in accessing healthcare and found that these result in additional stress and effort that compound health decision-making. Findings suggested that many social advantages contributed to the processes of negotiating candidacy, including the ability to access private and alternative healthcare, suggesting that autistic people with less access to social and material resources may experience increased challenges demonstrating

their candidacy for healthcare. Factors identified by participants which facilitated the negotiation of candidacy suggest ways in which services could be improved to allow for a smoother experience for autistic patients and break negative feedback loops in the adjudication of candidacy by health professionals.

## Chapter 6

### Autistic Adults' Experiences of Managing Wellbeing and Implications for Social Prescribing

This is the accepted version of *Featherstone, C., Sharpe, R. A., Axford, N., Asthana, S. & Husk, K. Autistic Adults' Experiences of Managing Wellbeing and Implications for Social Prescribing. Disability & Society*, available at

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## **Abstract**

Autistic people demonstrate poor outcomes on objective measures of wellbeing, yet research centring lived experience provides a more nuanced picture. There is growing support for person-centred, holistic and community approaches to enhancing wellbeing for autistic people. Social prescribing may be one such approach. This qualitative study explored the concept of wellbeing for autistic adults – including barriers and self-management – and the implications of this for modifying social prescribing. It involved semi-structured interviews with 21 autistic adults in the UK. Reflexive thematic analysis of the data supports research suggesting that self-determination may underlie many aspects of wellbeing for autistic people. The COVID-19 pandemic provided new opportunities to develop wellbeing strategies but also had negative impacts. Social prescribing could promote self-determination by signposting autistic people to peer support opportunities building on intrinsic interests.

## **Introduction**

A population's wellbeing can be an important indicator of broader quality of life, used to compare outcomes across regions and drive policy decisions (ONS, 2018). Although definitions of wellbeing vary, most models comprise multiple dimensions. For example, a general population survey conducted by the United Kingdom's Office for National Statistics (ONS) found the most acceptable definition of wellbeing comprises intrapersonal domains (e.g. life satisfaction and physical and mental health), interpersonal factors (e.g. relationships and loneliness), employment, leisure activities, living standards, and wider factors such as the economy and environment (ONS, 2016). Some dimensions can be measured objectively, while others rely on subjective evaluation (Department of Health, 2014b). Collective factors can also impact on wellbeing. These include shared values and interests of a population (such as location), relationships, networks, shared learning, social cohesiveness, equity and social justice, which interact with individual factors to achieve an overall sense of community wellbeing (Coburn and Gormally, 2020; Atkinson et al., 2017; Rayner et al., 2018).

Autistic adults are known to experience poor outcomes in many areas pertaining to wellbeing, including high rates of physical and mental health problems, unemployment, isolation, educational disadvantage and financial hardship (Brugha et al., 2011; Croen et al., 2015; Howlin, 2021). Studies measuring quality of life in autistic adults have found low scores across many domains when compared to population norms or non-autistic controls (Holmes et al., 2020; Lawson et al., 2020) and negative correlations between autistic traits and quality of life (Oakley et al., 2020). However, Oakley et al. (2020) observed a high level of individual variability, especially for adults, warranting further interrogation of subjective quality of life, including protective factors and developed coping strategies. Findings informed by lived experiences of autistic people, typically using qualitative methods, also present a more nuanced narrative (Welch et al., 2020; Welch et al., 2019). They sometimes

reframe medical diagnostic criteria and functional differences considered maladaptive such as how self-stimulatory behaviour may aid emotion regulation (Kapp et al., 2019) and have elicited concepts shared in autism-related communities but not classified in diagnostic criteria, including meltdowns, inertia, burnout and masking. These concepts are linked to wellbeing, impacting mental health, social interactions and daily activities (L. Bradley et al., 2021; Buckle et al., 2021; Cassidy et al., 2018; Cage and Troxell-Whitman, 2019; Hull et al., 2017; Raymaker et al., 2020; Welch et al., 2021). A coproduced quality of life scale for autistic samples led to inclusion of nine autism-specific items including autistic identity, sensory processing and healthcare barriers (McConachie et al., 2018).

Critical perspectives argue that measures developed in the general population, despite methodological robustness, may apply normative, individualistic and medicalised standards to autism research (Jones et al., 2022; Lam et al., 2021; D. Mason, Capp et al., 2021). This leads to poor outcomes being attributed to autism and resulting in a prevailing assumption that being autistic is incompatible with thriving (Chapman and Carel, 2022). Interventions often target individual behaviours and traits, yet these have shown little collective success over time at reducing wellbeing disparities (Howlin, 2021). Wellbeing-related constructs are less emphasised in outcome measurement (Featherstone et al., 2022). However, the constructs identified through subjective accounts emphasise contextual factors such as access to services, features of environments and social pressures on wellbeing, supporting models such as the neurodiversity paradigm and social model of disability which propose that poor fit between individual conditions (in this case, the lived reality of autism) and social context lead to disability (Shakespeare, 2013).

A literature review on self-reported outcomes found self-determination may instead underlie many areas pertaining to wellbeing for autistic people including employment, healthcare access and social participation (Kim, 2019). Self-determination theory (SDT)

describes a spectrum of motivation for action ranging from intrinsic motivation to external drivers, with higher levels of intrinsic motivation being more indicative of self-determination (Ryan and Deci, 2000). Three psychological needs – autonomy, connectedness and competence – contribute to intrinsic motivation within SDT (Gagne & Deci, 2005). Higher self-determination has been found to relate to life satisfaction in autistic young adults (K. White, Flanagan, and Nadig, 2018), and that markers assumed to indicate good outcomes, such as independent living, are not always indicative of life satisfaction and positive overall wellbeing (D. Mason, Capp et al., 2021; Scheeren et al., 2021; Pellicano et al., 2022; Henninger and Taylor, 2013). D. Mason, Capp et al. (2021) argue defining successful outcomes should be based on assessing each individual's values. These findings indicate a need for wellbeing support for autistic adults which takes self-determination, individual differences and social context into account (Kim, 2019). Other recommendations for improving support for autistic adults include using flexible and person-centred approaches which identify existing strengths to build skills and social connections, and allowing lived experience to drive wider research and practice (Howlin, 2021; Murray, Lesser, and Lawson, 2005).

Social prescribing describes a healthcare model where health professionals connect people to wellbeing-enhancing activity in communities, such as exercise groups, nature referrals and advice services (Bickerdike et al., 2017; Chatterjee et al., 2018; Kimberlee, 2015; Polley, Fleming et al., 2017). Social prescribing is often positioned as countering, complementing or extending traditional medical approaches, as a tailored and person-centred model taking account of biopsychosocial factors including individual values, goals and barriers (Calderón-Larrañaga et al., 2022; Ogden, 2018). It often targets people managing chronic illness or experiencing socially-derived problems such as loneliness, where medical intervention is insufficient to address wellbeing (Polley, Fleming et al., 2017). The typical

social prescribing model involves a link worker to coproduce an appropriate social prescription, matching clients' goals with the link worker's knowledge of community networks (Polley, Fleming et al., 2017). This role can be crucial to successful social prescribing (Hazeldine et al., 2021), as is the voluntary, community and social enterprise (VCSE) sector which provides much of the end-point support (Polley, Fleming et al., 2017).

Findings on social prescribing's effectiveness are mixed, with quantitative studies often demonstrating poor methodological quality, low uptake, and inconsistent outcome measures (Blodgett, Kaushal, and Harkness, 2022; Bickerdike et al., 2017). However, many features of social prescribing, such as person-centred tailoring and collaborative approaches, may facilitate engagement with community-based supports for autistic adults, although current social prescribing models may require some adaptation to benefit autistic people in the referral pathway (Featherstone et al., 2022). This might include widening referral methods and offering flexible levels of social interaction, as well as increasing understanding of autism amongst link workers, for whom a lack of training around 'complex' patients is often perceived as a barrier to success (Hazeldine et al., 2021; Holding et al., 2020; Wildman et al., 2019). Furthermore, qualitative research has linked social prescribing to self-determination through mechanisms of a supportive link worker relationship, centring of individuals' interests and goals, community participation and enabling self-management of health and wellbeing; these increased intrinsic motivation around health management and enhanced social competence (Bhatti et al., 2021; Hanlon et al., 2021).

However, few primary research studies have investigated whether social prescribing may benefit autistic people (Charlton et al., 2021; Featherstone et al., 2022). As part of a broader research project aiming to understand how social prescribing could be tailored towards this group, we formulated this study to explore the concept of wellbeing for autistic adults and the implications for modifying social prescribing. The study was conducted during

the first year of the Covid-19 pandemic in the United Kingdom, which affected wellbeing across populations and sectors, negatively impacting mental health, social isolation and finances, issues which were more pronounced for disabled people (ONS, 2020a; ONS, 2020b; Emerson et al., 2022). Impacts for autistic people were mixed, due to differing individual experiences of the effects on daily routines, social demands and access to services (Bundy et al., 2022; Pais and Knapp, 2021). The pandemic also impacted the social prescribing pathway, highlighting benefits and disadvantages of social prescribing models within this context and resulting in changes to practice likely to persist post-pandemic (Westlake, Elston et al., 2022). We aimed to understand how individuals defined wellbeing, their strategies for managing wellbeing and experiences of barriers to meeting their wellbeing needs, within the context of Covid-19.

## **Research Process**

### ***Theoretical approach***

Our study adopted a critical realist philosophy, which bridges constructivist and positivist approaches by recognising multiple interpretations and perspectives on reality. This is pertinent to the debates on how typical standards have been applied to autistic people without always considering diverse lived experience, which is often framed as an issue of heterogeneity in positivist approaches that aim to generate robust and standardised definitions and interventions for autism (Botha, 2021b; Chapman and Veit, 2021; Woods et al., 2018; Kourti, 2021). While a wholly constructivist approach may risk undermining observable differences generated by medical research, as well as the distinct social disadvantages affecting autistic people (Botha, 2021b), critical realism gives room for alternative models such as the neurodiversity paradigm and social model of disability. These positions represent those led by scholars with lived experience. Applying critical realism allows for the co-existence of paradigms and methods used to construct knowledge, in this case about subjective wellbeing; this can highlight power differentials and contextual factors in how the mechanisms of reality are realised (Rosqvist et al., 2023). For example, the “double empathy” theory re-evaluates what biomedical models have reinforced as theory of mind deficits in autism by presenting evidence of bi-directional difficulties and contextual factors affecting perspective-taking (Milton, 2012), with a negative impact on social and emotional wellbeing for autistic people (Mitchell et al., 2021).

We applied reflexive thematic analysis to analyse interviews, as this is a suitable methodology for the critical realist ontology (Braun and Clarke, 2022), which requires reflection on how knowledge is produced (Botha, 2021b; Kourti, 2021).

### ***Sampling strategy***

All but one participant had been recruited to a previous survey by the researchers that investigated autistic adults' wellbeing and access to healthcare and communities during Covid-19. Those who had consented to be contacted about future research opportunities were invited to take part in this study. Original recruitment methods involved advertising the study through the Autistica Discover Network, charities and organisations providing local support for autistic adults, university disability services, local governmental autism partnership boards, social media and autism-related forums. One participant in the interview study was recruited by word of mouth. Participants could either have a formal autism diagnosis or self-identify as autistic (ensuring representation of those who were either not able to access, or preferred not to seek, a formal diagnosis).

### *Ethics*

All procedures were approved by Plymouth University's Faculty of Health Ethics Board (reference: 19/20-1311). Participants received an information sheet and consent form in advance, which included their right to withdraw their data at any time prior to analysis. Their consent to the procedures was audio recorded along with their full names, except for one participant who gave written consent due to participating via email. Following interviews, participants received a debrief form with details of wellbeing support and advice.

Adjustments made at a universal level to support a diverse group of autistic individuals to participate included sending participants the interview questions in advance to reduce uncertainty and facilitate communication. Participants were also given options for taking part using Zoom, either as a video call, by phone (supported by Zoom) or by text using Zoom's chat function. All participants who self-selected for the study informed the researchers if further adjustments to procedures were required. These included providing easy-read information about interview concepts, such as social prescribing, to facilitate participation for



those with learning disabilities, and allowing the use of email to communicate, considered an appropriate accessible method of data collection for interviews with autistic people (Nicolaidis et al., 2019); an ethical amendment was granted to accommodate this. Use of terminology adhered to community guidelines and preferences (Bottema-Beutel et al., 2020). In transcription we removed names of people, organisations and places that might identify participants or others.

### ***Data collection***

Online interviews took place in summer 2021, so both interviewer (CF) and participants took part remotely. Interviews used a semi-structured format, with participants asked initially if there was any particular area of wellbeing they wanted to begin with. The interview schedule (Appendix 9) began by focusing on what wellbeing meant to each individual, with questions including: ‘What does wellbeing mean to you?’ and ‘What does it mean to feel at your best?’ Participants were asked about their strategies for keeping physically and mentally well, how these were developed, and when these had helped or been less helpful. They were also asked if the Covid-19 pandemic had affected how they were able to keep well. The complete interview covered a range of topics, including access to healthcare, places and environments, views on nature-based social prescriptions, and questions on community belonging, including the impact of the pandemic. In this paper we focus on responses relating to wellbeing experiences.

We used Zoom to conduct interviews, record audio files and generate transcripts. The auto-generated transcripts were corrected jointly by a researcher (CF) and a professional transcription service. Transcripts contained spoken dialogue only, in line with the approach of thematic analysis. The process of correcting transcripts enabled familiarisation with their content.

### *Data analysis*

In accordance with procedures for reflexive thematic analysis, one researcher (CF) coded transcripts inductively, using colour coding to differentiate responses for each research question. Initial codes were entered into a spreadsheet and organised into preliminary categories. We used NVivo to begin organising initial themes. Possible themes and links to theory were discussed in meetings with the broader research team, leading to further revisions to the overall theme structure.

## **Results**

### ***Participants***

Participants (N=21) were adults over 18 years old living in the UK. They were not asked if they had a formal autism diagnosis or self-identified, but all participants who had taken part in the previous survey had scored above the threshold of  $\geq 6$  on the AQ-10 measure, suggesting they would meet criteria for an autism assessment (Allison, Auyeung, and Baron-Cohen, 2012), and one participant recruited later had a formal autism diagnosis. 11 participants were male, 7 female and 3 nonbinary. 18 participants identified their ethnic background as white (British or other) and one as Black Caribbean; 2 did not state their ethnicity. Additional disabilities reported by participants, which may be relevant to their experiences of wellbeing, included mental health conditions (e.g. anxiety, depression, schizophrenia) (8 participants), physical disability or long-term illness (e.g. heart condition, cerebral palsy, chronic fatigue) (7 participants), specific learning difficulties (e.g. dyslexia, dyspraxia) (5 participants), ADHD (5 participants) and intellectual disabilities (2 participants). Age, measured in bands, ranged from under 25 to over 66, with most participants falling in the bracket of 56-65.

### ***Personal Wellbeing***

This theme comprised intra-personal factors involved in wellbeing. The first subtheme identifies ways of defining wellbeing and factors influencing subjective understanding. The second subtheme identifies participants' strategies and actions for managing wellbeing and their development. The third subtheme identifies how intrinsic traits and interests contributed to wellbeing and achievement of goals. The fourth subtheme reveals barriers internal to the person identified as affecting wellbeing.

**1.1 “My Normal is Very Different”: Wellbeing as Multidimensional.** Most participants viewed wellbeing as a multifaceted concept beyond simply physical or mental health to include such concepts as: environment; social connections; spirituality; finances; a sense of control; the ability to perform daily activities; achieving goals. Some understandings were subjective and had been developed through personal experience, learnt values and attitudes towards health. For example, education influenced personal definitions of wellbeing.

*“I think ever since I did some study in philosophy I’ve had a very holistic approach towards, you know, what constitutes the human being, human society - you’re both individual and community” (George, M, 66+)*

Other participants referred to recognised models, such as “five ways to wellbeing”. Some participants perceived that their understanding might defy accepted ideas of wellbeing that they inferred from the phrasing of interview questions.

*“Normal is a very broad term [...] my normal is very different from other people’s normal wellbeing” (Gavin, M, 46-55)*

Other participants avoided comparisons with standards, favouring internal feelings of self-acceptance and contentment as wellbeing markers. Many accounts portrayed a need for harmony and equilibrium.

*“Mental and physical health, and the two together. Not one. So if you’re not well with one of them, your overall wellbeing is not good. So you have to be well in both of them to have good wellbeing.” (Alan, M, 56-65)*

Some participants contrasted wellbeing to their current state, for example having more energy, being free of pain and being happier. This suggested they did not regard wellbeing as a realistic goal for themselves currently.

*“For me to feel my best is to just not feel tired, not just, just not feel permanently exhausted, and I do [...] I am never, never at 100%; I’m always at 50 or running below 50 the entire time.” (Lauren, F, 36-45)*

**1.2 “I Wonder if I Should Actually Just Get Some Running Shoes and Start Running”: Wellbeing Through Actions and Routines.** Following on from identifying

which areas of wellbeing were important to them, participants described actions and routines they used to help maintain those. Actions towards promoting physical health included exercise (running, swimming, sports, walking and gardening) and diet, but some participants also noted benefits to their mental health by taking part in exercise, and most people did not exercise for physical benefit alone. Other strategies to enhance emotional wellbeing included maintaining a sense of predictability and control over life, such as keeping to a regular routine or working from home. Some participants had learnt further techniques to manage emotional wellbeing through therapy, while others felt they had an innate pragmatic thinking style which helped with processing problems; some attributed this to being autistic.

Many participants adapted their environment to manage sensory input and also sought out positive environments to improve their wellbeing. Natural environments were preferred by many participants, as these had lower sensory input and calming features, which encouraged mindfulness and reflection.

*“I quite like being beside a river or brook, by running water, so the noise of it, it helps me calm myself down, it's something to focus on” (Noel, M, 46-55)*

Accounts also revealed how participants had developed their actions and strategies - through trial and error, education (for example, a post-cancer course) and seizing opportunities.

*“I used to run away a lot, because sometimes the anxiety would get so overwhelming I couldn't cope [...] I started thinking, I wonder if I should actually just get some running shoes and start running. And I did, and now I have a like a section in the day, where I just actually run [...] provided that happens, I'm fine.” (Fiona, F, 46-55)*

Small actions, such as purchasing inexpensive equipment, were noted for how quickly these could facilitate routines and contribute to broader wellbeing outcomes, for instance being able to access nature for wellbeing.

*“If you told me before I bought the map that [...] it would make such a difference I wouldn't have believed you [...] it would have helped way back when I was really having problems” (Alan, M, 56-65).*

Some participants looked to external validation, such as research on the benefits of exercise, to justify their strategies. Some also identified as a ‘healthy person’, prioritising exercise, diet, and preferring not to consume alcohol, smoke or use medication excessively.

Actions and routines participants used to support wellbeing were frequently linked to a sense of enjoyment, and there was less discussion of longer-term health goals. However, routines could sometimes become restrictive.

*“The biggest thing for me is a stable, solid, rigid routine [...] If anything gets in the way of me doing that [...] I feel like I can't cope.” (Lauren, F, 36-45)*

**1.3 “You’ve Done Something for Yourself”: Interests, Achievements and Personal Strengths.** Autistic people commonly have focused interests, categorised under restrictive and stereotyped behaviours in diagnostic criteria (Buckley, 2017). Participants in the present study described interests and occupations including art, reading, running, computer games, driving, metalwork, martial arts, theatre, learning, archaeology, nature, DJing, music and writing. Some participants led successful careers based on their interests, while others engaged in hobbies, voluntary work or more casual interests and daily activities, but these nevertheless provided occupation, stimulation and a sense of purpose. Some accounts suggested absorption in engaging with interests helped distract from daily stressors.

*“It's a sort of a place where I hyper-concentrate and I don't notice anything else, whilst I'm painting, and I just paint for hours and hours [...] I don't really hear, see or think or do anything other than what I'm doing.” (Fiona, F, 46-55)*

Interests could also provide opportunities to connect with others, either directly or in a more abstract sense. For example, one participant felt her interest in theatre helped her to “*observe humanity*” (Cheryl, F, 56-65), while another’s interest in archaeology gave him “*emotional connectivity*” (Ivan, M, 56-65) to a historical context, that he could convey to visitors of an exhibit he volunteered at. Another participant described how he connected with others through writing.

*“You're not just writing it for yourself [...] you have to make sure it resonates with everyone without them having to ask you what you meant” (Anton, M, 26-35).*

Developing skills and abilities through engaging with interests also gave participants a sense of achievement and success.

*“I literally planted my, my garden and I like doing very physical stuff sometimes because... it sort of helps to lift my mood you know [...] it's going to be amazing looking you know, and you just got a sense of pride, you have physically achieved something” (Noel, M, 46-55)*

Participants also identified personality strengths that they felt resulted from their autistic traits, including attention to detail, perseverance and creativity. Having enhanced sensory experiences led participants to feel more absorbed in their interests. Some considered these traits beneficial for their career choices, such as law and art.

**1.4 “It Just Seems So Boring”: Internal Barriers to Wellbeing.** Participants described how intrinsic traits and health problems could sometimes hinder achievement of wellbeing goals. Mental health issues such as depression, anxiety and trauma affected daily activities, relationships and enjoyment of environments, and several participants had experienced suicidal thoughts and suicide attempts. Some described physical health conditions, such as chronic pain and fatigue, limiting exercise, work and daily living. Other co-occurring conditions such as ADHD and dyspraxia could also cause barriers. Some participants experienced low motivation towards maintaining their wellbeing.

*“I do nothing and it's terrible, I used to go jogging once a day last year, but I've completely lost the motivation to exercise [...] It just seems so boring” (Alex, NB, 26-35).*

For some, executive dysfunction impacted on their motivation and ability to organise their daily routines, such as remembering to take medication. Some also felt a permanent sense of burnout and overwhelm.

*“Just getting up and existing - for me, it's just like I can get up and within 15-20 minutes of getting up I'm exhausted, again, I feel like I need to go back to bed and that's literally just from getting up and getting dressed.” (Lauren, F, 36-45)*

### ***Community, Identity and Belonging***

This theme is concerned with connection and comparison to other people in the development and maintenance of wellbeing. The first subtheme explores receiving an autism diagnosis and its impact on identity, belonging and people's place in society. The second subtheme explores ways in which people connected with others and achieved a sense of belonging within communities.

#### **2.1 “Like Being Let Out of Prison”: Identification With Autism Diagnosis.**

Receiving an autism diagnosis, particularly as an adult, contributed to some participants' sense of identity. Although the experience was initially described by some as a shock, this was followed by relief as it helped people to make sense of their lives, encouraging self-acceptance and understanding. Several people described how their diagnosis relieved longstanding emotional turmoil.

*“I used to get very suicidal contemplating ending my life, all the time. [Since diagnosis] that's all gone - I've stopped self-harming, I've stopped banging my head, you know it's, I can't describe it, it's like being let out of prison.” (Mandy, F, 56-65)*

Identification with their diagnosis (formal or self-identified) increased participants' understanding of their needs, abilities and disabilities. This helped them develop strategies and make changes to improve wellbeing, including changing their home environments to support their sensory needs, modifying their level of social engagement, and accessing services.

*“A parallel I draw is being Asperger (sic.) is a bit like going to a foreign country. [...] Their culture is a little bit different, and if you are aware of those differences you can navigate that country a bit easier.” (Norman, M, 66+)*



In self-identified individuals, the enhanced self-management was sometimes enough to decide that there was little benefit from pursuing formal diagnosis. Diagnosis and self-identification also improved understanding from others. However, some participants continued to experience shame despite having an increased understanding of their differences.

*“I still feel ashamed about it, like really ashamed, that this is how I have to live but I’ve got to a point now where I’ve got, I’ve accepted that that’s the way I’ve got to be in order to stop myself getting overwhelmed” (Lauren, F, 36-45).*

## **2.2 “You Can Feel Safe and Be Yourself”: Community and Belonging.**

Participants’ experiences of belonging to communities suggested this contributed to wellbeing. Some communities were connected by identity and interests, such as those based around autism or mental health diagnosis, on interests and values such as religious groups and political campaigns, and the LGBTQ+ community. These groups provided shared understanding, resources and knowledge, a sense of safety, lack of judgement, and a shared sense of humour.

*“There are places that you can feel safe and be yourself, without having to monitor yourself or mask.” (Helen, F, 36-45) [note ‘masking’ in this context refers to autistic camouflaging (see L. Bradley et al., 2021), not the Covid-19 public health measure].*

Many communities had moved online during the pandemic. Although this helped extend their reach, not everyone responded positively to this shift, suggesting it may have lessened community access for some.

*“I’ve noticed that some people [from local support group] who were there every time aren’t there on Zoom.” (Norman, M, 66+)*

Participants also described barriers to being involved in communities. Social challenges included managing group dynamics and remembering names, difficulty finding supportive communities due to a lack of availability or information, or feeling alienated in some groups. Community events, such as Pride for those who identified as LGBTQ+, could be inaccessible

due to crowding and sensory overwhelm. Others felt their identity, interests or values, such as religion, were personal to them and did not want to share them with others.

Many participants felt a lack of closeness and shared values with communities connected by their local area, although others valued their local heritage. Some felt local communities with shared values were reminiscent of the past. Some participants experienced a sense of alienation, hostility and lack of safety in their local area, including crime rates and distrust in local policing. Neighbours often caused problems such as noise, but some also provided support and a social network. Some people had very small support networks of close friends and family members, but valued these. For some participants, a lifelong perception of feeling different from others that impacted on their ability to feel a part of their community.

*“I feel very alien, I’m almost convinced I was born on a different planet; I’m like, I’m not human, these people are so different from me.” (Mel, NB, 36-45)*

Some people felt problems were due to their difficulties with communication and social interaction. Others felt a lack of understanding and stigma about autism, such as stereotyped media portrayals, was responsible for feelings of alienation.

### ***External Support and Barriers***

This theme explores external influences on wellbeing, which may support the person or pose barriers. In the first subtheme, participants described how seeking and receiving support from external sources contributed to wellbeing. In the second subtheme, participants described external influences which impacted negatively on their ability to seek support and manage wellbeing. The third subtheme summarises the positive and negative impacts of the Covid-19 pandemic on wellbeing.

### 3.1 “I Find a Lot of Things by Helping Other People.” Seeking External Support

**With Wellbeing.** Most participants had accessed professional support services, including psychological and occupational therapies, domiciliary care and support worker assistance. Participants had required help with managing emotions, trauma, relationships, employment and independence. Some participants emphasised the importance of support that was not focused on trying to change who they were as a person, which they felt was tied to being autistic.

*“Her normal sort of CBT handbook says do this, do that and the other. And I say hold on, you're actually really challenging a fundamental part of my persona, you know, this is actually, my autism you're challenging there and I can't do this, and she will sort of rethink and take a different approach.” (Ivan, M, 56-65).*

Support from the VCSE sector was another route to external support as it was the principal way of accessing autism peer support services, some of which offered unlimited low-cost counselling, which was perceived as easier to access than formal medical pathways.

Participants' wellbeing was also supported informally by friends and family. Friendships were important for managing emotions, sharing advice, enjoying shared interests and reducing loneliness, while family members and partners would help people solve problems, listen to concerns, organise services and manage routines, as well as enjoying leisure time together. However, time away from family was also important for some participants to avoid frustration.

Medication was used by some participants to manage depression, anxiety and ADHD. Finding suitable medication sometimes involved trial-and-error and frequent medication changes due to experiencing side effects or building tolerance. Some participants used technology to manage wellbeing, such as apps which helped build motivation to maintain daily routines, track mood changes to identify triggers and manage executive functioning in tasks such as shopping. A flexible and supportive working environment was also important

for wellbeing – this included helpful colleagues, home working and time off for medical appointments.

These external sources of support promoted health, developed skills to achieve goals such as employment and independence, provided structure and routine, and helped with reframing and re-establishing a sense of identity. Some participants also supported others, for example using their skills to provide practical help for friends, volunteering, and facilitating autism support groups, which could lead to discovering further resources to support their own wellbeing.

*“I find a lot of things [for myself] by helping other people.” (Bruce, M, 56-65)*

### **3.2 “They’re Still Using the Medical Model”: External Barriers to Wellbeing.**

Participants’ accounts suggested that despite benefits of support, there remained persistent barriers to accessing or benefiting from this. Individual barriers included financial difficulty, a lack of motivation or belief in the approach, or a lack of success from support they had received. Some perceived common psychological therapies, such as cognitive behavioural therapy and mindfulness, to be incompatible with their cognitive differences. Furthermore, participants identified gaps in services for autistic adults without learning disabilities. Many desired more follow-on support from a late autism diagnosis, which could be a confusing time. Some participants were given information on autism post-diagnosis, but felt it was not relevant to them and did not help signpost them towards support.

*“It was actually quite hard to find [...] I was diagnosed about two years before I even started going, and I was like ‘why didn't I go sooner?’, but it's just because I didn't know about it” (Sian, F, 26-35)*

Some services they valued had also had reductions in funding, leading to closure. Many participants felt the health service prioritised physical health over mental health, and that the medical approach of services could be inconsistent with their constructs around

wellbeing and neurodiversity. Participants felt the lack of research on autistic adults was a barrier to support being made available.

*“[Some services are] still using the medical model where you've got to change the autistic person and not change the environment to make society more inclusive” (George, M, 66+)*

Some environments posed barriers to wellbeing, including stressful workplaces and crowded or noisy environments that caused sensory overload. The barriers identified sometimes limited access to services, such as hospitals, or encroached into the home environment, as well as access to wellbeing-enhancing activity; for example, while many participants recognised benefits of natural environments, some were obstructed by issues such as lack of transport and a lack of accessible green spaces in their local area.

### **3.3 “I’m Always 100 Yards Behind the Starting Line”: COVID-19 Both**

**Facilitated and Hindered Wellbeing.** The COVID-19 pandemic, especially lockdown, had had negative effects on wellbeing for many participants, including isolation, anxiety and lack of outdoor access. It also disrupted usual coping strategies and daily routines, impacting socialisation, exercise and travel, and some people experienced a loss of confidence and skills, such as executive function and social skills. It became more difficult to plan for the future and some participants had had to postpone major plans such as moving home. There were other practical barriers to managing wellbeing due to pandemic restrictions.

*“I haven't been coping with my dietary problems because finding food that I want to eat in the house is quite an issue [...] it's been hard at times to go shopping whenever I want” (Ollie, M, 18-25)*

Some participants described feeling more vulnerable, including worrying about susceptibility to illness, although masks and vaccinations helped alleviate worries. Many experienced anxiety around adhering to lockdown rules, which were sometimes perceived as confusing and ambiguous.

However, lockdowns had also presented opportunities to improve wellbeing, such as establishing new working styles and routines, and reducing social demands. Many participants noted a positive effect on their mood from reduced noise levels and increased day-to-day predictability. Several participants felt lockdowns did not impact their lifestyles substantially, for example those already working from home or without existing high levels of social support and activities, who were able to maintain their normal routine. Some participants felt more connected to others through shared experiences of the pandemic and through technology, although some felt online interactions were not as fulfilling as in-person.

*“It's not quite as good. It's quite difficult to concentrate on the, the square, the square of people [...] it's much harder to stay in the room” (Helen, F, 36-45)*

As lockdowns eased, some participants felt they were being left behind once again, for example those who had benefited from increased online interactions.

*“Coming out of it [...] I'm back in that situation where, in a non-autistic, in a majority non-autistic society I'm always starting 100 yards behind the starting line” (George, M, 66+)*

Repeated lockdowns also caused strain as some participants struggled to cope with repeated isolation and confusing guidelines.

## **Discussion**

This study investigated autistic adults' subjective understandings and perceptions of wellbeing, to establish implications of this for personalised practice models, such as social prescribing. Most participants' definitions of wellbeing were multidimensional; this mirrors public health frameworks such as Five Ways to Wellbeing (described on the National Health Service [NHS] website) and the ONS (2016) definition suggesting that common experiences of wellbeing in the general population also resonate with autistic adults. However, the research also identified how the lived experience of autism contributes to these concepts. Participants had developed strategies for promoting positive wellbeing, through actions, routines, identity and connecting with others. Beliefs about what wellbeing meant in relation to their own lives informed these strategies. The study demonstrated that a positive sense of wellbeing can be achievable for autistic people, a perspective that has sometimes been obscured by mainstream research narratives (Chapman and Carel, 2022). However, they also identified barriers, both internal and external, to achieving and maintaining optimal wellbeing.

Research by Kim (2019) has suggested self-determination underlies many findings on quality of life for autistic adults. Similarly, self-determination appears to link the themes identified in the present study. The wellbeing activities described by participants were often intrinsically or internally motivated, for example through enjoyment and a prioritisation of present wellbeing over longer-term health goals. Autonomy is an essential component of intrinsic motivation (Gagné and Deci, 2005). Participants demonstrated autonomy by pursuing their interests and developing actions for meeting wellbeing goals, cultivating a positive sense of self and establishing themselves within communities, in ways which aligned with their personal definitions of wellbeing, their identity and values. This reflects the SDT concept of integrated regulation, a type of internal motivation. Other participants developed

their wellbeing strategies to achieve a goal or to relieve anxiety, which are closer to the centre of the spectrum of internal and external sources of motivation. Some accounts of wellbeing also suggested participants perceived expectations of others, aligning with the construct of external regulation and showing that many considered wellbeing interpersonal as well as individual. Sometimes, not meeting perceived standards due to poor health or internal barriers including executive dysfunction and low energy, led participants to feel less capable of achieving good wellbeing. In the case of those who lacked motivation to maintain their wellbeing in the way they wanted, this was sometimes due to a lack of external regulation, such as not having another person to exercise with.

One finding differing from previous research on autistic adults' wellbeing was a narrative suggesting external support was a facilitator to wellbeing through enabling independence and development of skills to support wellbeing self-management. Although a lack of need for support has been interpreted by participants and researchers as a marker of autonomy and success (A. A. Webster and Garvis, 2020), it could be argued that choice to seek and choose support is an expression of autonomy for those who face more profound barriers and reliance on support should not be considered a poor outcome in itself. The gains in health, employment, independence and motivation may facilitate self-determination. However, the results showed that to achieve a benefit to wellbeing it was important supports were accessible, relevant and easy to navigate, which was not always the case.

Connecting with others was also a recurring theme; despite social and communication challenges, many participants were motivated to establish and maintain social connections, which was achieved through seeking or encountering others connected by interest or identity. Belonging within communities encouraged a sense of safety, shared identity and positive roles. Participants also described not having to mask their autistic traits, which, despite short-term gains for social acceptance, has a negative long-term association with wellbeing (L.



Bradley et al., 2021; Cassidy et al., 2018). However, outside of specialist groups participants sometimes felt disconnected from others. Along with other studies that have challenged normative biases in autism research (e.g. Cassidy et al., 2018; Welch et al., 2019; Mitchell, Cassidy, and Sheppard, 2019), our findings contrast to theories which suggest autistic people lack social motivation (Chevallier et al., 2012). Instead, sensory overwhelm, miscommunication and social exclusion were barriers to social connection.

Some participants' experiences suggested some positive aspects of wellbeing were related to being autistic. For example, having focused intrinsic interests presented people with opportunities for employment, occupation and connection with others, and were seldom described negatively with regard to wellbeing, reflecting previous findings (Koenig and Williams, 2017). Autistic adults' motivation for engaging with interests is generally intrinsically motivated and integrated with personal values, a sense of enjoyment and flow, compared to more externally driven motivations (Grove et al., 2018; Grove, Roth, and Hoekstra, 2016). Participants' accounts in the present study also demonstrated flow, a state of absorption and competence around an activity (Csikszentmihalyi, 1990). Competence is one of three psychological needs outlined as underlying intrinsic motivation in SDT, along with autonomy and connection (Gagné and Deci, 2005). Previous research has found autistic people, their parents and employers note strengths including attention to detail, focus and creativity (Cheriyana et al., 2021; G. Russell, Kapp et al., 2019; Scott et al., 2017; Warren et al., 2021); these attributes were also reflected within these accounts. However, the enjoyment of interests suggested positive experiences of autism do not have to be tied to productive value to be seen as worthwhile. While these experiences may also reflect interests in the wider population, for autistic people these are considered a restrictive behaviour, sometimes targeted through treatment. However, scholars with lived experience of autism have proposed that monotropism, a neurological processing style, underlies differences in focus, executive

function, sensory and social processing that may compel an enhanced focus on interests, within a spectrum of attention that spans the wider population (Murray et al., 2005).

Receiving an autism diagnosis also positively impacted wellbeing by making sense of past experiences, which encouraged self-acceptance. Autistic people often construe autism as an integral part of identity (Botha, Dibb, and Frost, 2020) and diagnosis can aid self-understanding and encourage empowerment and autonomy to restructure identity (Lilley et al., 2022). However, stigma about autism and others' negative responses to disclosure can also link an autism diagnosis with reduced wellbeing (Botha, Dibb, and Frost, 2020; Chapman and Carel, 2022; Lilley et al., 2022). Several participants in the present sample described seeking an autism diagnosis late in life; although some had already developed adaptive strategies, for others diagnosis was important for making changes to support wellbeing. Although it sometimes evoked negative emotions, another study found this often dissipates over time as a more positive identity develops (Corden et al., 2021). This may lead to improved wellbeing and reduced stigma (Gillespie-Lynch et al., 2017; Maitland et al., 2021). This demonstrates how receiving an accurate and affirmative diagnosis at any age may support autonomy and wellbeing.

However, some participants experienced disabling internal barriers to wellbeing including executive dysfunction, burnout, fatigue and co-occurring physical and mental health conditions. Furthermore, although participants' wellbeing management strategies demonstrated autonomy, without the capability for resilience and flexibility some routines became restrictive, negatively impacting on wellbeing if these were disrupted. Environments and their interaction with sensory processing were other contributors to wellbeing, although a minority of participants did not regard these aspects as important. Environmental barriers, including the COVID-19 pandemic, sometimes led to a need for additional support from external sources, and reduced autonomy and competence. However, new opportunities

presented by a changing environment may have renewed a sense of autonomy that helped some people achieve wellbeing goals in novel ways, though during the pandemic the isolation and anxiety experienced in lockdown reduced wellbeing for others. These findings add to research showing mixed impacts of the COVID-19 pandemic on autistic people's wellbeing (Bundy et al., 2022; Mosquera et al., 2021; Pais and Knapp, 2021). The person-environment interaction can be overlooked by studies which focus on individual traits as markers of wellbeing, yet Lai et al. (2020) emphasise person-environment fit as a key component of support for autistic people at all stages of life. To maximise benefits of approaches such as social prescribing it will be especially important to support navigation of barriers, modifying environments in which activities take place and manage executive dysfunction and burnout.

### ***Application to Practice: Social Prescribing***

The approach of social prescribing may align with our participants' views of wellbeing as holistic and multidimensional by allowing people to focus on areas of wellbeing which matter to them; some participants were wary of more medicalised approaches. Social prescribing may be able to support wellbeing for autistic people through signposting to activities that build on intrinsic interests and strengths, which could create opportunities for enjoyment, flow, connection with others and self-development. Volunteering, for example, could connect people with meaningful activity in areas of interest.

Research has found that peer support groups can benefit autistic adults through empathetic interactions and an accepting social environment, which help to build positive self-understanding and resilience (Crane, Hearst et al., 2021; Crompton et al., 2021). On the other hand, quantitative research is yet to demonstrate strong evidence for the impact of peer support on mental wellbeing in general samples (Blodgett, Kaushal, and Harkness, 2022), however the present study and previous research suggests that for autistic people, social

participation is an important implicating factor for wellbeing and self-determination (Kim, 2019). As peer support opportunities were sometimes difficult to find, social prescribers could facilitate this by signposting to local community autism groups and charities, especially those led by autistic adults.

External supports also included self-directed use of technology, which aided motivation, executive function and social connection, especially in the context of COVID-19. Historically, technology has been fundamental in connecting autistic communities previously experiencing isolation and lacking a collective voice (Bagatell, 2010). Recently, research has shown that autistic adults appreciate technology which “scaffolds” independence rather than aiming to reduce autistic traits (Zheng et al., 2022), reflecting the motivations of seeking support in the present sample. Social prescribing approaches could signpost to digital solutions such as apps to support wellbeing. Although access to other resources such as books, education and information are common forms of social prescription (Chatterjee et al., 2018), the potential of prescribing technology to enhance wellbeing has not been widely discussed. Finally, it is important to note that although autistic adults struggling with wellbeing may require intervention, not all autistic adults will need or want support at all times. Some participants identified a desire to access inexpensive equipment to support their wellbeing; schemes such as enablement funds may facilitate independence for individuals requiring less direct support.

### ***Strengths and Limitations***

A strength of this study is its diverse sample, comprising people of a range of ages, genders, occupations and life experiences, as well as those who self-reported having learning disabilities, physical comorbidities, and difficulties communicating through speech. The findings suggest it could be worthwhile for future research using quantitative or mixed

methods designs to explore how age, occupation, relationships and intersectional aspects of identity, such as gender, may be associated with wellbeing for autistic adults; these were not identified as broad themes within the data but were relevant to some participants' experiences. In particular, research on autistic older adults is very limited (Michael, 2016); the higher proportion of participants in older age bands may help to highlight wellbeing issues applicable to an older population, such as the impact of receiving a diagnosis late in life.

Remote interviewing increased reach to a wider pool of participants and during tiered Covid restrictions was essential for this study, but may be less accessible for some with higher communication needs, who were less represented by this study. Alternative methodologies, such as PhotoVoice, may be more suitable for capturing understandings of wellbeing in autistic samples with these needs (e.g. Lam et al., 2020). The use of critical realism strengthened the study by enabling the identification of internal barriers to wellbeing but situating these within the wider social context, such as the pandemic, neither positioning autism as inherently detrimental to wellbeing (in many cases, participants identified positive experiences associated with autism) nor dismissing disabling experiences. This provides justification for personalised care models focused on autonomy over more standardised approaches.

Participants were also invited to choose a topic to begin the interview, which shifts control from the research team and led to some important insights not identified by the interview schedule such as the impact of adult autism diagnosis on wellbeing. However, by using the methodology of semi-structured interviews, this study may still focus too strongly on wellbeing as an individualised concept. Future research could explore autistic adults' wellbeing on a collective and societal level, such as further research into ethnographies of autistic community wellbeing, research into which is in its infancy. For example, Ryan Idriss

(2021) used ethnographic methods to explore autistic social infrastructure and community strengths.

### ***Conclusions***

This study affirms that wellbeing and autonomy are achievable for autistic people and that while these can be linked to the experience of being autistic, there is much common ground in wellbeing constructs relevant to autistic adults and the general population, suggesting that generic theories and supports relating to wellbeing may be inclusive of this population. For example, self-determination theory may be an avenue for further theoretical exploration in relation to autistic adults' wellbeing as a persistent thread throughout the identified themes.

This suggests that costly autism-specific services may not always be necessary to support and promote wellbeing. Social prescribing, as an example, could foster self-determination for autistic adults in a similar way to other populations, by facilitating navigation of barriers and working alongside individuals to identify existing strengths, supports and opportunities to promote wellbeing self-management, connection to communities and autonomy.

## Chapter 7

### A Qualitative Study Exploring Acceptability of Social Prescribing for Addressing Wellbeing in Autistic Adults

#### Abstract

Autistic adults experience poorer health and wellbeing outcomes compared to the general population and there is a lack of evidence on how services can be delivered to reduce these disparities. Social prescribing (SP), involving referrals to wellbeing support in communities, is a readily available preventative resource that may be easier to access than other primary care services. It also focuses on addressing a range of health concerns in a personalised way that aligns with autistic adults' preferences. In stage 1, 21 autistic adults took part in semi-structured interviews to assess their experiences and awareness of SP and their attitudes towards the approach as a solution for managing wellbeing. Interviews intended to elicit the acceptability and accessibility of current models, as well as other forms of community-based wellbeing support accessed by participants. In stage 2, four autistic adults, who were involved in providing community-based peer support, were interviewed about their experiences of delivering support, to elicit how peer-designed activities for autistic adults might employ different service pathways and approaches compared to top-down models of support. Data were analysed using reflexive thematic analysis. Themes constructed from the data focused on 'Context of social prescribing for autistic adults' comprising existing service provision for autistic adults in relation to their views on SP; 'Features of services' that were facilitators or barriers to engagement; and 'Personal factors' that influenced participants' attitudes and experiences. Findings suggest ways SP could be better tailored to support autistic adults with managing wellbeing and identified mutual benefits of collaborations between SP pathways and autism community expertise.

## **Introduction**

Autistic adults experience avoidable physical and mental health disparities that contribute to lower life expectancy (Hirvikoski et al., 2016; Croen et al., 2015). Evidence for ways to improve outcomes is limited, with reviews of mental health services inconclusive about effectiveness of interventions for autistic adults (Linden et al., 2023) and limited research addressing physical health disparities (Warner et al., 2019). Health issues likely intersect with social determinants affecting autistic people, including low employment and educational attainment, poorer housing and minority stress (Brugha et al., 2011; Howlin, 2021; ONS, 2022; Botha & Frost, 2018; J. L. Taylor & Seltzer, 2011). Lifestyle factors (e.g. sleep and diet) and structural barriers that impede access to health services for this population may also contribute to observed health disparities (Howlin, 2021; Doherty et al., 2022; Lai et al., 2020; D. Mason et al., 2019). These issues highlight a need for accessible healthcare that can tackle complex health inequalities to address disparities faced by autistic adults.

The UK Government's Department of Health & Social Care (2022) and National Institute of Health and Care Excellence guidance (Buckley, 2017) recognise these inequalities and their impact towards costly and intensive intervention being required when timely support is not accessed. They emphasise that provision of support in community settings may contribute to a preventative approach. Recently, participatory research on mental health supports indicated that autistic adults endorsed interventions which could be "self-initiated or managed, or were accessible in their communities" (Benevides, Shore, Palmer et al., 2020), including art and music therapies, exercise and animal-assisted therapy. These were favoured above interventions such as talking therapies, suggesting higher acceptability by autistic individuals. Such examples are typical of social prescribing (SP), a healthcare referral pathway aiming to improve wellbeing outcomes by connecting individuals to non-medical, community-based



services (Barnes, 2020; Polley, Fleming et al., 2017), including exercise groups, nature-based prescriptions, volunteering, financial advice and creative pursuits (Chatterjee et al., 2018).

SP is often targeted at people presenting with long-term health conditions, mental health conditions or social isolation (Polley, Fleming et al., 2017; M. Cooper et al., 2022) for which medical services that treat problems in isolation or focus on a particular outcomes may be less appropriate due to interacting socially-determined factors and co-occurring conditions (Baska et al., 2021; Cawston, 2011). SP is not intended to replace medical support, but through linking to community resources and prioritising low-level preventative support, it represents a personalised approach to health focused on outcomes of importance to each individual to encourage ownership of wellbeing (Cawston, 2011). SP approaches typically comprise: a referral from a health or social care professional; one-to-one consultation with a link worker with expertise on local resources; and development of a personalised prescription or signposting offer linking clients to services, supports and groups in the voluntary, charity and social enterprise (VCSE) sector embedded in communities (Polley, Fleming et al., 2017). SP has received funding from the UK government as part of the NHS (2019) Long Term Plan's targets for accelerating personalised care, to involve individuals in decision-making encompassing their preferences and values, to promote empowerment and health self-efficacy.

SP could present opportunities for autistic adults to access support within communities in line with policy for improving their health outcomes. However, despite health and social care disparities affecting autistic adults, a recent systematic review suggested there is underreporting of disability in SP referrals and research (Cartwright et al., 2022). There is therefore a knowledge gap around potential outcomes and mechanisms to facilitate progression through the SP pathway for autistic adults. Broader evaluations of SP services have identified that uptake and effectiveness may be affected by referrer professions and buy-

in, the amount of link worker support and patient expectations and beliefs (M. Cooper et al., 2022; Bertotti et al., 2018; Husk, Blockley et al., 2019; Westlake, Ekman et al., 2022; C. White et al., 2022). A review of community-based, non-medical support for autistic adults outside of SP pathways suggested the tailored and collaborative approach of SP might facilitate access for autistic adults by focusing on personal strengths and interests, but that adaptations may enhance accessibility of the pathway, such as providing options for accommodating different communication needs and including flexible opportunities for social interaction (Featherstone et al., 2022). Furthermore, findings suggested that managing client expectations and ensuring staff are trained about autism as possible facilitators to acceptability; other reviews have also found that perceptions of staff capabilities affect adherence to SP (Husk, Blockley et al., 2019).

However, reliance on previous research to evaluate possible outcomes of SP may overemphasise researchers' definitions of success rather than service users'. Though observational and self-report measures have been included (comprising both quantitative and qualitative methods), outcomes overwhelmingly focus on reducing autistic traits, revealing less on subjective improvements to health and wellbeing (Featherstone et al., 2022; Provenzani et al., 2020). Policy experts emphasise how strength-based approaches and personalised models may improve autonomy and wellbeing for autistic adults in alignment with individual goals (Howlin, 2021; Huntley et al., 2019). Objective acceptability indicators, such as satisfaction with interventions, are less prevalent in research on community-based supports for autistic adults (Featherstone et al., 2022). Interventions that have been reviewed were not delivered within an SP pathway, so may miss some essential components of the approach. Samples have also lacked diversity, with overrepresentation of younger male participants, resulting in potential bias (Featherstone et al., 2022).

Through semi-structured interviews exploring autistic adults' views and experiences of social prescriptions and similar non-medical support in community settings, this study aimed to investigate the acceptability and accessibility of the SP pathway from first-hand perspectives.

## **Methods**

### ***Participants***

Interviews formed part of a mixed-methods study comprising an initial online survey of 128 autistic adults examining wellbeing and access to healthcare and communities during the Covid-19 pandemic. Recruitment primarily used the Autistica Network, a voluntary UK database of over 20,000 individuals with connections to autism held by research charity Autistica, and supplemented by individually contacting services and support groups serving autistic adults, including groups listed in the National Autistic Society's directory, local branches of mental health charity Mind, disability advocacy groups and university disability societies. All survey participants who consented to further contact were invited to take part in interviews. When giving permission, they had no knowledge of the intended interview topics, and the researcher re-contacting participants was not aware of their survey answers.

### ***Procedures***

In a two-stage process, we initially interviewed autistic-identifying individuals about views on SP and experiences of accessing support for wellbeing, in line with study aims. During interviews, several interviewees described facilitating peer support opportunities for autistic adults. They gave their perspectives both as service users and providers, which warranted further investigation examining how peer-designed activities for autistic adults might employ different service pathways and approaches, with implications for accessibility and acceptability compared to top-down models of community-based support.

**Stage 1.** Participants were emailed invitations to be interviewed on “experiences of managing wellbeing and accessing services, including social prescribing”, described as: “*a referral to wellbeing services, support or activities based in local community spaces (such as art groups, community gardening or financial advice). It sometimes involves an appointment with a link worker or community connector who will help you find the right activity for you.*” Invitations stated SP experience was desirable but not essential for the study; this would determine the questions included in interviews. Some participants requested an easy-read summary of SP to aid understanding. This was accessed from a publicly available online resource at [https://www.beaconmedicalgroup.nhs.uk/wp-content/uploads/2021/11/social\\_prescribing\\_easy\\_read\\_leaflet.pdf](https://www.beaconmedicalgroup.nhs.uk/wp-content/uploads/2021/11/social_prescribing_easy_read_leaflet.pdf) that gives a clear and concise description using images to illustrate concepts.

Interviews were carried out by CF, a PhD student with previous experience of qualitative interviewing and both lived and clinical experience of autism. Interview questions aimed to elicit participants’ wellbeing needs, experiences of accessing primary care (often the initial point of access to SP) and experiences or attitudes towards SP, in the context of the Covid-19 pandemic. SP-focused questions aimed to elicit:

- Their existing awareness of the SP offer
- Feelings about a hypothetical SP referral – aspects they liked/disliked
- Views on how SP compares to other types of healthcare

Those with experience of accessing SP or services with similar features were also asked:

- Reasons for seeking support and receiving a referral
- Expectations of the pathway and the resulting offers
- Types of activity or support offered and accessed
- Impacts of the SP pathway on wellbeing

- Reasons for disengagement at any stage of the pathway

To help those without experience of SP evaluate their attitude towards a social prescription, we described nature-based SP as an example, but also explored any thread where participants mentioned (either before or during interviews) using community-based services or pathways for wellbeing, group-based wellbeing activities, one-to-one or personalised support from a non-medical service, or services involving signposting. All participants were also asked to describe the ideal service for supporting their wellbeing.

Interviews occurred between July-September 2021 and ranged from approximately 30-90 minutes. Participants received information sheets and consent forms before their interview and agreed a date and time with the lead researcher through email exchanges. In response to frequently changing Covid-19 restrictions, interviews were offered online-only using Zoom, either as a video call, phone call, text-based messaging, or a combination, to maximise accessibility of communication for autistic adults, except for one interview for which a participant asked to use email exchanges, as all options offered by Zoom were not accessible for this participant. Ethical approval was sought to adjust the procedures to enable email participation email, including a written expression of consent. For participants using Zoom, verbal consent was recorded at the start of the calls.

**Stage 2.** Follow-up interviews with peer support providers built upon previous studies which had used the COM-B model of health cognition (Michie et al., 2011) to understand the role of the voluntary sector (Baxter & Fancourt, 2020); the acronym refers to how *Capability* (knowledge and skills), *Opportunity* (environmental and social factors) and *Motivation* (decision-making and emotional processes relating to personal goals) influence health *Behaviour* and can apply to behaviour of both service users and providers. The present research involved asking providers of peer support about: resources needed to provide

services (opportunity and capability); how their offers compared to other statutory services in response to their local community's needs (opportunity); how they accommodated different access needs (capability and opportunity); and positive and negative experiences of delivering services, including impacts on their own wellbeing (motivation). All interviews, conducted between September-November 2021, used a Zoom video call and newly-recruited participants were taken through the consent procedures as above.

### *Analysis*

Both stages of the study were analysed iteratively, with individual interviews analysed first using reflexive thematic analysis (Braun & Clarke, 2022). CF transcribed and re-read interview transcripts, reflecting on common threads running throughout interviews and their position to our expectations and existing knowledge on SP, its context and the needs of autistic adults identified in the research literature and through lived experience. Whole transcripts were coded whether responses related to SP or other parts of the interviews, since the broad topics of wellbeing management and healthcare access provided relevant context.

Codes were organised by topic in an Excel spreadsheet and loose categories were created which linked similar codes. The team reflected on an initial theme structure in relation to existing theory, and used NVivo (2020) to organise interview extracts into themes.

These procedures were repeated for follow-up interviews. Some themes fitted into the structure generated from initial interviews and others were more unique due to the different perspective offered by service providers. We then reviewed the organisation of all themes and subthemes, and the potential for using existing frameworks for their organisation but decided to retain themes which reflected our inductive approach.

## Results

### *Sample*

20 participants from the survey study took part in interviews. Another participant who had not taken the survey was referred by a contact. Two participants from the initial interviews took part in follow-up interviews, and two other follow-up participants were newly identified through a call for leaders of peer support groups in existing networks. Limitations on time restricted further follow-up recruitment, final N=4. Demographics of participants are presented in Table 7.1. Participants' gender and approximate age at time of interview are reported with their quotations. Where quotations refer to a service, this is also reported.

**Table 7.1.**

### *Participant Characteristics*

<b>Characteristic</b>	<b>Participants (N)</b>
Gender identity:	
Male	13
Female	7
Nonbinary or bigender	3
Age band:	
18-25	1
26-35	3
36-45	5
46-55	3
56-65	7
66+	2
Not stated	2
Ethnicity:	

White British	19
Other white background	1
Black Caribbean	1
Not stated	2
<b>Additional disabilities:</b>	
Mental health (anxiety, depression, social phobia, schizophrenia, bipolar disorder, PTSD)	8
Physical disability or long-term illness (heart, COPD, cerebral palsy, long Covid, neuropathy, diabetes, sleep disorders, ME/CFS)	7
Intellectual disability	2
Specific learning difficulty (dyslexia, dyspraxia, dyscalculia)	5
ADHD	5

### ***Experiences of SP and Community-based Support with SP Features***

Table 7.2 shows examples of community-based support and activities participants had accessed focusing on wellbeing. None of the participants described a SP model involving a link worker to help identify and engage with activities, but some described social workers performing a similar role. Services such as a health champion offered personalised consultations to discuss wellbeing goals and develop action plans, but lacked signposting or referral to services and activities. Autistic providers of peer support sometimes worked with individuals accessing their service to identify goals and interests, signpost them to supports and assist with engagement. Some participants had engaged with activities similar to common SP offers, including walking groups, woodland management, exercise programmes and community hubs, either independently or through signposting.



**Table 7.2**

*Examples of Services*

<b>Description</b>	<b>Examples from participants</b>	<b>Provider</b>	<b>Setting</b>	<b>Activity types</b>
Support groups provided by VCSE sector	Adult autism peer support groups Mental health support groups Domestic abuse support groups	Large charities (e.g. National Autistic Society, Mind) Independent organisations	Indoor community setting (e.g. cafes, meeting rooms) Online Outdoors	Facilitated meetings Walking groups
Services with a connecting or signposting role	Autism post-diagnostic service	NHS/Local authority	Indoor community setting	Wellbeing advice Referral to community-based activities/services
	Signposting by mental health social worker with lived experience	NHS/Local authority	Secondary mental health services	Wellbeing advice Signposting to community-based activities/services
	Adult autism peer support group	Independent organisations	Indoor community settings Online outdoors	Facilitated peer support meetings Coaching Signposting to community-based activities/services
	Volunteering scheme	Support worker	Community	Signposting/referring to volunteering opportunities
Person-centred support	Health champion programme	VCSE sector/local authority	Remote (telephone)	Wellbeing advice Goal setting and action planning
	Exercise referral scheme	VCSE sector	Community sports centre (no cost during scheme)	Referral to tailored exercise sessions with a personal trainer
	Autism post-diagnostic service	NHS/Local authority	Home-based	One-to-one support with independence at home

Coproduced services in health/social care sector	Expert patient groups	NHS/Local authority/advocacy organisations (e.g. Healthwatch)	Indoor health/social care settings Online	Providing feedback and advice based on lived experience of using services
	Autism partnership board	Local authority	Indoor local authority setting Online	Providing feedback and advice based on lived experience of using services
Volunteering	Facilitating events for high support needs disabled people Providing IT support to older adults Writing a newsletter for disability community Compiling a directory of local services Community café Woodland management project for autistic adults Guide at local attraction	VSCE sector Self-led	Community Remote (home-based)	Self-led volunteering Organised volunteering opportunities (e.g. with charities)
Clubs and interest groups	Historical societies LGBT groups Churches Women's Institute Political groups	VCSE sector	Community	Meetings, campaigning, events
Nature/animals for wellbeing	Equine therapy/horse-riding	Private sector	Outdoor private settings	One to one appointments

	Animal-based day trip with peer support group (e.g. cat café)	VCSE sector	Community	Group activity
	Pet ownership/enjoyment of animal videos online	Self-led	Home	Noted where participants described these having a function for wellbeing e.g. enjoyment, structure, companionship
	Regular outdoor activities (e.g. hobbies and exercise)	Self-led	Outdoor community	Exercise, mindfulness, fishing, birdwatching, allotment

### *Findings of Thematic Analysis*

The analysis indicated three overarching themes (Table 7.3). The broadest level comprises the context of SP including existing service provision for autistic adults and participants' views on SP's position to other service models. The second theme identifies features of services which may contribute to acceptability and accessibility of the SP pathway, relevant to both the prescribed activity and link worker consultations. The third theme identifies personal factors affecting participants' likelihood of taking up an offer, which link workers may need to consider when working with autistic adults.

**Table 7.3.**

#### *Final Themes and Subthemes*

<b>Theme</b>	<b>Subthemes</b>
Context of social prescribing for autistic adults	Social prescribing's relationship to medicine
	Service provision and responsiveness
Features of services	Navigation, referral and enrolment
	Accessibility
	Supportive approach
	Tailoring and personalisation
	Training and lived experience
	Collaboration and signposting
	Adaptation to change
Personal factors	Expectations
	Choices, preferences and interest
	Motivation

#### **Theme 1: Context of SP for Autistic Adults.**

*SP's Relationship to Medicine.* Participants held diverse views on the position of SP in relation to other models of care. Some found it more acceptable compared to other health services. While most participants recognised the need for medical care to treat physical complaints, those who had experienced harm or trauma in conventional health services,

especially in mental health settings, viewed SP as a way of escaping further harm, facilitated by its holistic approach as opposed to treating problems in isolation.

*“I think it’s [SP] invaluable personally, I think that a lot of people are just shoved pills nowadays - I know because I’ve been in the psychiatric system for so long [...] there isn’t time to spend with people, it’s just [...] “Oh you can’t sleep? Okay, let me prescribe sleeping pills” when actually [...] that person might not have strategies” (Interview 8, F, 56-65)*

Other participants felt medicine was necessary to treat mental illness and some viewed SP as a symptom of the health service failing to provide appropriate care through low-cost outsourcing of patients into the VCSE sector.

*“It just makes me angry that the NHS is so underfunded [...] I get so cross at the idea of being sent to a charity [...] because this is what the NHS is for” (Interview 2, F, 36-45)*

Most participants felt that SP could provide low-level or preventative support that they could access when they were not in need of acute care, complementing medical services.

Nevertheless, some participants felt limitations of the NHS may affect referrals to SP.

*“Doctors are very busy nowadays and don’t really get much time to spend that time with you and it’s [SP] going to be a very difficult path to go down” (Interview 19, M, 36-45)*

The link worker role was viewed positively as a solution to this due to the ability to have longer consultations. Others felt increased access to SP might have a positive impact on NHS services, such as reducing GPs’ workloads and cost-saving.

***Service Provision and Responsiveness.*** Unmet needs of autistic individuals and communities identified by participants included emotional wellbeing, employment, social isolation, finances, advocacy, transport and healthcare access. Participants perceived gaps in

provision of suitably-targeted post-diagnostic support, with existing provision limited in depth and breadth or adaptation to autistic adults' needs.

*“All [autism charity] catered for were children [...] they weren't doing anything for adults.” (Interview 6, M, 36-45)*

Peer support providers were aware of the lack of response to the unmet needs of adults. Their aims included providing social opportunities, day trips/short breaks, outdoor activity, safe members-only spaces, intersectional groups (e.g. women's groups), advice and coaching.

*“The things that I think that I need and will always need, and I associate with people with autism needing are structure, an adequate sensory environment, having activity but being left alone and not bullied or interfered with and having psychological input and a chance to explore and understand feelings.” (Follow-up 2, peer support group)*

## **Theme 2: Features of Services.**

***Navigation, Referral and Enrolment.*** Some participants had heard of SP through the media or through working in health services. Some viewed having a referral system important, particularly in the context of signposting to autism-specific services, to ensure only eligible people were referred. Others viewed the idea of a formal prescription to support as “paternalistic [...] the nanny state telling you how to live your life” (Interview 20, M, 66+), or preferred self-referral or drop-in models to avoid a waiting list or risk discharge. Others felt a formal prescription would motivate them to engage with the activity more, and not all participants knew how they would access community-based wellbeing support without assistance.

*“I know a community garden in the area, I'm not sure how I can volunteer there” (Interview 11, NB, 26-35).*

Peer support providers reported limited success engaging with primary care and social prescribers to create a referral pathway to their support, and mainly relied on social media

and collaborations with charities to raise their profile. One service described how using blogs helped build trust:

*“It will provide more authenticity, because when people look at the website, they see that the contributions are by members who are autistic” (Follow-up 4, peer support group).*

They also highlighted the importance of affordable community venues as access points for support, relying on local community centres, churches and parks to host activities.

**Accessibility.** Facilitators and barriers to accessing community-based supports both short- and long-term included travel and location (notably distance), sensory environment and fit for the activity. A participant who volunteered with a disability charity reflected:

*“They’d had like a disco type thing [...] don’t know how they stood it. And because of my Asperger’s I just could not be in the same room as it. It was just far too loud for me.” (Interview 9, M, 46-55)*

Another participant noted that some local areas may not be well-suited to certain activities, for example those lacking natural environments.

*“They’re going to be told go for a nice walk in that crowded high street? Well, how is that any good?” (Interview 8)*

Timing of activities often affected participants who were employed, who highlighted that they would either need to work flexibly or seek time off to access activities of interest. Many participants emphasised the importance of low- or no-cost activities, but felt sustained funding would be needed to avoid risk of closure. For accessing peer support opportunities online, digital connectedness was important. Too many practical barriers, or features such as having to complete large amounts of paperwork, could lead to emotional burden.

Some participants also reported how they may require autism-specific adaptations and adjustments to access supports, including managing the sensory environment, allowing for breaks and facilitating communication. One participant gave an example of a communication aid used in an autism advisory group:

*“They use coloured, traffic light coloured cards. Okay, so green for if “I want to speak”, because you know people on the spectrum find it difficult to know about turn taking with conversations [...] which then gives the autistic people an equal chance in the conversation.” (Interview 26, M, 66+).*

However, providers of peer support explained that it could be difficult to meet all needs; for example, not all community settings could be adapted to minimise sensory discomfort. Some participants had differing views on features they felt would enhance accessibility, suggesting that this can involve subjective judgement.

**Supportive Approach.** Participants valued services with a compassionate, non-judgemental approach and a sense of safety. This helped to encourage compassion and flexibility in their self-appraisals.

*“If I feel overwhelmed I then remember that it's about breaking down the goals into manageable steps [...] They want you to make mistakes, it's healthy - they've said to me that you know, this really is trial and error and they said that, you know, you won't actually progress or achieve things if you don't fail sometimes” (Interview 13, NB, 36-45, health champion)*

Some participants suggested being paired with a ‘buddy’ could facilitate engagement with a new activity. One provider of an autism peer support group whose role included signposting participants to wellbeing activities reported how he sometimes attended a new activity with a client to assist with communication and practical tasks:



*“I would go along and be there and they would see me, and if they need help filling the forms, or anything like that, do that. Yeah, just keeping communication.”*  
(Interview 3, M, 56-65, peer support group)

**Tailoring and Personalisation.** Participants wanted to be recognised as individuals rather than reduced to stereotypes about their diagnosis, which they felt could lead to inappropriate support.

*“What is good for one person may not be good for another. And, and particularly if you have autism, not... Whilst there are traits, people on the autistic spectrum are individuals like anyone else”* (Interview 1, M, 56-65)

Participants felt they should be able to trust that the professional making a SP referral would take care to understand their feelings about an offer; some felt this might be best achieved by working with a professional whom they trusted, such as a familiar GP.

Individuals’ needs also varied according to their circumstances. For a carer, it was important that his exercise prescription took account of this:

*“He [trainer] was kind of wanting me to go harder and to overcome certain weight limits and things like that. But if I was to get a bad back then that would be really bad and he didn't quite understand that.”* (Interview 3, M, 56-65, exercise referral)

**Training and Lived Experience.** Participants felt that staff at all points of the pathway from primary care to activity provision should have an understanding of autism that avoided common stereotypes, and have knowledge on subgroups such as autistic adults and women:

*“It would have to start with, with the GP surgery from ... from the receptionists through to the nurses and to the doctors, so everyone has an understanding.”*  
(Interview 1, M, 56-65).

Many participants felt that providers with lived experience of autism would lead to greater adaptation and relevance in tailoring of their practice; one participant drew from reflections on a signposting service delivered by a mental health social worker:

*“She has already been an autistic parent and so having a family with autism, because of that she knew where, all the places to go [...] that gave her an absolute, considerable edge and actually knowing where the services were, what worked, what didn't work, where to go, who to talk to, because she'd done it first-hand” (Interview 10, M, 46-55).*

Several participants mentioned how a trauma-informed approach would be important for understanding their needs. This may respond to established findings about increased prevalence of trauma in autistic adults (34) combined with first-hand experiences reported by several participants.

Peer support providers reflected that their reliance on volunteers meant that they could not manage highly complex cases and could result in a lack of structure, but that volunteers with lived experience helped reduce pressure and promote equality.

*“Maybe it's a good thing that the facilitation was not always on the ball because it meant that people were not pressed to tell things about themselves. That they could just come and attend” (Follow-up 2).*

**Collaboration and Signposting.** For providers and participants, a single service did not need to meet all needs if there was sufficient signposting to other services with expertise or activities to help group members meet their wellbeing goals.

*“You need to deal with everything that they want. Like if we say, “oh, you want to go and play football?”, or something like that, “we don't do that,” then it's kind of, it's losing out on the whole social prescribing network.” (Interview 3, M, 56-65, peer support group)*

Support groups sometimes provided an initial link to other services by involving experts or helping with advocacy. Collaboration with larger organisations was important when setting

up or to provide a continued service as these had more stable funding, but sometimes required compromising on aims and values, such as whether a service should be targeted only at autism or at neurodiversity more generally. Fundraising was a particularly challenging part of providing a peer support service for those with less experience.

*“We got like £15,000 I think it was for the three years, which we wanted. But it was an awful lot of stress to find all the information [the trust] wanted and half the time I couldn't understand what they wanted.” (Follow-up 1)*

Some providers had won awards for their services, but while personally satisfying, felt it did not always contribute to long-term success.

***Adaptation to Change.*** Service providers often sought feedback from users and adjusted their service according to the group's needs.

*“We sort of changed it to do more, the picnic sort of thing, where people can just come and enjoy the wood [...] and then you might get a few people who wanted to volunteer. So we had to sort of change the emphasis of it quite a bit” (Follow-up 3, woodland project)*

Services had to adapt to the challenge of Covid-19 by switching to remote delivery or moving outdoors, which did not always meet all the needs and expectations of groups and sometimes led to disengagement. Remote video calls allowed members to join from further away and access more communication options, but this did not always lead to greater attendance. Email was used to keep in touch with members who did not feel confident to join online meetings.

*“Whilst the online world and this relative isolation can be beneficial, it means long periods without contact with other people. So, we've really had to manage people's expectations about when we'll go back to traditional face to face events.” (Follow-up 4).*

### **Theme 3: Personal Factors.**

*Expectations.* While some participants were positive about the concept of SP, others were more sceptical about its benefits for themselves. Some lacked interest in certain types of offers, and others were already engaged with services providing similar opportunities, such as a mental health key-worker. Others felt able to seek community-based opportunities to enhance wellbeing at their own convenience, so felt less need for SP.

*“I kind of do this stuff without a prescription, at times and places convenient to me.”  
(Interview 26, M, 66+)*

However, some remarked that there may be benefits for people who lacked opportunities or who were unaware of the options available to them.

Participants described how they may need to overcome uncertainty and anxiety to feel ready to engage with a SP referral, particularly around their social capabilities in a group.

Participants felt that being able to discuss and reflect on their worries might build motivation to persevere with engagement.

*“My first reaction to things like that are a little bit of panic and a little bit of the urge to say no [...] I suppose to be able to, to an extent, get over that by just letting it settle and thinking about it [...] to recognise I need time to not just give my instant reaction, which is ‘no’, but to give breathing space.” (Interview 25, NB, 56-65)*

While some participants found that an activity did not meet their needs despite their efforts, others had enjoyed and benefited from some services they were initially apprehensive attending.

*Choice, Preferences and Interest.* Participants wanted to access activities they enjoyed through SP, with suggestions including birdwatching, fishing, horse-riding or reading.

*“Going for a walk doesn't work, like it has to be something that I kind of feel a connection for.” (Interview 18, F, 26-35)*

Some participants reported they would feel most comfortable in an autism peer group with similar needs and abilities. Others felt they wanted to broaden their social networks and focus on other aspects of wellbeing:

*“I am wanting to get involved with – not loads of different groups about autism because I don't want my world just to be about autism. I want it to be about different kinds of people” (Interview 8, F, 56-65)*

Some people also wanted to apply existing skills, and to add variety to their daily life. Group characteristics that were a poor match could be off-putting, and participants emphasised the need for activity facilitators to create a sense of equality in a group to ensure that more vocal individuals did not dominate.

*“I noticed that there was a distinct gender divide at [support group]. Men were still in position of authority and males most vocal.” (Interview 14, F, 56-65, typed response, peer support group).*

**Motivation.** Perceiving benefits of an activity helped motivate participants to continue engaging, with some suggesting they might disengage without this reinforcement. The structure of having regular activity helped provide a change of scenery and a routine for some. Connecting socially with others supported emotional wellbeing by offering opportunities to discuss problems, relate to others and build a positive identity. One participant's experience from volunteering demonstrates the impact of connection:

*“A lady [...] gave me a ‘thank you’ card for all the help I'd given her, not knowing that after that morning session I was going to jump off a car park. When she gave me that card I just broke down, completely, in tears. Fortunately I was all on my own. But, yeah it can just be one tiny little thing that one person says.” (Interview 9, M, 46-55)*

Participants reported how motivation and positive wellbeing were also achieved through community-based support by building social connections, confidence to advocate for themselves and skills to solve practical problems. One participant felt the application of the skills learnt could lead to other opportunities such as employment.

*“[Health champion service] inspired me so much that I want to become a life coach and work in wellbeing” (Interview 13)*

Peer supporters reported wellbeing benefits from providing services, such as a sense of purpose, connection with others and reduced anxiety, but felt disappointed if group members lacked motivation or disengaged, suggesting a lack of readiness or confidence as reasons for this. However, lower engagement did not always negatively affect service quality and was sometimes seen as beneficial as those who did engage received more attention, but lower engagement conflicted with the need to sustain funding.

## **Discussion**

This study identified factors which may affect the acceptability and accessibility of social prescribing to community-based support and services for autistic adults. Autistic people are disproportionately affected by barriers to accessing healthcare (Doherty et al., 2022; D. Mason et al., 2019); long waits and inconsistent recording of autism diagnosis can also affect the identification of suitability for services (Featherstone et al., 2022; Sharpe et al., 2019). Participants in the study highlighted a lack of suitably-tailored post-diagnostic support, which has been highlighted previously as a concern (Huang et al., 2020). Through links with community assets, SP can offer a wide range of services and activities to support wellbeing (Chatterjee et al., 2018). The Royal College of Psychiatrists (2020) has recommended utilising a wider range of support options for autistic adults including access to peer support

and leisure opportunities. While not necessarily focused on autism, social prescriptions can reflect this population's preferences for wellbeing support (Benevides, Shore, Palmer et al., 2020) as well as addressing areas of priority such as employment, social isolation and finances.

Findings suggested autistic adults may require enhanced support at certain stages of the SP pathway compared to other clients. Anxiety, uncertainty and a lack of readiness and confidence were barriers to engaging with a service, while clarifying expectations and being accompanied to a first session by the link worker or a 'buddy' might reduce anxiety. Previous research on SP suggests that this level of support from a link worker can facilitate engagement with a prescription (Husk, Blockley et al., 2019), but was sometimes overlooked by participants in the study who had existing capabilities to find and engage in activities themselves. However, many autistic adults are dissatisfied with their current levels of community participation (Shea et al., 2021); working with a consistent professional over time in a focused way may help autistic adults navigate transition periods and services (Howlin, 2021). Services such as the health champion scheme and post-diagnostic signposting service in this study demonstrated positive experiences of personalised support. For widespread provision, one-to-one support may need to be tailored according to communication needs; for example, telephone support may be offered (Husk, Blockley et al., 2019), but can be less accessible for autistic people (Doherty et al., 2022). Furthermore, C. White et al. cautioned against social prescribers encouraging too much independence beyond an individual's level of capability or readiness, which could be an accessibility barrier for unidentified autistic adults in particular (C. White et al., 2022), leading to disengagement and anxiety.

Participants also emphasised being recognised as individuals and offered choices that respected their preferences and circumstances. Although best practice in SP is debated (Kimberlee, 2015), the personalisation and tailoring of an offer is considered central to

progression through the referral pathway (Foster et al., 2021; Tierney, Libert et al., 2022); some evidence suggests this also applies to autistic adults (Featherstone et al., 2022).

Tailoring is closely tied to accessibility and acceptability by building confidence and trust in SP offers (Tierney, Libert et al., 2022). The ethos of person-centred care, which aims to understand a person's issues and strengths holistically rather than reducing them to a single diagnosis or set of deficits (Polley et al., 2017, Fleming; Lloyd et al., 2017), reflects the preferences of many of participants in the present sample. However, reflection on the findings suggests that acknowledging and accommodating disability as a facet of an individual's reality should be part of this personalisation rather than considered a barrier; although many accessibility issues mentioned by participants, such as transport, time and cost, reflected those in other populations (Husk, Blockley et al., 2019; Tierney, Potter et al., 2022), there were also specific barriers for this sample which practitioners will need to acknowledge, including the sensory environment, executive dysfunction and consideration of communication needs, especially in those who mask their autism.

Research has also identified that link workers may lack specialist training to support clients with more complex needs (Hazeldine et al, 2021; Holding et al., 2020; Wildman et al., 2019). This study's findings suggest that autism awareness training for link workers, referrers and activity providers may help with retention, promote accessibility and ensure that autistic adults' priorities are considered. This would need to be up-to-date and reflect the lived experience of autistic people, including common health disparities and co-occurring conditions, as health providers are often unaware of these issues (Micai et al., 2021). It has been suggested that understanding of autism amongst social prescribers follow the Autism Capabilities Framework set by Health Education England (Charlton et al., 2021), including making reasonable adjustments to support (Department of Health & Social Care, 2019).



Furthermore, professionals should be aware of different presentations of autism traits and diverse social needs (Charlton et al., 2021). This might mitigate assumptions that all autistic adults may be too complex for SP. It is highly likely that many autistic adults, including those who may not have a formal diagnosis or choose to disclose a diagnosis, already access SP due to its focus on resolving issues such as social isolation. For example, older adults accessing SP represent a population where autism may be under-identified (C. White et al., 2022). Clinicians may also assume that autistic people are uninterested in social interaction, yet many participants in this study benefitted from connecting with others. However, group interventions are not always appropriate or acceptable for all people (Stuart et al., 2021). A potential adjustment to SP for autistic people would be to offer a variable level of social engagement for an activity (Featherstone et al., 2022), or to consider prescriptions with a low level of social interaction; the autism-focused woodland management project referenced by two participants in this study demonstrates such an approach. Not all participants wanted offers focused on autism, preferring to make more diverse connections, while others felt best able to integrate with peers; a personalised approach would allow flexibility around this. Autistic adults achieve meaningful social participation in a variety of ways, including through online interactions, local interest groups and interactions with animals (Chan et al., 2023); SP could help with identifying opportunities that offer alternative routes to social participation. Peer supporters identified that they often took on supportive roles aligned to that of link workers, such as signposting where they were unable to provide specialist support. Health professionals have sometimes expressed scepticism about autistic individuals' capabilities to provide peer support (Valderrama et al., 2023) and so may overlook these opportunities, yet peer support has been found to have wellbeing benefits for autistic adults, including aiding self-understanding and identity development following diagnosis, developing resilience and reducing internalised stigma about autism (Crane, Hearst et al., 2021; Crompton, Hallett et

al., 2020; Crompton et al., 2022). Participants valued providers with lived experience, including volunteers, offering a less formal approach that reduced pressure and created a sense of equality and authenticity. Nevertheless, peer supporters identified challenges including relying on untrained volunteers, inexperience navigating funding streams, raising awareness of their service within established pathways, responding to complex needs and maintaining contact with members during Covid-19. These affected participants' views on acceptability and reflect concerns expressed by autism peer supporters in previous research, notably a need for more training on facilitation, professional supervision and support from other services with managing co-occurring health conditions affecting autistic adults (Crompton et al., 2022).

Offering a referral route to autism peer support groups through SP might balance the value of lived experience with the expertise of social prescribers and the wider VCSE sector to address some of these needs. This could create a mutually beneficial arrangement for all parties by helping link workers to identify community connections that would help tailor signposting for autistic adults more suitably. In turn, the primary care and VCSE sectors' input could provide an established referral pathway to peer support, as well as offering expertise including knowledge about funding as well as the mechanisms which helped SP provide a resilient response to the challenge of Covid-19 (Cole et al., 2020). This may support sustainability for peer-led services and provide a stable signposting route for patients post-diagnosis, as well as those who are awaiting an assessment of autism, as community-based support has fewer eligibility criteria than specialist services. Social prescribers could also make use of the proposed health checks for autistic adults, which are a policy commitment by the UK government (Department for Education; Department of Health & Social Care, 2021) that aims to identify autistic people's support needs beyond physical complaints (H. Taylor et al., 2023), some of which may be appropriate for SP.

### ***Strengths and Limitations***

Criticisms of research on SP have included its lack of follow-up with those who disengage (M. Cooper et al., 2022), resulting in positive biases. Although participants in this study did not have direct experience of the complete SP pathway, their experience of a diverse range of community-based supports identified motivations for disengagement or disinterest, and barriers accessing services. As none of the participants had navigated the full SP pathway, there may be some unidentified factors that affect accessibility and acceptability, although the findings commonly reflected previous research.

The study relied on a self-selected sample who may have above-average interest in health and health services due to the topics of the prior survey. The survey sample also had high educational attainment and interview participants showed limited ethnic diversity. Therefore, experiences compounded by intersectional marginalisation may be underemphasised. However, initial interview participants ranged in age, gender, co-occurring conditions and support needs. All follow-up interviewees identified as white males between the ages of 35-65; other services with more diverse leadership were contacted but did not respond to requests in time. Follow-up services were all based in London except for the woodland project in Devon, so may offer limited perspectives on service delivery across different local areas.

### ***Conclusion***

This study has identified possible ways to tailor SP towards supporting the wellbeing needs of autistic adults. While it is important that personalised care models recognise people as individuals with diverse preferences and needs, it is also important that SP is accessible to populations who may benefit from it by recognising and accommodating disability and neurodiversity. Some autistic adults may require enhanced support to enrol and engage with

SP, which could be supported through coproduced autism awareness training for SP providers. Furthermore, autistic adult peer supporters may be an untapped resource for the autistic community and for link workers. Enhanced collaboration with SP providers could create a smoother referral pathway to strengthen peer support offers as a means of post-diagnostic support for autistic adults.

## **Chapter 8**

### **Discussion**

This research applied a mixed methods design to explore the potential for social prescribing to address unmet physical, emotional and social wellbeing needs of autistic adults and how it might best be tailored to maximise accessibility for this population. This chapter will synthesise the findings from all components of the study and demonstrate their position within the context of existing literature and policy to contribute novel understandings about this area and lead to recommendations for shaping practice. The strengths and impacts of this research, as well as its limitations and areas for further investigation, will be discussed.

#### **Overview of This Research**

There has been little prior research into social prescribing for this population, despite persistent health disparities. These present a need for investigation into the types of services and service delivery models which could improve outcomes for autistic adults through addressing the high prevalence of mental health concerns, equipping individuals with skills for employment and influencing the social conditions to better accommodate neurodiversity. There is also a need to align research with policy priorities that suggest providing more access to community-level support may reduce reliance on more costly or unsuitable medical responses to poor outcomes (such as inpatient mental health admissions or antipsychotic medication).

While some specific interventions that may be available through social prescribing have been researched in relation to autistic adults, such as leisure activities, exercise and horticultural programmes, prior research has revealed less about how these may function in the form of a social prescription from primary care. This includes attending to the facilitators and barriers that impact progression through the social prescribing pathway. While previous research

indicates some of the mechanisms that affect a broad range of populations, this study aimed to identify specific factors which may affect autistic adults' access to social prescribing, its acceptability for this population and its ability to address the wellbeing needs identified as important by autistic individuals and community leaders.

The majority of findings were based on self-reported data collected first-hand from autistic adults in the United Kingdom. Across the components of this study, inferences were drawn from research findings and participants' experiences of other models of support delivered in community settings, due to the paucity of provision of social prescribing for this population and limitations imposed by the Covid-19 pandemic, which limited the samples and settings accessed for this research. The mapping review evaluating research on community-based, non-medical services for autistic adults identified a series of barriers and facilitators to progressing through service pathways. A mixed-methods study involving interviews and a survey explored autistic adults' experiences of using services and suggested how barriers to accessing healthcare and adjudications of candidacy could further impact the stage of enrolment in social prescribing through primary care networks. Furthermore, interviews eliciting experiences of using community-based services identified features which had led to adherence to a service, disengagement or evaluations of acceptability. The findings of all studies are summarised in Table 8.1.

***Research Question 1: What Are the Wellbeing Needs of Autistic Adults and Is Social Prescribing an Acceptable Response?***

Wellbeing and quality of life indicators in previous research have suggested autistic adults have poorer outcomes than the general population, but that in many cases, these have been based on normative measures that may not consider different ways autistic adults experience and define wellbeing, identify unmet needs or respond to these needs (D. Mason, Capp et al.,

2021; Welch et al., 2019). The question of understanding wellbeing from autistic adults' perspectives was answered primarily through interviewing autistic adults to identify wellbeing needs and how individuals had developed strategies for managing wellbeing, including how these had been impacted by the context of the Covid-19 pandemic. The study identified ways in which participants managed wellbeing, including through self-determined mechanisms such as daily routines, or through engagement with services, as well as how wellbeing needs can remain unmet due to barriers to adopting these strategies. The findings suggest that self-determination – the ability to achieve autonomy, connection and a sense of competence – underlies wellbeing for autistic adults in the study sample.

Findings on existing use of services and supports identified contexts and beliefs which affect service engagement in this group, with implications for the acceptability of social prescribing as an approach to managing health and wellbeing. For example, practitioners' understandings of disability may differ from individuals' understandings, so awareness of concepts such as neurodiversity and the specific issues autistic people experience around communication, sensory processing and executive functioning, may improve engagement and widen the range of offers available.

In addition, the mapping review study explored how community-based services targeted at autistic adults measure outcomes, identifying that outcomes relating to wellbeing have been deprioritised and lacked alignment with community understandings of wellbeing and neurodiversity. This means that there are gaps in knowledge around the utility of such services as approaches for supporting the health and wellbeing of autistic adults. The survey study also addressed this research question by identifying several associations between dimensions of wellbeing and experiencing barriers to healthcare, showing that the experience of accessing healthcare may contribute to self-reported perceptions of wellbeing.

***Research Question 2: What Factors May Affect Access to the Social Prescribing Pathway for Autistic Adults?***

The mapping review study, which looked broadly at community-based service provision for autistic adults in the UK, synthesised barriers and facilitators that were reported in previous literature to affect progression through the pathway of enrolment, engagement and adherence to services. These included referral mechanisms, staff training, individual differences between service users, and the benefits of collaboration with other services for sharing expertise.

Both the qualitative study and the survey of autistic adults' barriers to accessing healthcare during Covid-19 identified how access to social prescribing via healthcare service pathways, particularly primary care, may be impacted by barriers occurring at various stages and levels, including the service context, organisational factors, staff interactions and service users' personal and social circumstances. Findings suggest the experience of candidacy is likely to impact on access to social prescribing via the NHS primary care route. Exploration of wellbeing understandings amongst participants demonstrated how access to services and community assets may support or hinder achieving a sense of wellbeing. Investigating autistic adults' use of community-based supports and services identified how participants perceived the accessibility and usefulness of different service features that may be components of social prescribing models.

***Research Question 3: What Implications Do the Study Findings Have for Policy and Practice?***

Analysis of the research findings identified many practical and simple ways in which services could be adapted to better meet the wellbeing and accessibility needs of autistic adults. These included additional training for staff such as link workers, the use of creative and flexible



methods of targeting and referring autistic service users, widening communication options and improving the sensory environment of services. These may improve the experience of candidacy by addressing service permeability, and facilitate progression through service pathways, leading to enhanced adherence to social prescribing offers. Studies also demonstrated how incorporating community expertise to coproduce services could strengthen these pathways. Exploring methods of wellbeing self-management used by autistic adults identified potential for exploring novel social prescriptions, including technology-based solutions and funding to enable engagement with individual wellbeing pursuits.

### **Synthesis of Findings**

The overall study findings indicate three consistent themes related to tailoring the service offer which have implications for individual wellbeing, service delivery and policy, future research and wider understandings of autism, which will be explored in this discussion.

Tailoring involves high quality communication with individuals and collaboration with relevant services to produce appropriate social prescribing offers that reflect the needs and preferences of a population (Holding et al., 2020; Tierney, Libert et al., 2022). Tailoring may also be a necessary response to the wider context, such as Covid-19, to ensure social prescribing offers remain accessible and relevant (Tierney, Libert et al., 2022). Studies have found that inadequate tailoring is linked to lower uptake of offers (Wildman et al., 2019).

In the first theme, the unique features of the social prescribing model are considered in relation to the wellbeing needs and strategies experienced by autistic adults. This discussion will consider how social prescribing could support wellbeing in a way that is meaningful to personal priorities, present opportunities to signpost to appropriate supports in the community to address gaps in service provision and overcome barriers to wellbeing self-management.

The role of the link worker is particularly relevant to identifying wellbeing goals and

opportunities, managing expectations and facilitating initial engagement with an unfamiliar service or activity. This research considers how the link worker role could be utilised and adapted to best support autistic adults accessing social prescribing. In the second theme, the research highlighted the need for adaptations to be made to enhance service accessibility for autistic adults throughout the pathway, and also revealed how this can be achieved through relatively simple changes, but can also be influenced by broader factors including provider perceptions and socioeconomic circumstances which affect how adjustments to care are implemented and for whom. In the final theme, the results highlight how building collaborations with autism community partners in social prescribing research and practice may have advantages for individuals, services and communities.

This chapter will discuss these themes and suggest how the findings compare with and build upon the existing literature. I will also reflect on the processes of data collection and analysis which resulted in these findings and identify gaps and limitations that indicate a need for further research.

**Table 8.1** *Study components and findings*

Stage/Methods	Publications	Aims/RQs	Findings
Literature review: Systematic mapping review	Featherstone, C., Sharpe, R. A., Axford, N., Asthana, S., & Husk, K. (2022). Health and wellbeing outcomes and social prescribing pathways in community-based support for autistic adults: A systematic mapping review of reviews. <i>Health &amp; Social Care in the Community</i> , 30(3), e621-e635. <a href="https://doi.org/10.1111/hsc.13635">https://doi.org/10.1111/hsc.13635</a>	<ol style="list-style-type: none"> <li>1. What is the nature and variety of non-medical, community-based support for autistic adults that has been reviewed?</li> <li>2. Which outcomes are measured for these services and how do they align with the wellbeing priorities of autistic adults?</li> <li>3. What can existing research reveal about the characteristics of referral pathways underlying services and their contributions to the access to and success of services?</li> </ol>	“There has been minimal evaluation of holistic, low intensity services for autistic adults, such as those offered in social prescribing approaches. Outcome measures remain focused on features of autism and reveal less about the effects of interventions on health and wellbeing. Pathway barriers and facilitators included referral mechanisms, staff training, collaboration, managing expectations, tailoring, and flexible opportunities for social interaction.”
Quantitative study: Online survey	Featherstone, C., Sharpe, R. A., Axford, N., Asthana, S., Ball, S., & Husk, K. (2022). Barriers to healthcare and their relationship to wellbeing and social support for autistic adults during COVID-19. <i>Primary Health Care Research &amp; Development</i> , 23, e79. <a href="https://doi.org/10.1017/S1463423622000755">https://doi.org/10.1017/S1463423622000755</a>	“We hypothesised (H1) that there would be a significant difference in the number of barriers to healthcare over time in accordance with the progression of the Covid-19 pandemic and (H2) that barriers to healthcare would be significantly associated with emotional and social wellbeing variables.”	“The average number of barriers to healthcare showed no significant change between all four time points. However, the nature of barriers to healthcare changed at the point of lockdown and persisted beyond the easing of Covid-19 restrictions. Barriers to healthcare were associated with some social and emotional wellbeing variables and demographic groups including gender, education and presence of additional disabilities.”
Qualitative study: Semi-structured interviews	Featherstone, C., Sharpe, R., Axford, N., Asthana, S., & Husk, K. (2023). Autistic adults’ experiences of managing wellbeing and implications for social prescribing. <i>Disability &amp;</i>	“We formulated this study to explore the concept of wellbeing for autistic adults and the implications for modifying social prescribing [...] We aimed to understand how individuals defined wellbeing, their strategies for managing wellbeing and experiences of barriers to	“Analysis of the data supports research suggesting that self-determination may underlie many aspects of wellbeing for autistic people. The COVID-19 pandemic provided new opportunities to develop wellbeing strategies but also had negative impacts. Social prescribing could promote self-determination by

	<p>Society, 0(0), 1–29.  <a href="https://doi.org/10.1080/09687599.2023.2263628">https://doi.org/10.1080/09687599.2023.2263628</a></p>	<p>meeting their wellbeing needs, within the context of Covid-19.”</p>	<p>signposting autistic people to peer support opportunities building on intrinsic interests.”</p>
	<p>Featherstone, C., Asthana, S., Axford, N., Sharpe, R. A. &amp; Husk, K.  Running the gauntlet, fighting a battle or choosing self-defence: A candidacy framework analysis of autistic adults’ experiences of accessing healthcare in the United Kingdom.  [In preparation]</p>	<p>“Our study aimed to qualitatively explore the experiences of access and barriers to healthcare for autistic adults, and applied a candidacy framework to the themes identified to embed findings in established theory.”</p>	<p>“Barriers to healthcare were consistent with those found in previous research. Participants’ accounts demonstrated factors which facilitated or impeded the negotiation of candidacy, including access to social and material resources and the ability to communicate with providers in ways which met expectations.”</p>
	<p>Featherstone, C., Axford, N., Sharpe, R. A., Asthana, S. &amp; Husk, K.  A Qualitative Study Exploring Acceptability of Social Prescribing for Addressing Wellbeing in Autistic Adults  [In preparation]</p>	<p>“Through semi-structured interviews exploring autistic adults’ views and experiences of social prescriptions and similar non-medical support in community settings, this study aimed to investigate the acceptability and accessibility of the SP pathway from first-hand perspectives.”</p>	<p>“Themes constructed from the data focused on ‘Context of social prescribing for autistic adults’ comprising existing service provision for autistic adults in relation to their views on SP; ‘Features of services’ that were facilitators or barriers to engagement; and ‘Personal factors’ that influenced participants’ attitudes and experiences. Findings suggest ways SP could be better tailored to support autistic adults with managing wellbeing and identified mutual benefits of collaborations between SP pathways and autism community expertise.”</p>

### ***Theme 1: Tailoring Link Worker Support, Offers and Training***

The link worker or community navigator is a central feature of many social prescribing programmes (M. Cooper et al., 2022) and a key component of the NHS model, with the number of link workers set to triple under the NHS Longterm Workforce Plan (NHS England, 2023a). Research suggests link workers may be a crucial mechanism to observed success in social prescribing through facilitating many of the mechanisms that contribute to clients' progression through the care pathway (Husk, Blockley et al., 2019); clients who have more link worker appointments have been found to have better outcomes (J. Mason et al., 2019). An important role for link workers is to assist clients in navigating barriers to enrolling in and engaging with social prescribing offers by managing expectations and providing support with transitions (Husk, Blockley et al. 2019).

In the field of autism research, a study found that a substantial proportion of autistic adults were interested in increasing their level of participation in community-based activities, but were not achieving this to the desired level (Shea et al., 2021). The present research found that participants did not always consider that there may be potential benefits of engaging with the link worker social prescribing model compared to self-sought opportunities for managing wellbeing. However, when providing peer support to others, the actions of autistic peer support facilitators frequently reflected characteristics of the link worker role, including signposting group members to other sources of community-based wellbeing support, but also sometimes assisting with initial engagement into a new group or service. Some qualities participants valued for building their trust in health professionals are also desirable qualities for link workers, such as demonstrating empathy and listening in a non-judgemental way (NHS England, 2023b; Wildman et al., 2019). The qualities of a link worker and their ability to adapt their practice can impact the success of social prescribing over and above other mechanisms (Hazeldine et al., 2021).

Social prescribing has previously been found to lead to improved outcomes around many of the wellbeing issues faced by autistic people. These include mental and physical health, social connections and skill acquisition (Chatterjee et al., 2018) and intrapersonal outcomes such as self-determination (Bhatti et al., 2021; Hanlon et al., 2021) and a sense of personal coherence (Wood et al., 2021) (which may ordinarily be diminished for autistic people due to experiences such as masking) (L. Bradley et al., 2021; Cage & Troxell-Whitman, 2019). The present study suggested if social prescribing can consistently achieve these outcomes, this would be of value for autistic people.

In the present research, analysis of findings from interviews suggested that autonomy and self-determination should be goals of link workers working towards supporting autistic adults' wellbeing, allowing for personalised selection of wellbeing goals rather than pre-determined outcomes that, as shown in the mapping review, may have little application to wellbeing for autistic people. Support from services was not in itself a barrier to autonomy if they were suitably tailored, accessible and able to address identified wellbeing needs.

Participants' accounts of wellbeing self-management demonstrated a high level of internal motivation aligning with intrinsic goals; strategies were often interest-driven and built around being able to establish routines that worked for the individual. Experts in self-determination theory suggest that interventions prioritising intrinsic goals and psychological needs of autonomy, competence and connectedness can facilitate health behaviour change (Ryan et al., 2008).

While the findings demonstrated participants' creativity and resilience, they also suggest that for social prescribing, careful matching of a prescription with a person's goals and interests, and support with navigating their personal barriers (such as assistance with executive skills), would be important features of tailoring to promote self-determination, as also indicated by the findings of the systematic mapping review. This reflects recent recommendations in

autism practice for building in approaches that identify and enhance individuals' strengths, capabilities and resources with the aim of reducing stigma and enhancing control over care (Howlin, 2021; Huntley et al., 2019; Pellicano et al., 2022). These features are key features of social prescribing pathways. Some participants' motivation for self-managing wellbeing also had external alignments which suggests potential benefits of the prescription model to enhance motivation, as demonstrated previously as a further mechanism to progression through the social prescribing pathway (Husk, Blockley et al, 2019).

The present research identified factors which contributed to wellbeing for autistic adults as well as barriers and facilitators to achieving wellbeing goals. Meaningful connections to others with similar identities and interests contributed to wellbeing, but services may need to recognise how social motivation can present differently for autistic people, while also avoiding assumptions that the 'social' element of a prescription may be wholly unsuitable; this may require some flexibility to be applied.

Morris et al. (2022) have identified that a sense of community belonging can influence beliefs about and engagement with services, and that the community should be seen as a potential collaborative partner in the tailoring of care. Similarly, peer support was an important mechanism to connection for autistic people, with preliminary studies in previous literature suggesting this can have both qualitatively and quantitatively measurable benefits for wellbeing, including shaping a positive identity around autism and sharing information to support wellbeing (Crane, Hearst et al., 2021; Crompton et al., 2022). The identification of participants in interviews with experience of using, assisting with or leading peer support services presented an opportunity to explore this in relation to a potential social prescribing pathway.

However, the availability and types of peer support vary by location as there is not a standardised approach; like social prescribing, peer support groups have arisen out of local need, so may require flexibility to make connections. For example, signposting to online communities and technology-based solutions could supplement a lack of face-to-face support groups for autistic adults, such as in rural areas where such groups may be sparsely distributed. For those who may find socialising in a face to face group intimidating, online settings may also offer a means to self-regulate levels of social engagement as well as to connect with others based on interests that might be more difficult to identify within a socially demanding group setting.

There may be a need for some individuals to access digital literacy supports to enable these opportunities, with other barriers to technology use by autistic adults including costs, concerns about privacy and lack of tailored and accessible user interfaces (Zheng et al., 2022). Connecting people to local, in-person networks may provide greater access to tangible support that a person may have difficulty identifying without support from a community navigator; tangible support has been found to have a stronger association with reduced suicidal ideation for autistic adults compared to other forms of social support (Hedley et al., 2017). Social prescribing could also provide resources to reduce barriers that may have so far limited self-directed engagement with community-based activity to enhance wellbeing, such as providing equipment or information needed to utilise public spaces.

C. White et al. (2022) suggest link worker support at transition points may be especially important for individuals who experience anxiety and lower confidence, and caution against focusing too early on moving clients towards self-efficacy and independence. This is another area in which previous interventions for autism may have misplaced their aims by focusing too highly on independence and less on autonomy towards choosing how to interact with services; Schott et al. (2021) found that greater independence in autistic adults in the United



States correlated with having more unmet health needs and isolation, whereas those who received higher levels of support had greater connection to a community and services.

These findings demonstrate how there may be advantages of working with a link worker for autistic adults to enhance wellbeing by making more connections with communities in a personalised way. However, link workers have reported that the complexity of managing patients with co-occurring medical or psychiatric conditions can be a barrier to performing their role to the best of their abilities (Holding et al., 2020; Rhodes & Bell, 2021). They have expressed a need for more training to be better prepared to manage referrals where issues such as mental health problems, trauma and abuse may present (Fixsen et al., 2020).

Social prescribing referral documentation often lacks detail on patients' needs (Hazeldine et al., 2021) and sometimes more complex issues may emerge over time spent with a link worker that were underexplored in the referral consultation (Rhodes & Bell, 2021). Autistic adults are more likely to present with a range of unmet co-occurring medical and social issues (Brugha et al., 2011; Croen et al., 2015; H. Taylor et al., 2023), which may contribute to complexity, many of which may not be well-understood by health professionals (Micai et al., 2021). Although link worker perspectives of this have not been explored, other health professionals, especially in mental health services, have been shown to assume that this complexity would surpass their existing competencies (Hallett & Crompton, 2018; Maddox et al., 2020).

Autistic participants in the present research suggested that more training and awareness on autism was needed for professionals in a variety of health service roles. Professionals' lack of understanding about autism was considered a barrier to asserting candidacy for care, while demonstrating more knowledge about autism led to more positive perceptions. Relevant areas of knowledge to target based on these samples' experiences should include diverse

presentations of autism (e.g. understanding autism in women and late-diagnosed adults), common co-occurring conditions, effective communication with autistic clients and making reasonable adjustments.

The Oliver McGowan mandatory training on autism, which has had input from people with lived experience, is a training package available for health and social care professionals (Health Education England, 2022); ensuring link workers undertake this training may enable them to build their confidence around supporting autistic adults in the social prescribing pathway, though evaluation of this training's ability to improve care for autistic people is currently unexplored. It is arguable that those leading community activities and link workers based outside the primary care setting should also have similar training around autism, but this may be more difficult as these services are not standardised and involve many branches of the VCSE sector; this setting has been found to impact the level of training link workers are offered (Rhodes & Bell, 2021). There may be a need to raise awareness of training opportunities for those situated within the VCSE sector to provide the same level of support as NHS professionals.

However, there is a risk of overburdening link workers, as it may not be feasible to provide training on every condition they may come across in their work. On the other hand, the study findings also showed that patients can experience burden from having to educate providers on their lived experience, and this adds additional communication demands. There may be a case for specialised link workers based within autism services, in a similar manner to those deployed in children's and young people's services or services for armed forces veterans.

Another solution may be to provide training on general disability awareness and how to make reasonable adjustments that may benefit people with a range of conditions, such as providing different communication methods and understanding the impact of the sensory environment.

Findings by Rhodes and Bell (2021) suggested that processes such as supervision, shadowing and peer support networks can also help link workers gain skills and access support in a way that is less dependent on structured training, which can be seen as box-ticking, but that access to these mechanisms varied depending on the context of their work, such as differing settings. Increasing access to wider networks for peer supervision could support link workers to learn from colleagues with more experience of neurodiversity.

In addition, previously identified learning needs for link workers, including broadening general skills around communication, counselling skills and understanding of social determinants of health (Wildman et al., 2019), would also be relevant to the needs identified by autistic adults in improving their interactions with health professionals. This could provide advantages for autistic adults who may be undiagnosed or choose not to disclose their autism, as these skills are more general rather than specific to working with those with disabilities. C. White et al. (2022) suggest that many older adults who are referred through the social prescribing pathway, due to problems such as social isolation, may be of this type of profile. Others who are referred with high levels of healthcare utilisation or co-occurring conditions may also be more likely to be autistic due to the number of unmet health needs that present in this population.

Some autistic clients seen by a link worker may not disclose their diagnosis due to perceptions of stigma or expectations that it will not improve their care; others may be undiagnosed or mask their autistic traits (whether consciously or as a learned coping mechanism). Adopting a more disability and neurodiversity affirmative approach may help build confidence around disclosure which can lead to further steps for tailoring the approach to individuals' profiles. This should take account of the multifaceted nature of autism: as part of a person's identity, a disability which interacts with the social and physical environment, and a facet of natural human diversity. Professionals in the social prescribing pathway will

need to position their understanding of autism beyond the medical model and avoid making autistic traits the focus of treatment or seeing this as a medical label that obscures the individual and is incompatible with social prescribing's holistic and person-centred approach (Polley, Fleming et al., 2017). Understanding the diverse experiences of how autistic people construe autism and the relationships between individuals' strengths and difficulties with their wellbeing will strengthen tailoring.

### ***Theme 2: Adapting Care Pathways to Reduce Barriers***

The present research project reinforced the impact of barriers to healthcare experienced by autistic adults that have been identified in previous literature, which has found environmental, organisational and interpersonal factors may lead to barriers with communication, sensory processing and navigating services for autistic adults (Doherty et al., 2022; D. Mason et al., 2019). Intersectional and social issues, including gender, co-occurring conditions, education level, employment, social support, access to material resources and provider perceptions affect access to healthcare which could lead to barriers from the initial stages of enrolling in social prescribing and also extend to accepting and engaging with offers. Statistical analysis of survey responses (see [Chapter 4](#)) tentatively suggested there may also be associations between barriers to healthcare and social and emotional wellbeing, with potential influence by changing contexts of service delivery, showing the importance of tackling barriers to healthcare for the improvement of overall wellbeing.

Individuals with disabilities are entitled to equal access to services under the UK Equality Act 2010, which requires providers to make reasonable adjustments to facilitate access. The sparsity of autism services for adults and the health inequalities already faced by this population make access to alternative services highly important. This research suggests that

making social prescribing accessible for autistic adults includes making modifications to referral pathways, sensory environments of healthcare and community settings, and increasing communication options (see Table 8.2 below).

The NHS Reasonable Adjustments Flag is a new policy area which will introduce a universal system to indicate the needs of disabled individuals across all sectors of the health service; this should include social prescribers who are situated in primary care networks. This will help implement adjustments for individuals rather than rely on assumptions about what all autistic adults might need, as the diversity of the autism spectrum means that some people may need different adaptations to others.

Furthermore, as the in-depth consultations offered by link workers often flag previously unidentified needs, the link worker could be well-placed to add detail to medical records, which may improve future experiences of accessing other health services. However, this would not be available to the VCSE sector who often provide the community-based support offered through social prescribing; modifications may need to be made at this stage to support adherence to an activity (Charlton et al., 2021). Link workers could work with neurodivergent clients to coproduce a 'passport' that can detail the individual's profile of needs to leaders of supports and services, which could specify suitable accommodations to the social and sensory environment to facilitate engagement and adherence to activities.

Few studies of social prescribing have explored accessibility barriers at the stage prior to enrolment in the social prescribing pathway (Cartwright et al., 2022; Tierney, Cartwright et al., 2022). This may be because research studies have focused on gathering data from patients who have successfully completed a social prescription, but as fewer than 50% of patients referred to social prescribing may attend the initial link worker appointment, this may lead to

some bias in the research literature regarding the success of social prescribing offers (Bickerdike et al., 2017).

The present study made use of both hypothetical scenarios and examination of participants' use of other primary care and community-based services, to understand some of the decisions, beliefs and barriers that may present prior to an initial referral to social prescribing, from identifying a wellbeing need and factors involved in self-management, to navigating services and making initial contact. This highlighted the role of internal processes such as health cognitions, interpersonal issues including social support and gatekeeping, and structural barriers such as method of communication available to patients.

NHS England is trialling an annual health check for autistic adults (H. Taylor et al., 2023), with trial models including the potential for social prescribing as a possible action to respond to identified wellbeing needs (Autistica, 2023). As an autism-specific pathway this could fast-track access to social prescribing and form part of a public health response to the inequalities faced by autistic people (Sharpe et al., 2019). However, the mapping review in [Chapter 3](#) also identified that there may be issues with creating targeted social prescribing programmes for autistic adults as early as the enrolment stage, because methods of identifying autistic adults through medical records and other databases are often unreliable.

The social prescribing literature suggests that there may be a lack of diversity in the reach of some social prescribing programmes or that demographic factors, such as disability, may be deprioritised in recording access by different populations (Cartwright et al., 2022).

Socioeconomic factors also affect progression through the social prescribing pathway; these can include characteristics of populations, with reviews indicating lower uptake amongst those from ethnic minority backgrounds and people with intellectual disability, and higher disengagement from younger clients; this may be due to a lack of targeting of social

prescribing for these groups (J. Mason et al., 2019). Financial status, employment and time availability can also influence the acceptability and accessibility of social prescribing for individuals (Gibson et al., 2021). Fixsen et al. (2020) also found that clinical judgements on who social prescribing is appropriate for can be influenced by changing socio-political contexts and these decisions may be made at multiple levels.

The present research also supported findings that individual and social factors interact with provider adjudications, affecting who is able to communicate a need for, and receive, adjustments to care. For example, receiving reasonable adjustments to care often relies on a person being able to communicate their needs, or have an advocate who can do so on their behalf. In the survey study, the types of barriers experienced more by women and gender minorities more often related to asserting candidacy, such as being believed and understood by providers. Autistic people with lower levels of education struggled the most during the acute stages of the pandemic when there were more barriers to communicating with services. Interviews also pointed to financial factors being involved in the selection of services for their level of permeability and the ability to make modifications to support access to care, such as by purchasing noise-cancelling headphones or using the private healthcare sector. The ability to communicate verbally or rely on the help of an advocate as factors that facilitate candidacy also demonstrated how disparities in individual abilities and resources could influence access.

A benefit of the social prescribing model not being diagnosis-focused is that it may be more accessible for people awaiting autism diagnosis due to lengthy wait times and those who face barriers to diagnosis. Given autistic adults' barriers to accessing health services, there may be a benefit for peer supporters and others who work with autistic people in the community to make referrals to social prescribing where unmet needs are identified. Although social workers are another frequent referral source for social prescribing (C. White et al., 2022),

there has been less consideration to referral from peer supporters, family members, or the use of self-referral or drop-in services, which the present research suggested could facilitate initial enrolment into the social prescribing pathway for those who experience more barriers.



**Table 8.2.**

*Adjustments to Maximise Accessibility of Social Prescribing for Autistic Adults*

<b>Stage of pathway</b>	<b>Barriers and issues</b>	<b>Recommended adjustments</b>
<b>Health service navigation and booking systems</b>	Communicating by telephone Negotiating with receptionists Lack of autism diagnosis or recording of diagnosis	Online booking Fast-track system (bypassing receptionists/gatekeeping) Universal-level adjustments (e.g. attention to sensory environment, offering multiple communication options)
<b>Primary care consultation</b>	Communicating concerns Having communication understood Masking	Demonstrate empathy and listening Support communication Training about autism (e.g. masking, interoception, underserved groups)
<b>Referral to social prescribing</b>	Identifying issues of concern Presenting to GP services Lack of consistency of autism diagnostic recording (e.g. if offering an autism-only service)	Self-referral using online forms Proxy referral Referrals from other services (e.g. autism assessment services; social care services; private therapists) Drop-in services Health passport and reasonable adjustments flagging
<b>Link worker consultation</b>	Perception of complexity Lack of understanding about autism (e.g. making reasonable adjustments; potential for tailoring) Anxiety and uncertainty Communication barriers	Coproduced training about autism Personalised adjustments Longer/more consultations to talk through expectations Demonstrate empathy and listening Offer consultations by email/online forms
<b>Engagement with activities</b>	Group-based activity Anxiety and uncertainty	More peer support signposting Enablement funding Low social interaction opportunities Online opportunities Supported engagement (e.g. link worker or buddy to attend initial sessions; support with completing forms) Drop-in services/relaxed rules about attendance Provide detailed information in advance
<b>Adherence to activities</b>	Overstimulation (sensory, social) Communication barriers	Adjustments to sensory environments Flexible levels of interaction/ability to take breaks Supports to facilitate communication

### ***Theme 3: Centring Collaboration and Coproduction in Social Prescribing Models***

Some criticisms of social prescribing have focused on the lack of robust evidence for its effectiveness and potential for bias in studies of the approach, arguing that the heterogeneity of social prescribing studies due to lacking a standardised approach for implementation may contribute to these issues and make it difficult to run comparison studies with other more established services (Bickerdike et al., 2017; Costa et al., 2021). Some of this heterogeneity stems from the way social prescribing has often arisen as a response to a variable picture of local need across regions, with distribution of resources also differing by area (Husk, Blockley et al., 2019; Polley et al., 2020). Polley et al. (2020) argue a positivist focus on evaluating outcomes may miss other aims and values of the holistic social prescribing model, and that evaluations should involve stakeholders to ensure they are measuring experiences accurately.

In its adoption of social prescribing as part of the personalised care model, the NHS is implementing a more standardised top-down approach, which includes creating a dedicated link worker role and social prescribing pathway within primary care networks and issuing advice for best practice (NHS England, 2019, 2023a). This may help reduce heterogeneity across models of social prescribing deployed and is not necessarily in contrast with social prescribing's origins as a more organic and redistributive model if there is a continued effort to tailor offers to local need and assets.

However, some scholars suggest that by embedding social prescription in the health service, this aligns more with the medical model of 'intervention' (Gibson et al., 2021; Mackenzie et al., 2020), with link workers based in primary care found to take a more medicalised approach to health needs compared to those situated in the voluntary sector (Cole et al., 2020). This reinforces a transactional and individualised approach to health which may risk

exclusion of some sections of the population by failing to address underlying inequalities and may contradict some of the core values and aims of holistic social prescribing (Calderón-Larrañaga et al., 2021; Lent et al., 2022; Mackenzie et al., 2020), as well as those that the present research suggested would support self-determination for autistic adults. Inequalities may also be exacerbated if social prescribing becomes over-relied upon to reduce costs of providing healthcare by diverting referrals out to an also underfunded VCSE sector, increasing bureaucracy, overstretching resources and failing to meet more basic healthcare needs at both the individual and community level by over-emphasising self-management (R. C. H. Brown et al., 2021; Dayson, 2017). These arguments support retaining, as far as possible, a community-driven and assets-based approach, which may be heterogeneous by necessity.

For autistic adults, a diverse group whose ‘heterogeneity’ presents difficulties for targeting medical interventions (J. A. Hughes, 2021), a suitably heterogeneous and community-based support system may be advantageous due to its greater potential for tailoring and personalisation to reflect neurodiversity. These features have been emphasised as mechanisms to maximise the person-environment fit to improve outcomes for autistic adults (Howlin, 2021; Lai et al., 2020; Royal College of Psychiatrists, 2020). Autistic people’s access to their community and to health services may depend on local-level factors but also wider contexts, as shown in this research by the impact of the Covid-19 pandemic on service delivery and individual wellbeing.

Taking a collaborative approach to the design of care pathways was a facilitator for engagement identified in this research; this may help implement training and make adaptations more efficiently by ensuring these are well-targeted to the issues of priority raised by autistic adults. As previously mentioned, concepts such as autistic masking, inertia, burnout and meltdowns, which have a substantial impact on wellbeing (L. Bradley et al.,

2021; Buckle et al., 2021; Cage & Troxell-Whitman, 2019; Hull et al., 2017; Raymaker et al., 2020; Welch et al., 2021), have been prevalent topics of discussion within autistic communities longer than they have existed in the research literature, where replication of findings and their translation into policy and practice can take time.

Collaboration and coproduction of services align with the principles of more holistic and tailored models of social prescribing, which at a basic level aim to deliver person-centred prescriptions, with more advanced models centring coproduction of the broader community offer as a core value (Dayson, 2017; Malby et al., 2019; Tierney, Libert et al., 2022). This includes involving communities in the design, tailoring and evaluation of services, building relationships, and taking account of community needs to understand the landscape of local assets (Dayson, 2017; Malby et al., 2019). Studies suggest building strong partnerships should be upheld as a key responsibility of link workers, as this is linked to higher rates of referral (Tierney, Libert et al., 2022) and positive outcomes in social prescribing (Holding et al., 2020). Collaborations with sectors providing community assets can facilitate tailoring by supporting understanding of the needs of marginalised groups and gaps in services, improving the reach of offers and information about their suitability for individuals (Tierney, Libert et al., 2022; Holding et al., 2020). Studies have found that coproduction and co-design features in evaluations of social prescribing services improved wellbeing and empowerment for users, although methodological quality as rated by reviewers remains low (Elliott et al., 2022; Thomas et al., 2021).

Autistic adults in the present research and elsewhere have reported a lack of suitably tailored post-diagnostic services and supports (Crane et al., 2018; Crompton et al., 2022; Griffith et al., 2012; Huang et al., 2020). However, reviewing the literature and interviewing study participants suggests that there were many community-based support models available through other pathways that may facilitate wellbeing for autistic people. Analysis of prior

research and first-hand perspectives of community-based support suggested that it may be beneficial for social prescribers to collaborate with autism organisations as well as autistic individuals to enhance tailoring, which may facilitate engagement as participants were eager to see evidence of community input on training and service facilitation. This may encourage empowerment by helping people to feel they have more control over the design of services (Tierney, Libert et al., 2022).

Interviewees who provided peer support felt they held knowledge on the variety of needs affecting their local autistic community as well as being able to signpost to suitable support and assist with navigating barriers. They felt peer support and signposting could be strengthened by collaborating with established services who could offer advice with funding and facilitation and refer individuals to their services, leading to a more sustainable landscape of support. Tierney, Libert et al. (2022) emphasise how working together in this way may lead to benefit for individuals by helping social prescribing offers to focus on common goals.

In reality, some evidence suggests social prescribing does not always promote a focus on community collaborations. A focus group study that examined public perspectives on social prescribing within primary care network regions in the North West UK suggested there was a perception that local decision-making around social prescribing had low levels of public involvement, but that communities wanted to be more involved; individuals felt this would help build link workers' knowledge and empathy towards their communities (Khan et al., 2022). Collaboration between providers at different stages of the pathway has often been found to be limited, with referrers in the medical sector, link workers and community-based organisations reporting a lack of awareness of each other's roles and resources (Hogg-Graham et al., 2020; Pescheny et al., 2018b; Rhodes & Bell, 2021; Wood et al., 2021). Tierney, Libert et al. (2022) emphasised how more work to improve communication and expand outreach may strengthen collaborations. The Covid-19 pandemic also demonstrated

how community knowledge, such as understandings of structural barriers, can lead to a more rapid and targeted response to tailor health information and interventions to communities' needs (Marston et al., 2020). Coproduction in the evaluation of social prescribing services may improve trust and offer more diverse insights into the observed mechanisms of social prescribing (Elliott et al., 2022).

Coproduction of autism research and services is an area that has recently been gaining traction, as this can lead to services which are better equipped to meet the needs identified by autistic individuals (Howlin, 2021). An example is the Academic Autism Spectrum Partnership in Research and Education (AASPIRE) collaborative, who have used coproduction to develop a tailored healthcare toolkit, employment outcome measures and carry out research into under-researched priority areas including suicide, reproductive health and abuse. This has led to guidelines for coproducing projects with the autistic community that could be useful for tailoring in a collaborative way; these emphasise the importance of having a mutual understanding about goals, facilitating communication in an accessible way and building trust (Nicolaidis et al., 2019). Many of these principles align with the mechanisms of tailoring involved in social prescribing offers for other populations (Tierney, Libert et al., 2022).

Thomas et al. (2021) emphasise the concept of 'realignment' within coproduced approaches to social prescribing, which involves a levelling of power between those typically in control, such as healthcare professionals and policymakers, and those representing communities, achieved through re-evaluating cultural values. Their review found that where attempts were not made to see all parties as equal, this was a barrier to a fully holistic social prescribing model; conversely, where there was more attention to community input, this encouraged a greater sense of ownership for community members. The AASPIRE guidelines for codesign in autism research emphasise defining the roles of all parties, but also paying attention to

existing power dynamics and making adaptations to enable power to be shared, such as by modifying communication and social demands, valuing lived experience and providing opportunities for community members to gain skills or take up a staff role (Nicolaidis et al., 2019). This can promote empathy, challenge stigma and enhance inclusion of autistic perspectives in service design and delivery (McCowan et al., 2022).

Neurodiverse healthcare professionals could be well-positioned to develop collaborative training models and service design and may be viewed as more acceptable to autistic clients, helping to address barriers to asserting candidacy. Other healthcare professionals could benefit from collaborations by gaining an improved understanding of autism and reasonable adjustments which may help to minimise the association of autism with complexity. The present research suggests these issues may relate to factors underlying barriers to adjudication of candidacy for autistic adults; this could then benefit individuals by helping to reduce inequalities in access to healthcare and build understanding of the diversity of individual needs to enhance person-centredness, enabling social prescribing to achieve its core values.

The present research suggested that there was a need for more sustainable and joined-up options for post-diagnostic support for autistic adults, such as peer support services, backing up findings of previous research (Crompton et al., 2022). Coproduction of a national-level autism-centred social prescribing pathway through tailoring may help to address these gaps in an acceptable and accessible way which could contribute to a package of community-level wraparound support for wellbeing for autistic adults at any stage of the diagnostic process. This could support government priorities for community-based interventions to prevent escalation of needs (Department of Health & Social Care, 2022). Helping autistic adults find strategies to manage their mental and physical health may also ease pressure on the diagnostic pathway as it may be less necessary to get a diagnosis to access more specialised health and care services.

However, while social prescribing may be a suitable solution to some of the gaps in pre- and post-diagnostic support for autistic people, it will not be able to address all health and wellbeing needs, with scholars in doubt over the NHS model's ability to improve social determinants of health without additional effort being made to avoid the pitfalls of the medical model (R. C. H. Brown et al., 2021; Gibson et al., 2021; Mackenzie et al., 2020). Link workers have also reported that some of the issues with complexity in their caseloads may stem from inappropriate referrals to social prescribing where mental health support is less available (Cole et al., 2020). Some social prescribing programmes exclude patients already accessing mental health services (Sandhu et al., 2022), yet the results of the present research suggest populations may have concerns about social prescribing replacing other forms of care they may need.

Instead, social prescribing should be an item in a toolbox which is scaffolded by access to timely mental health support and medical care when needed. As social prescribing is unlikely to be suitable or acceptable for all people on the autistic spectrum, these areas of the health service will continue to need further strengthening to support autistic adults.

### **Contribution to Knowledge**

This research has led to important empirical, theoretical and methodological developments applicable to future research and practice. Empirically, findings supported the growing evidence for peer support and self-determination as important mechanisms for wellbeing for autistic adults, identifying how social prescribing may be well-placed to respond to some of the challenges affecting peer support services for autistic adults (Crompton et al., 2022). Strengthening the social prescribing offer for autistic adults by applying the understandings of wellbeing, accessibility and community expertise identified in this study, could facilitate



sustainability of support services and links to the health service due to social prescribing's positioning in long-term NHS policy, which will create a more efficient pathway for support around autism diagnosis and long-term wellbeing. Such links would also benefit health services by embedding understanding about autism, especially in relation to how autistic communities can empower themselves. The study also led to recommendations for adaptations and training content which should be implemented to increase accessibility of the social prescribing pathway when working with autistic adults and tailoring services to their needs. This has addressed an empirical gap in social prescribing research, which has lacked attention to underserved populations including people with disabilities.

The findings also contribute to theoretical understandings of wellbeing applicable to autistic adults; approaching the research through the lens of critical realism and the neurodiversity model were novel ways in which themes were developed. Thus far, the neurodiversity perspective has not gained attention in the social prescribing literature, yet is a concept applicable to the whole population, where differences in cognition and sensory processing fall across a wide spectrum. The findings of the study will, therefore, not only be applicable to autistic service users, but can be applied to improve accessibility of social prescribing for cognitive differences more broadly by extending social prescribing's ethos of taking a holistic understanding of people's individual needs, strengths and difficulties.

The findings suggest a need to avoid reliance on over-medicalised and normative models of disability and wellbeing; for autistic adults, the study found that observed mechanisms which contribute towards the concept of wellbeing may not always align with recognised understandings, such as ways of connecting with communities. Previous reviews have suggested that flexibility around the level and types of social engagement expected may support engagement for autistic adults by avoiding social overstimulation (Charlton et al., 2021). Participants' positive experiences of wellbeing also demonstrated individual and

community resilience and creativity, balancing pathology narratives that portray autism as incompatible with thriving (Chapman & Carel, 2022). These more flexible understandings of wellbeing as an achievable outcome for autistic adults should motivate policymakers to work to address inequalities and improve service accessibility. However, the study also affirms many of the areas of unmet need previously identified as affecting autistic adults (Howlin, 2021), as well as the extent of these needs, demonstrating a need for effective targeting and tailoring of interventions and the use of personalised approaches.

The mixed-methods research identified areas where intersectional factors, including gender, disability and socioeconomic conditions, play a role in barriers to healthcare, requiring services to determine where additional resource and guidance will need to be aimed to address inequalities in access to personalised care pathways. Methodologically, the application of the candidacy framework also facilitated many of these findings; this framework has previously been applied to social prescribing, identifying the role of individual traits and beliefs and their interaction with neoliberal models of healthcare (Westlake, Ekman et al., 2022). In the current study, applying the candidacy framework to a novel population identified interactions between individuals and the socio-political context, suggesting there are hierarchies of disadvantage that may play into interactions with health services; for autistic adults, negotiations of candidacy extended to access to the right to receive reasonable adjustments to care, despite this being a requirement of the Equality Act. These barriers may represent an area of health inequality for this population that has been underexplored.

Further, although there were sample limitations, the study has highlighted how people who may face more invisible struggles or who are considered ‘high-functioning’ still experienced acute barriers to accessing services and maintaining wellbeing. These issues may contribute to inequalities such as those observed by Hirvikoski et al. (2016), with higher recorded

functioning level being related to increased risk of severe mental health problems. Findings helped identify where additional adaptations or training may ensure underserved groups are not further marginalised by systems of healthcare, including recognising the multifaceted, rather than linear, nature of the autism spectrum. Many adaptations that could be made to maximise accessibility for autistic adults may be beneficial to other groups with reduced access to services due to disabling environments and practices. For example, accommodating different sensory and communication needs could benefit those with other sensory-related disabilities, as well as introducing more flexibility and reducing overwhelm for service users in general.

A further methodological and empirical contribution in this study is the generation of evidence for the value of community expertise and resilience in policy development. The analysis of first-hand experiences of access to other community-based and primary care services helped to ground these findings in the lived reality of autistic adults. The study identified that autistic adults represent not only a category of patient but also community leaders and experts through experience that lends support to the overall theme of coproduction as key aspect of tailoring. Reflexivity throughout the process, not only in analysis but from the point of conceptual development, enabled the iterative process of identifying further gaps at each stage where bringing in more community perspectives could strengthen the findings – this included developing follow-up interviews for those in community leadership roles, which highlighted issues affecting sustainability, funding and awareness of community-led groups where integrating social prescribing may strengthen the offer for autistic adults. Furthermore, the study has demonstrated how considering accessibility in the design of research procedures helped incorporate the perspectives of participants who were multiply disabled or had particular communication needs which have

often been neglected in their access to healthcare and other services. This has resulted in novel perspectives such as the role autistic masking can play in healthcare candidacy.

To expand the objective of coproduction, I applied for funding from Autistica's Social Care Development Awards with support of my supervisory team, aiming to hold participatory community meetings with stakeholders, including autistic adults and carers, to explore the social care needs of autistic adults and embedding of social prescribing to address those needs. This aimed to support the development of a proposal to NIHR's Research for Social Care call with a focus on areas of priority co-identified by Autistica and the autistic community. A full report on this work which explains the background, methods and recommendations in full is available in Appendix 15. I aimed to conduct scoping meetings with social care experts (e.g. professionals and researchers) and those in the voluntary, community and social enterprise sector, to understand the scope for adult social care to support social prescribing referral pathways. The resulting work identified useful directions for future research:

1. Conducting a scoping review of autism services and community hubs to identify gaps including area mapping, assessment of autistic community involvement, realist evaluation and estimation of social value (e.g. impact on quality of life).
2. Trialling coproduced upskilling of social prescribing and/or hubs services through community-informed training and provision of additional support for autistic adults (e.g. piloting a 'pop-up shop' model where services could host events targeted at providing the local autistic community with information and resources for improving wellbeing and access to healthcare).
3. Investigation into digital exclusion of autistic people in rural communities, the challenges this presents for wellbeing, and how to resolve this.

4. Initiating novel social prescribing solutions with autistic adults presenting to primary care, mental health services or post-diagnostic autism services, such as embedding link workers within autism service pathways and adapting digital social prescribing tools.

The method of coproducing research with public contributors presented challenges, including negotiating with the university on how contributors could be paid for their involvement without excluding those receiving state benefits, who represented people experiencing hardship and those more vulnerable in the community; this was eventually resolved by arguing for voucher-based payments for the majority of contributors. Overall, contributor views suggested that research funding was an unsuitable route to developing the service model required, and limitations in the scope of social care to partner on this project meant that a full grant was not pursued. However, Plymouth City Council have developed upon the research questions identified by aiming to upskill community hubs to improve their suitability and acceptability for Plymouth's autistic community; I was able to assist with site auditing for this initiative and the contributions of the present research continue to inform meetings with the local autism partnership board. The experience of conducting participatory research has been extremely helpful in guiding my approach to creating further public engagement workshops for Autistica in my role as Policy Officer that I took on after completion of the study.

In May 2023 I presented a summary of the PhD research findings to NHS England staff as part of a webinar on social prescribing for autistic adults, and will present findings to NHS England's autism and learning disabilities team in January 2024. Social prescribing is embedded into the NHS long-term workforce plan spanning 15 years (NHS England, 2023b), so presenting these findings to these specialist teams helps to inform the expanding workforce about how autistic adults can be supported in social prescribing pathways, and may lead to recommendations being translated into policy.

In June 2023 in my role as Research and Partnerships Manager at Autistica, I worked together with NIHR and NHS England to develop priorities for the Health Technology Assessment funding strand focusing on support for autistic adults; I drew on the findings and gaps generated in this research to propose a call to explore social prescribing as part of a wellbeing support pathway for autistic adults. While conducting the research I also disseminated preliminary findings to practitioners and the public via presentations to the Devon Adult Autism and ADHD Service, the National Autistic Society Plymouth Branch and the Asperger London Area Group (ALAG). The study findings have also informed literature reviews for studies of social prescribing for autistic adults developed by other organisations, including a project on the potential of social prescribing to provide bridging services to autistic people and those with learning disabilities by the National Development Team for Inclusion, and an evaluation of the Bristol Autism Spectrum Service's social prescribing pathway.

### **Strengths, Limitations and Reflections**

Strengths and limitations of separate components involved in this research are detailed in earlier chapters. A core strength of the research overall is its focus on service models and wellbeing, which is highly relevant to community priorities for autism research (Benevides, Shore, Palmer et al., 2020; Pellicano et al., 2014; Putnam et al., 2023). The research has also given a platform to some powerful narratives which have demonstrated participants' and communities' resilience and resourcefulness. The main limitations included sample size or characteristics that may affect representativeness, and the use of semi-structured interviews that may contribute to an individualised understanding of wellbeing and service use that could overlook some community and contextual factors.

Throughout the research process I engaged in reflective practice using a reflexive journal which is both integral to the process of reflexive thematic analysis (Braun & Clarke, 2022), the main analytic method applied to the qualitative components of the research, as well as something I had prior experience of finding beneficial from a previous role in clinical health psychology. This included reflecting on my own position to the research questions and theoretical positions throughout the research process, for which I also took inspiration from similar accounts by other researchers with lived experience in their field (Ademolu, 2023; Botha, 2021a; A. Grant & Kara, 2021; Higson-Sweeney et al., 2022) to recognise how my own lived experience may have influenced my selection of methods, processes of data collection and interpretation of findings.

Decisions on sampling across all stages of the research required consideration of both representativeness and inclusivity. In autism research it can be difficult to have a sense of a representative sample as statistics on autism prevalence and the characteristics of those diagnosed are often updated. Having reflected above on how the challenges of access to autism diagnosis for marginalised groups impacts access to services, the same also applies to research.

As identified in the mapping review, samples in autism research are disproportionately made up of younger, white male individuals; previously this was the profile of the vast majority of those who received a diagnosis due to a lack of awareness of how autism may present differently in people outside of this profile (Lai & Baron-Cohen, 2015). However, recent research has highlighted increasing rates of diagnosis amongst autistic females, older individuals, people without intellectual disability, and people in ethnic minority populations, highlighting how such groups have been underdiagnosed in the past (O'Nions et al., 2023; Roman-Urrestarazu et al., 2021; G. Russell et al., 2021).

Allowing for people who self-identified as autistic to take part within the target population of UK-based autistic adults was an important decision to open the research up to those who may be excluded from clinical diagnosis or prefer not to seek this option. Self-identified autistic adults experience comparable barriers and outcomes as diagnosed individuals (Doherty et al., 2022; McDonald, 2020). In adults where there is no autism screening pathway, self-identification also commonly precedes formal diagnosis (Crane, Hearst et al., 2021).

It is also worth noting that individuals who took part in these studies generally had access to material resources, social support and had a higher than average level of education. People without those privileges may need enhanced support to overcome structural barriers; work alongside the autistic community should include representation of those who remain marginalised, for example through working with leaders of community-based peer support to identify underserved groups, and paying participants for their involvement in research.

The context of the Covid-19 pandemic also posed problems for sampling. There was less access to samples in clinical or supported living settings due to Covid regulations to protect vulnerable groups. We established that online methods would be the most feasible and stable approach for obtaining a sample in the context of uncertainty about how protective measures against Covid-19 would change over time. While these methods can offer advantages for reaching under-researched populations, in qualitative research they can be more likely to target individuals with more self-directed and fluent communication styles (Wilkerson et al., 2014). The use of the Autistica mailing list may have introduced bias by targeting those with a pre-existing interest in autism research as well as those more digitally equipped due to this being an email-based mechanism of contact only; outreach via community groups attempted to reduce some of this bias. However, as community engagement could primarily only be carried out online at this time, this may have failed to reach those who are digitally excluded. Given that peer supporters in the study reported some loss of engagement during times when



community groups were only held remotely, it may be that those with fewer material resources or lower digital literacy were unable to take part in these studies. Additionally, gender biases have been shown to affect responses to online participation methods (W. G. Smith, 2008), which may have contributed to having a sample with a gender profile that was unrepresentative of diagnosed autistic adults more generally.

Populations may also have experienced survey fatigue as this was the main method researchers used to access participants during the pandemic, leading to a survey sample smaller than anticipated which limited the ability to carry out some group comparisons, such as investigating the intersection of autism with minority ethnic backgrounds. Opportunities to identify autistic users of social prescribing services and to consult with communities on research design were also limited by the Covid measures and the time constraints posed by the urgency of reshaping the research to respond to this change.

This also limited the scope to consider including or adapting methods to be more accessible for autistic people with various co-occurring conditions or profiles that may impact communication; using modified methods without suitable validity testing could erode methodological rigour, while using less accessible methods could compromise ethical practice by subjecting participants with high support needs to a difficult and lengthy research process that could cause distress. However, accessibility was prioritised as far as possible in the selection and design of online methods, such as providing text-based methods of communication, using the alt-text option on online images for those using screen readers, and providing downloadable copies of study materials, easy-read explainers and interview questions in advance to facilitate communication and reduce uncertainty that can contribute to anxiety.

The Covid-19 pandemic also presented opportunities to consider how this broad context impacted population wellbeing and service management. Findings highlighted how intersectional inequalities, such as education and employment levels, interacted with the changes to services, with results suggesting those with lower attainment levels were impacted by changes to communication methods during Covid. Findings also showed how some changes that were perceived positively by autistic people, such as quieter clinical environments, could be retained for maximising accessibility.

Additionally, the move to more online interaction presented new opportunities for participant recruitment and dissemination by enabling engagement with different stakeholder groups based across the UK, including groups of autistic adults. The discussions arising within these interactions aided the reflexive process around this research by reaching people who provided alternative perspectives or commented on aspects of the research, as well as on their perception of my position as the researcher: for example, that it was a relief to know the research was being undertaken by someone who was “in the club” who understood the importance of the topic and the perspectives of participants, and was not going to treat participants like “zoo exhibits”, which may have established a sense of trust for the group and facilitated engagement.

Conversely, there were reduced opportunities for group-based reflections with academic peers as well as training opportunities, but I sought out these opportunities online as far as possible. I was able to join new academic peer groups, such as Reason, a group for neurodivergent academics, and an intersectional neurodiversity and disability reading group, both based online.

In the qualitative components of the study ([Chapters 5-7](#)), which presented opportunities to receive real time feedback from participants, some commented positively on the relevance of

the questions to their own experience as a novel feature of this research and on the accessible communication methods used; this may be another strength of approaching the research from a position of lived experience. Research has shown communication by same-neurotype dyads is more effective than those of differing neurotypes, through which miscommunications more readily occur due to difficulties with perspective-taking affecting both participants (Crompton, Ropar et al., 2020; Milton, 2012), which may have facilitated communication and rapport.

I also had a clear idea of the adjustments that would be needed to increase accessibility of the research methods to maximise participant uptake and retention. Furthermore, I also felt that my lived experience helped make links between different areas of research literature, such as how social prescribing research findings relate to engaging with health services as an autistic person.

On the other hand, a concern which I reflected on was how my methodology remained limited by only allowing people to express themselves through words and not through other means, which may not be fully accessible in a population with known communication barriers and limit the ideas explored. Additionally, the findings were based on my interpretation of their words and could be biased by holding privileges such as educational attainment, but I took care to challenge my own biases. For example, frequent findings of surveys (e.g. Keating et al., 2023; Kenny et al., 2016; Lei et al., 2021), conversations within autistic community spaces and neurodiversity-aligned academic discourse (Bottema-Beutel et al., 2020), reflect both a preference and a sound rationale for avoiding language that centres the medical model and in aiming to centre the neurodiversity paradigm I prioritised and justified this to reviewers of articles derived from the present research submitted for peer-reviewed publication throughout the development of this research. However, over time, I recognised how many voices are marginalised from these discourses who may only have

access to medical model terminology and lack the opportunities to critically examine impacts of language choices, favouring other priorities out of necessity. In this way, it was important not to challenge viewpoints I disagreed with that may stem from differing life experience, but to consider how to incorporate them to expand my understandings. I also drew from the wide ranging expertise of my supervisory team to integrate analysis into existing theoretical perspectives and consider nuanced viewpoints where findings posed complexity.

I recognised that there was sometimes a need to ask participants to elaborate on constructs that would be familiar to myself and others in certain community spaces but may be less familiar to some readers such as medical professionals in order to convey these constructs in ways that would be helpful to policymakers. On reflection, I felt I would amend the interview structure if I was to repeat the study, positioning questions on attitudes towards social prescribing earlier in the interview schedule; although I aimed to explore these in the context of individuals' experiences of wellbeing and access to services, the position of this section in the latter stages of interviews may have been impacted by participants' fatigue and left underexplored. This resulted in data which I experienced as nebulous and which required several iterations of analysis to reach a set of coherent themes. In future, splitting the interview into stages may avoid these limitations and enable the chance to develop follow-up questions on topics mentioned in the earlier stage, resulting in richer data and analysis.

### **Recommendations for Future Research**

The scope of the research was limited by the context of prevailing uncertainty around Covid-19 restrictions and the need to quickly adapt research questions and methodologies. This led to a study based on critically reflecting on spoken or written accounts of first-hand experiences, but lacked the opportunity to undertake an intervention study or service evaluation. There is a need for more applied analysis of autistic adults' experiences and

outcomes of using social prescribing pathways now that group activities have largely resumed. It will be important that such research is coproduced with diverse groups of autistic adults to ensure outcomes are attentive to neurodiversity, intersectionality and the social context underlying individual outcomes. Further analysis on changes to community-based support since the outbreak of Covid-19, such as online support groups targeted at autistic adults, may also be beneficial now that this option has become increasingly available and the suggested there may be benefits of signposting to these opportunities within social prescribing models.

It would be beneficial for the myriad research studying link workers' experiences to attend to variables that would elicit their understandings about neurodiversity and how this affects perceptions of complexity. This will help establish how well social prescribing is aligned with the neurodiversity model; alignment with this model to assist with building a positive identity around autism focused on strengths and capabilities may be associated with reduced self-stigma and better wellbeing outcomes for autistic people (Corden et al., 2021; Ferenc et al., 2023; Gillespie-Lynch et al., 2017). This could be analysed within the candidacy framework which would extend the application of this framework to the social prescribing setting; an ethnographic study using participatory approaches may be a useful and interesting way to carry out this research that would continue to attend to critical realist perspectives. To apply the findings of this research to practice, it would also be useful to design and test a training and support package around neurodiversity for providers of social prescribing. No standardised link worker training package currently exists, so there is an opportunity to build this priority into future development by NHS England and the National Association of Link Workers.

Another practical recommendation would be to consider providing social prescribing as part of the pre-/post-diagnostic pathway for autistic adults, and to evaluate services offering this

option. This would offer access to a tailored, wraparound support option for supporting the wellbeing of people on lengthy waiting lists for assessment or those who have received a diagnosis but have the common experience of a lack of onward signposting. Studies should evaluate how the impact on wellbeing when social prescribing is implemented at these stages.

Research should also prioritise assessment of the suitability of social prescribing for autistic adults who have learning disabilities and other co-occurring conditions that contribute to higher levels of support needs around communication or personal care, as this may require a greater level of adaptation and tailoring, possibly within a specialist programme designed for this group. It will also be important to develop research methods to open this area of research up to a wider sample, including adapting survey measures for people with higher support needs and using alternative qualitative methods such as PhotoVoice (e.g. Lam et al., 2020), to explore experiences and coproduce research and services.

## **Conclusions**

There is a lack of accessible services designed to meet the unmet health and wellbeing needs of autistic adults in a person-centred and strengths-based way, despite increasing understanding of the potential benefits of these approaches. The personalised approach of social prescribing may be well-placed to enable autistic adults to identify and build on existing capabilities and assist with navigating both internal and external barriers to accessing support for wellbeing. Analysis of findings suggested success will rely on appropriate training of providers and assets-based collaboration with the autistic community, leading to a tailored and accessible approach that understands and affirms neurodiversity. This social prescribing model may be a helpful tool in managing wellbeing during transition periods, such as while waiting for autism assessment, coming to terms with a diagnosis or looking for a supportive community to connect with. The implementation of this would be supported by

improving the provision of existing services (e.g. mental health and social care) and increasing accessibility of primary care pathways more generally. Organisations could explore ways to build social prescribing into existing autism service pathways or introduce new components for autistic adults within the expanding NHS social prescribing pathway, especially those with higher levels of complexity; more research will be needed to determine the likely success of this approach.

## Bibliography

- Adams, J., Hillier-Brown, F. C., Moore, H. J., Lake, A. A., Araujo-Soares, V., White, M., & Summerbell, C. (2016). Searching and synthesising 'grey literature' and 'grey information' in public health: critical reflections on three case studies. *Systematic Reviews*, 5(1), 164. doi:10.1186/s13643-016-0337-y
- Ademolu, E. (2023). Birds of a feather (don't always) flock together: Critical reflexivity of 'Outsiderness' as an 'Insider' doing qualitative research with one's 'Own People'. *Qualitative Research*, 14687941221149596. <https://doi.org/10.1177/14687941221149596>
- Ader, D. N. (2007). Developing the Patient-Reported Outcomes Measurement Information System (PROMIS). *Medical Care*, 45(5), S1. <https://doi.org/10.1097/01.mlr.0000260537.45076.74>
- Akobirshoev, I., Mitra, M., Dembo, R., & Lauer, E. (2020). In-hospital mortality among adults with autism spectrum disorder in the United States: A retrospective analysis of US hospital discharge data. *Autism*, 24(1), 177-189. <https://doi.org/10.1177/1362361319855795>
- Alderwick, H. A. J., Gottlieb, L. M., Fichtenberg, C. M., & Adler, N. E. (2018). Social Prescribing in the U.S. and England: Emerging Interventions to Address Patients' Social Needs. *American Journal of Preventive Medicine*, 54(5), 715-718. <https://doi.org/10.1016/j.amepre.2018.01.039>
- Allison, C., Auyeung, B., & Baron-Cohen, S. (2012). Toward Brief "Red Flags" for Autism Screening: The Short Autism Spectrum Quotient and the Short Quantitative Checklist in 1,000 Cases and 3,000 Controls. *Journal of the American Academy of Child & Adolescent Psychiatry*, 51(2), 202-212. <https://doi.org/10.1016/j.jaac.2011.11.003>
- Allwood, L., & Bell, A. (2020). Covid-19: understanding inequalities in mental health during the pandemic. <https://www.centreformentalhealth.org.uk/covid-19-inequalities-mental-health>
- Alvares, G. A., Bebbington, K., Cleary, D., Evans, K., Glasson, E. J., Maybery, M. T., Pillar, S., Uljarević, M., Varcin, K., Wray, J., & Whitehouse, A. J. O. (2019). The misnomer of 'high functioning autism': Intelligence is an imprecise predictor of functional abilities at diagnosis. *Autism*, 24(1), 221-232. <https://doi.org/10.1177/1362361319852831>
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders (DSM-5®)*. (5th ed.). American Psychiatric Publishing. <https://doi.org/10.1176/appi.books.9780890425596>
- American Psychological Association. (2020). Disability. APA Style. <https://apastyle.apa.org/style-grammar-guidelines/bias-free-language/disability>
- Anderson, A., Moore, D. W., Rausa, V. C., Finkelstein, S., Pearl, S., & Stevenson, M. (2017). A Systematic Review of Interventions for Adults with Autism Spectrum Disorder to Promote Employment. *Review Journal of Autism and Developmental Disorders*, 4(1), 26-38. <https://doi.org/10.1007/s40489-016-0094-9>
- Annandale, E., Harvey, J., Cavers, D., & Dixon-Woods, M. (2007). Gender and access to healthcare in the UK: a critical interpretive synthesis of the literature. *Evidence & Policy: A Journal of Research, Debate and Practice*, 3(4), 463-486. <https://doi.org/10.1332/174426407782516538>



- Archibald, M. M., Ambagtsheer, R. C., Casey, M. G., & Lawless, M. (2019). Using Zoom Videoconferencing for Qualitative Data Collection: Perceptions and Experiences of Researchers and Participants. *International Journal of Qualitative Methods*, 18, 1609406919874596. <https://doi.org/10.1177/1609406919874596>
- Aromataris, E., Fernandez, R., Godfrey, C. M., Holly, C., Khalil, H., & Tungpunkom, P. (2015). Summarizing systematic reviews: Methodological development, conduct and reporting of an umbrella review approach. *International Journal of Evidence-Based Healthcare*, 13(3), 132. <https://doi.org/10.1097/XEB.0000000000000055>
- Aromataris, E., Fernandez, R., Godfrey, C., Holly, C., Khalil, H., & Tungpunkom, P. (2017). Chapter 10: Umbrella Reviews. In: Aromataris E. & Munn Z (Editors). *Joanna Briggs Institute Reviewer's Manual*. The Joanna Briggs Institute. Retrieved from <https://reviewersmanual.joannabriggs.org/>
- Ashman, R., Banks, K., Philip, R. C. M., Walley, R., & Stanfield, A. C. (2017). A pilot randomised controlled trial of a group based social skills intervention for adults with autism spectrum disorder. *Research in Autism Spectrum Disorders*, 43-44, 67-75. doi:10.1016/j.rasd.2017.08.001
- Atherton, G., Edisbury, E., Piovesan, A., & Cross, L. (2022). Autism Through the Ages: A Mixed Methods Approach to Understanding How Age and Age of Diagnosis Affect Quality of Life. *Journal of Autism and Developmental Disorders*, 52(8), 3639-3654. <https://doi.org/10.1007/s10803-021-05235-x>
- Atkinson, S., Bagnall, A.-M., Corcoran, R., South, J., Curtis, S., di Martino, S., & Pilkington, G. (2017). What is Community Wellbeing? Conceptual Review. [https://whatworkswellbeing.org/wp-content/uploads/2020/01/Conceptual-review-of-community-wellbeing-Sept-2017\\_0130230900.pdf](https://whatworkswellbeing.org/wp-content/uploads/2020/01/Conceptual-review-of-community-wellbeing-Sept-2017_0130230900.pdf)
- Autistica. (2023). *Autistica Health Checks Plan*. <https://www.autistica.org.uk/downloads/files/Health-Checks-Plan.pdf>
- Bagatell, Nancy. (2010). "From Cure to Community: Transforming Notions of Autism." *Ethos* 38 (1):33-55. doi: 10.1111/j.1548-1352.2009.01080.x.
- Bagnall, R., Russell, A., Brosnan, M., & Maras, K. (2021). Deceptive behaviour in autism: A scoping review. *Autism*, 26(2), 293-307. <https://doi.org/10.1177/13623613211057974>
- Bal, V. H., Wilkinson, E., White, L. C., Law, J. K., Feliciano, P., & Chung, W. K. (2021). Early Pandemic Experiences of Autistic Adults: Predictors of Psychological Distress. *Autism Research*, 14(6), 1209-1219. <https://doi.org/https://doi.org/10.1002/aur.2480>
- Balderaz, L. (2020). Social Skills Interventions for Adults with ASD: A Review of the Literature. *Journal of Psychosocial Rehabilitation and Mental Health*, 7(1), 45–54. <https://doi.org/10.1007/s40737-020-00158-9>
- Barber, C. (2017). Meeting the healthcare needs of adults on the autism spectrum. *British Journal of Nursing*, 26(7), 420–425. <https://doi.org/10.12968/bjon.2017.26.7.420>
- Barnes, D. E. (2020). Social prescribing. *InnovAiT: Education and inspiration for general practice*, 13(11), 638-641. <https://doi.org/10.1177/1755738020950340>
- Baska, A., Kurpas, D., Kenkre, J., Vidal-Alaball, J., Petrazzuoli, F., Dolan, M., Śliż, D., & Robins, J. (2021). Social Prescribing and Lifestyle Medicine—A Remedy to Chronic Health

- Problems? *International Journal of Environmental Research and Public Health*, 18(19), 10096. <https://doi.org/10.3390/ijerph181910096>
- Baxter, L., & Fancourt, D. (2020). What are the barriers to, and enablers of, working with people with lived experience of mental illness amongst community and voluntary sector organisations? A qualitative study. *PLOS ONE*, 15(7), e0235334. <https://doi.org/10.1371/journal.pone.0235334>
- Bell, S. L., & Foley, R. (2021). A(nother) time for nature? Situating non-human nature experiences within the emotional transitions of sight loss. *Social Science & Medicine*, 276, 113867. <https://doi.org/10.1016/j.socscimed.2021.113867>
- Benevides, T. W., Shore, S. M., Andresen, M.-L., Caplan, R., Cook, B., Gassner, D. L., Erves, J. M., Hazlewood, T. M., King, M. C., Morgan, L., Murphy, L. E., Purkis, Y., Rankowski, B., Rutledge, S. M., Welch, S. P., & Wittig, K. (2020). Interventions to address health outcomes among autistic adults: A systematic review. *Autism*, 24(6), 1345-1359. <https://doi.org/10.1177/1362361320913664>
- Benevides, T. W., Shore, S. M., Palmer, K., Duncan, P., Plank, A., Andresen, M.-L., Caplan, R., Cook, B., Gassner, D., Hector, B. L., Morgan, L., Nebeker, L., Purkis, Y., Rankowski, B., Wittig, K., & Coughlin, S. S. (2020). Listening to the autistic voice: Mental health priorities to guide research and practice in autism from a stakeholder-driven project. *Autism*, 24(4), 822-833. <https://doi.org/10.1177/1362361320908410>
- Benford, P., & Standen, P. (2009). The internet: a comfortable communication medium for people with Asperger syndrome (AS) and high functioning autism (HFA)? *Journal of Assistive Technologies*, 3(2), 44-53. <https://doi.org/10.1108/17549450200900015>
- Bertotti, M., Frostick, C., Hutt, P., Sohanpal, R., & Carnes, D. (2018). A realist evaluation of social prescribing: an exploration into the context and mechanisms underpinning a pathway linking primary care with the voluntary sector. *Primary Health Care Research & Development*, 19(3), 232-245. <https://doi.org/10.1017/S1463423617000706>
- Bhatti, S., Rayner, J., Pinto, A. D., Mulligan, K., & Cole, D. C. (2021). Using Self-Determination theory to understand the social prescribing process: a qualitative study. *BJGP Open*, 5(2). <https://doi.org/10.3399/BJGPO.2020.0153>
- Bickerdike, L., Booth, A., Wilson, P. M., Farley, K., & Wright, K. (2017). Social prescribing: less rhetoric and more reality. A systematic review of the evidence. *BMJ Open*, 7(4), e013384. <https://doi.org/10.1136/bmjopen-2016-013384>
- Billstedt, E., Gillberg, I. C., & Gillberg, C. (2011). Aspects of quality of life in adults diagnosed with autism in childhood: A population-based study. *Autism*, 15(1), 7–20. <https://doi.org/10.1177/1362361309346066>
- Bishop-Fitzpatrick, L., & Kind, A. J. H. (2017). A Scoping Review of Health Disparities in Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, 47(11), 3380-3391. <https://doi.org/10.1007/s10803-017-3251-9>
- Blagrave, A. J., Colombo-Dougovito, A. M., & Healy, S. (2021). “Just Invite Us”: Autistic Adults' Recommendations for Developing More Accessible Physical Activity Opportunities. *Autism in Adulthood*. <https://doi.org/10.1089/aut.2020.0055>
- Blodgett, J., Kaushal, A., & Harkness, F. (2022). Rapid Review of Wellbeing Evaluation Research Using the Warwick-Edinburgh Mental Well-Being Scales (WEMWBS) What Works Centre

for Wellbeing. [https://whatworkswellbeing.org/wp-content/uploads/2022/05/WEMWBS\\_Rapid\\_Review\\_final.pdf](https://whatworkswellbeing.org/wp-content/uploads/2022/05/WEMWBS_Rapid_Review_final.pdf)

- Botha, M. (2021a). Academic, Activist, or Advocate? Angry, Entangled, and Emerging: A Critical Reflection on Autism Knowledge Production. *Frontiers in Psychology*, 12, 4196. <https://doi.org/10.3389/fpsyg.2021.727542>
- Botha, M. (2021b). Critical realism, community psychology, and the curious case of autism: A philosophy and practice of science with social justice in mind. *J Community Psychol*, n/a(n/a). <https://doi.org/10.1002/jcop.22764>
- Botha, M., Dibb, B., & Frost, D. M. (2020). "Autism is me": an investigation of how autistic individuals make sense of autism and stigma. *Disability & Society*, 37(3), 427-453. <https://doi.org/10.1080/09687599.2020.1822782>
- Botha, M., & Frost, D. M. (2018). Extending the Minority Stress Model to Understand Mental Health Problems Experienced by the Autistic Population. *Society and Mental Health*, 10(1). <https://doi.org/10.1177/2156869318804297>
- Botha, M., Hanlon, J., & Williams, G. L. (2023). Does Language Matter? Identity-First Versus Person-First Language Use in Autism Research: A Response to Vivanti. *Journal of Autism and Developmental Disorders*, 53(2), 870-878. <https://doi.org/10.1007/s10803-020-04858-w>
- Bottema-Beutel, K., Kapp, S. K., Lester, J. N., Sasson, N. J., & Hand, B. N. (2020). Avoiding Ableist Language: Suggestions for Autism Researchers. *Autism in Adulthood*. <https://doi.org/10.1089/aut.2020.0014>
- Boyce, M., Bungay, H., Munn-Giddings, C., & Wilson, C. (2018). The impact of the arts in healthcare on patients and service users: A critical review. *Health & Social Care in the Community*, 26(4), 458-473. <https://doi.org/10.1111/hsc.12502>
- Bradley, G., & Scott, J. (2023). Social Prescribing Nomenclature, Occupational Therapy and the Theory of Institutional Work: Creating, Maintaining and Disrupting Medical Dominance. *Occup Ther Health Care*, 37(1), 40-53. <https://doi.org/10.1080/07380577.2021.1926046>
- Bradley, L., Shaw, R., Baron-Cohen, S., & Cassidy, S. (2021). Autistic Adults' Experiences of Camouflaging and Its Perceived Impact on Mental Health. *Autism in Adulthood*, 3(4), 320-329. <https://doi.org/10.1089/aut.2020.0071>
- Brandling, J., & House, W. (2009). Social prescribing in general practice: adding meaning to medicine. *British Journal of General Practice*, 59(563), 454-456. <https://doi.org/10.3399/bjgp09X421085>
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77-101. <https://doi.org/10.1191/1478088706qp063oa>
- Braun, V., & Clarke, V. (2022). *Thematic Analysis: A Practical Guide*. Sage Publications Ltd.
- Brede, J., Cage, E., Trott, J., Palmer, L., Smith, A., Serpell, L., Mandy, W., & Russell, A. (2022). "We Have to Try to Find a Way, a Clinical Bridge" - autistic adults' experience of accessing and receiving support for mental health difficulties: A systematic review and thematic meta-synthesis. *Clinical Psychology Review*, 93, 102131. <https://doi.org/10.1016/j.cpr.2022.102131>

- Brown, H. M., Stahmer, A. C., Dwyer, P., & Rivera, S. (2021). Changing the story: How diagnosticians can support a neurodiversity perspective from the start. *Autism, 25*(5), 1171-1174. <https://doi.org/10.1177/13623613211001012>
- Brown, L. Identity-First Language. Autistic Self Advocacy Network. <https://autisticadvocacy.org/about-asan/identity-first-language/>
- Brown, R. C. H., Mahtani, K., Turk, A., & Tierney, S. (2021). Social Prescribing in National Health Service Primary Care: What Are the Ethical Considerations? *The Milbank Quarterly, 99*(3), 610-628. <https://doi.org/10.1111/1468-0009.12516>
- Brownlow, C., & O'Dell, L. (2006). Constructing an Autistic Identity: AS Voices Online. *Mental Retardation, 44*(5), 315-321. [https://doi.org/10.1352/0047-6765\(2006\)44\[315:CAAIIV\]2.0.CO;2](https://doi.org/10.1352/0047-6765(2006)44[315:CAAIIV]2.0.CO;2)
- Brugha, T. S., McManus, S., Bankart, J., Scott, F., Purdon, S., Smith, J., Bebbington, P., Jenkins, R., & Meltzer, H. (2011). Epidemiology of Autism Spectrum Disorders in Adults in the Community in England. *Archives of General Psychiatry, 68*(5), 459-465. <https://doi.org/10.1001/archgenpsychiatry.2011.38>
- Brugha, T., McManus, S., Meltzer, H., Smith, J., Scott, F. J., Purdon, S., Harris, J., & Bankart, J. (2009). Autism Spectrum Disorders in adults living in households throughout England Report from the Adult Psychiatric Morbidity Survey 2007. [http://doc.ukdataservice.ac.uk/doc/6379/mrdoc/pdf/6379\\_apms\\_2007\\_autism\\_report.pdf](http://doc.ukdataservice.ac.uk/doc/6379/mrdoc/pdf/6379_apms_2007_autism_report.pdf)
- Buckle, K. L., Leadbitter, K., Poliakoff, E., & Gowen, E. (2021). “No Way Out Except From External Intervention”: First-Hand Accounts of Autistic Inertia. *Frontiers in Psychology, 12*. <https://doi.org/10.3389/fpsyg.2021.631596>
- Buckley, C. (2017). Autism in adults. *InnovAiT, 10*(6), 319-326. <https://doi.org/10.1177/1755738016683410>
- Buescher, A. V. S., Ciday, Z., Knapp, M., & Mandell, D. S. (2014). Costs of Autism Spectrum Disorders in the United Kingdom and the United States. *JAMA Pediatrics, 168*(8), 721-728. <https://doi.org/10.1001/jamapediatrics.2014.210>
- Bundy, R., Mandy, W., Crane, L., Belcher, H., Bourne, L., Brede, J., Hull, L., Brinkert, J., & Cook, J. (2022). The impact of early stages of COVID-19 on the mental health of autistic adults in the United Kingdom: A longitudinal mixed-methods study. *Autism, 26*(7), 1765-1782. <https://doi.org/10.1177/13623613211065543>
- Burgess, A. F., & Gutstein, S. E. (2007). Quality of Life for People with Autism: Raising the Standard for Evaluating Successful Outcomes. *Child and Adolescent Mental Health, 12*(2), 80-86. <https://doi.org/10.1111/j.1475-3588.2006.00432.x>
- Cage, E., & Troxell-Whitman, Z. (2019). Understanding the Reasons, Contexts and Costs of Camouflaging for Autistic Adults. *Journal of Autism and Developmental Disorders, 49*(5), 1899-1911. <https://doi.org/10.1007/s10803-018-03878-x>
- Calderón-Larrañaga, S., Greenhalgh, T., Finer, S., & Clinch, M. (2022). What does the literature mean by social prescribing? A critical review using discourse analysis. *Sociology of Health & Illness, 44*(4-5), 848-868. <https://doi.org/10.1111/1467-9566.13468>
- Calderon-Larranaga, S., Milner, Y., Clinch, M., Greenhalgh, T., & Finer, S. (2021). Tensions and opportunities in social prescribing. Developing a framework to facilitate its implementation

- and evaluation in primary care: a realist review. *BJGP Open*, 5(3).  
<https://doi.org/10.3399/BJGPO.2021.0017>
- Cameron, L. A., Borland, R. L., Tonge, B. J., & Gray, K. M. (2022). Community participation in adults with autism: A systematic review. *Journal of Applied Research in Intellectual Disabilities*, 35(2). <https://doi.org/10.1111/jar.12970>
- Cartwright, L., Burns, L., Akinyemi, O., Carder-Gilbert, H., Tierney, S., Elston, J., & Chatterjee, H. (2022). Who is and isn't being referred to social prescribing? <https://socialprescribingacademy.org.uk/media/jaibqf4q/evidence-review-who-is-accessing-social-prescribing.pdf>
- Cascio, M. A., Weiss, J. A., & Racine, E. (2020). Making Autism Research Inclusive by Attending to Intersectionality: a Review of the Research Ethics Literature. *Review Journal of Autism and Developmental Disorders*, 8(1), 22-36. <https://doi.org/10.1007/s40489-020-00204-z>
- Cassidy, S., Au-Yeung, S., Robertson, A., Cogger-Ward, H., Richards, G., Allison, C., Bradley, L., Kenny, R., O'Connor, R., Mosse, D., Rodgers, J., & Baron-Cohen, S. (2022). Autism and autistic traits in those who died by suicide in England. *The British Journal of Psychiatry*, 221(5), 683-691. <https://doi.org/10.1192/bjp.2022.21>
- Cassidy, S., Bradley, L., Shaw, R., & Baron-Cohen, S. (2018). Risk markers for suicidality in autistic adults. *Molecular Autism*, 9(1), 42. <https://doi.org/10.1186/s13229-018-0226-4>
- Cassidy, S. A., Nicolaidis, C., Davies, B., Rosa, S. D. R., Eisenman, D., Onaiwu, M. G., Kapp, S. K., Kripke, C. C., Rodgers, J., & Waisman, T. C. (2020). An Expert Discussion on Autism in the COVID-19 Pandemic. *Autism Adulthood*, 2(2), 106-117. <https://doi.org/10.1089/aut.2020.29013.sjc>
- Cawston, P. (2011). Social prescribing in very deprived areas. *British Journal of General Practice*, 61(586), 350-350. <https://doi.org/10.3399/bjgp11X572517>
- Cella, D., Riley, W., Stone, A., Rothrock, N., Reeve, B., Yount, S., Amtmann, D., Bode, R., Buysse, D., Choi, S., Cook, K., DeVellis, R., DeWalt, D., Fries, J. F., Gershon, R., Hahn, E. A., Lai, J.-S., Pilkonis, P., Revicki, D., Rose, M., Weinfurt, K., & Hays, R. (2010). The Patient-Reported Outcomes Measurement Information System (PROMIS) developed and tested its first wave of adult self-reported health outcome item banks: 2005–2008. *Journal of Clinical Epidemiology*, 63(11), 1179-1194. <https://doi.org/10.1016/j.jclinepi.2010.04.011>
- Cervantes, P. E., Matheis, M., Estabillo, J., Seag, D. E. M., Nelson, K. L., Peth-Pierce, R., Hoagwood, K. E., & Horwitz, S. M. (2021). Trends Over a Decade in NIH Funding for Autism Spectrum Disorder Services Research. *Journal of Autism and Developmental Disorders*, 51(8), 2751-2763. <https://doi.org/10.1007/s10803-020-04746-3>
- Chan, D. V., Doran, J. D., & Galobardi, O. D. (2023). Beyond Friendship: The Spectrum of Social Participation of Autistic Adults. *Journal of Autism and Developmental Disorders*, 53(1), 424-437. <https://doi.org/10.1007/s10803-022-05441-1>
- Chapman, R. (2020). The reality of autism: On the metaphysics of disorder and diversity. *Philosophical Psychology*, 33(6), 799-819. <https://doi.org/10.1080/09515089.2020.1751103>
- Chapman, R., & Carel, H. (2022). Neurodiversity, epistemic injustice, and the good human life. *Journal of Social Philosophy*, 53(4), 614-631. <https://doi.org/10.1111/josp.12456>
- Chapman, R., & Veit, W. (2021). "The essence of autism: fact or artefact?". *Mol Psychiatry*, 26(5), 1440-1441. <https://doi.org/10.1038/s41380-020-00959-1>

- Charlton, R. A., Crompton, C. J., Roestorf, A., Torry, C., & The Autistica Physical Health and Ageing Study Group. (2020). Social prescribing for autistic people: A framework for service provision. *AMRC Open Research*, 2, 19. <https://doi.org/10.12688/amrcopenres.12901.1>
- Charlton, R. A., McQuaid, G. A., Bishop, L., Lee, N. R., & Wallace, G. L. (2023). Predictors of sleep quality for autistic people across adulthood. *Autism Research*, 16(4), 757-771. <https://doi.org/10.1002/aur.2891>
- Chatterjee, H. J., Camic, P. M., Lockyer, B., & Thomson, L. J. M. (2018). Non-clinical community interventions: a systematised review of social prescribing schemes. *Arts & Health*, 10(2), 97-123. <https://doi.org/10.1080/17533015.2017.1334002>
- Cheriyian, Chinnu, Sergey Shevchuk-Hill, Ariana Riccio, Jonathan Vincent, Steven K. Kapp, Eilidh Cage, Patrick Dwyer, Bella Kofner, Helen Attwood, and Kristen Gillespie-Lynch. 2021. "Exploring the Career Motivations, Strengths, and Challenges of Autistic and Non-autistic University Students: Insights From a Participatory Study." *Frontiers in Psychology* 12:4455. doi: 10.3389/fpsyg.2021.719827.
- Chevallier, C., Kohls, G., Troiani, V., Brodtkin, E. S., & Schultz, R. T. (2012). The social motivation theory of autism. *Trends in Cognitive Sciences*, 16(4), 231-239. <https://doi.org/10.1016/j.tics.2012.02.007>
- Chinn, D., & Abraham, E. (2016). Using 'candidacy' as a framework for understanding access to mainstream psychological treatment for people with intellectual disabilities and common mental health problems within the English Improving Access to Psychological Therapies service. *Journal of Intellectual Disability Research*, 60(6), 571-582. <https://doi.org/10.1111/jir.12274>
- Christou, E. (2016). A Spectrum of Obstacles: An Inquiry into Access to Healthcare for Autistic People. Retrieved from Westminster Commission on Autism website: [https://westminsterautismcommission.files.wordpress.com/2016/03/ar1011\\_ncg-autism-report-july-2016.pdf](https://westminsterautismcommission.files.wordpress.com/2016/03/ar1011_ncg-autism-report-july-2016.pdf)
- CHS Healthcare. (2023). Autism and ADHD: The damaging waits for assessment. CHS Healthcare. <https://chshealthcare.co.uk/services/mental-health-services/>
- Clatworthy, J., Hinds, J., & M. Camic, P. (2013). Gardening as a mental health intervention: a review. *Mental Health Review Journal*, 18(4), 214-225. <https://doi.org/10.1108/mhrj-02-2013-0007>
- Coburn, A., & Gormally, S. (2020). Defining well-being in community development from the ground up: a case study of participant and practitioner perspectives. *Community Development Journal*, 55(2), 237-257. <https://doi.org/10.1093/cdj/bsy048>
- Cole, A., Jones, D., & Jopling, K. (2020). Rolling Out Social Prescribing: Understanding the experiences of the voluntary, community and social enterprise sector. *National Voices*. [https://www.nationalvoices.org.uk/sites/default/files/public/publications/rolling\\_out\\_social\\_prescribing\\_-\\_september\\_2020\\_final.pdf](https://www.nationalvoices.org.uk/sites/default/files/public/publications/rolling_out_social_prescribing_-_september_2020_final.pdf)
- Colombo-Dougovito, A. M., Blagrove, A. J., & Healy, S. (2021). A grounded theory of adoption and maintenance of physical activity among autistic adults. *Autism*, 25(3), 627-641. <https://doi.org/10.1177/1362361320932444>
- Cooper, C., Lovell, R., Husk, K., Booth, A., & Garside, R. (2018). Supplementary search methods were more effective and offered better value than bibliographic database searching: A case

- study from public health and environmental enhancement. *Research Synthesis Methods*, 9(2), 195-223. doi:10.1002/jrsm.1286
- Cooper, M., Avery, L., Scott, J., Ashley, K., Jordan, C., Errington, L., & Flynn, D. (2022). Effectiveness and active ingredients of social prescribing interventions targeting mental health: a systematic review. *BMJ Open*, 12(7), e060214. <https://doi.org/10.1136/bmjopen-2021-060214>
- Corden, K., Brewer, R., & Cage, E. (2021). Personal Identity After an Autism Diagnosis: Relationships With Self-Esteem, Mental Wellbeing, and Diagnostic Timing. *Frontiers in Psychology*, 12. <https://www.frontiersin.org/article/10.3389/fpsyg.2021.699335>
- Corden, K., Brewer, R., & Cage, E. (2022). A Systematic Review of Healthcare Professionals' Knowledge, Self-Efficacy and Attitudes Towards Working with Autistic People. *Review Journal of Autism and Developmental Disorders*, 9(3), 386-399. <https://doi.org/10.1007/s40489-021-00263-w>
- Costa, A., Sousa, C. J., Seabra, P. R. C., Virgolino, A., Santos, O., Lopes, J., Henriques, A., Nogueira, P., & Alarcão, V. (2021). Effectiveness of Social Prescribing Programs in the Primary Health-Care Context: A Systematic Literature Review. *Sustainability*, 13(5), 2731. <https://doi.org/10.3390/su13052731>
- Crane, L., Batty, R., Adeyinka, H., Goddard, L., Henry, L. A., & Hill, E. L. (2018). Autism Diagnosis in the United Kingdom: Perspectives of Autistic Adults, Parents and Professionals. *Journal of Autism and Developmental Disorders*, 48(11), 3761-3772. <https://doi.org/10.1007/s10803-018-3639-1>
- Crane, L., Goddard, L., & Pring, L. (2009). Sensory processing in adults with autism spectrum disorders. *Autism*, 13(3), 215-228. <https://doi.org/10.1177/1362361309103794>
- Crane, L., Hearst, C., Ashworth, M., Davies, J., & Hill, E. L. (2021). Supporting Newly Identified or Diagnosed Autistic Adults: An Initial Evaluation of an Autistic-Led Programme. *Journal of Autism and Developmental Disorders*, 51(3), 892-905. <https://doi.org/10.1007/s10803-020-04486-4>
- Crane, L., Sesterka, A., & den Houting, J. (2021). Inclusion and Rigor in Qualitative Autism Research: A Response to Van Schalkwyk and Dewinter (2020). *Journal of Autism and Developmental Disorders*, 51(5), 1802-1804. <https://doi.org/10.1007/s10803-020-04634-w>
- Croen, L. A., Zerbo, O., Qian, Y., Massolo, M. L., Rich, S., Sidney, S., & Kripke, C. (2015). The health status of adults on the autism spectrum. *Autism*, 19(7), 814-823. <https://doi.org/10.1177/1362361315577517>
- Crompton, C., Fletcher-Watson, S., Hallett, S., & C. Stanfield, A. (2021). Autistic-Led Post-Diagnostic Peer Support for Adults: A Qualitative Examination of Community Priorities. <https://doi.org/10.6084/m9.figshare.14541210.v1>
- Crompton, C. J., Hallett, S., McAuliffe, C., Stanfield, A. C., & Fletcher-Watson, S. (2022). "A Group of Fellow Travellers Who Understand": Interviews With Autistic People About Post-diagnostic Peer Support in Adulthood. *Frontiers in Psychology*, 13. <https://www.frontiersin.org/article/10.3389/fpsyg.2022.831628>
- Crompton, C. J., Ropar, D., Evans-Williams, C. V. M., Flynn, E. G., & Fletcher-Watson, S. (2020). Autistic peer-to-peer information transfer is highly effective. *Autism*, 24(7), 1704-1712. <https://doi.org/10.1177/1362361320919286>

- Crompton, C. J., Hallett, S., Ropar, D., Flynn, E., & Fletcher-Watson, S. (2020). 'I never realised everybody felt as happy as I do when I am around autistic people': A thematic analysis of autistic adults' relationships with autistic and neurotypical friends and family. *Autism*, 24(6), 1438-1448. <https://doi.org/10.1177/1362361320908976>
- Csikszentmihalyi, M. (1990). *FLOW: The Psychology of Optimal Experience* (Vol. 1990). Harper & Row.
- Czech, H. (2018). Hans Asperger, National Socialism, and “race hygiene” in Nazi-era Vienna. *Molecular Autism*, 9(29). <https://doi.org/https://doi.org/10.1186/s13229-018-0208-6>
- Dalkin, S. M., Greenhalgh, J., Jones, D., Cunningham, B., & Lhussier, M. (2015). What’s in a mechanism? Development of a key concept in realist evaluation. *Implementation Science*, 10(1), 49. <https://doi.org/10.1186/s13012-015-0237-x>
- Davison, E., Hall, A.-M., Anderson, Z., & Parnaby, J. (2019). Connecting communities and healthcare: Making social prescribing work for everyone. [https://www.tnlcommunityfund.org.uk/media/social\\_prescribing\\_connecting\\_communities\\_healthcare.pdf?mtime=20190715141932](https://www.tnlcommunityfund.org.uk/media/social_prescribing_connecting_communities_healthcare.pdf?mtime=20190715141932)
- DaWalt, L. S., Taylor, J. L., Movaghar, A., Hong, J., Kim, B., Brilliant, M., & Mailick, M. R. (2021). Health profiles of adults with autism spectrum disorder: Differences between women and men. *Autism Res*, 14(9), 1896-1904. <https://doi.org/10.1002/aur.2563>
- Dayson, C. (2017). Social prescribing ‘plus’: a model of asset-based collaborative innovation? *People, Place and Policy*, 11(2), 90-104. <https://doi.org/10.3351/ppp.2017.4839587343>
- Dayson, C., Painter, J., & Bennett, E. (2020). Social prescribing for patients of secondary mental health services: emotional, psychological and social well-being outcomes. *Journal of Public Mental Health*, 19(4), 271-279. <https://doi.org/10.1108/jpmh-10-2019-0088>
- DeJesus, B. M., Oliveira, R. C., de Carvalho, F. O., de Jesus Mari, J., Arida, R. M., & Teixeira-Machado, L. (2020). Dance promotes positive benefits for negative symptoms in autism spectrum disorder (ASD): A systematic review. *Complementary Therapies in Medicine*, 49, 102299. <https://doi.org/10.1016/j.ctim.2020.102299>
- Department for Education, & Department of Health and Social Care. (2021). The national strategy for autistic children, young people and adults: 2021 to 2026 [Government Website]. GOV.UK. [https://www.gov.uk/government/publications/national-strategy-for-autistic-children-young-people-and-adults-2021-to-2026](https://www.gov.uk/government/publications/national-strategy-for-autistic-children-young-people-and-adults-2021-to-2026/the-national-strategy-for-autistic-children-young-people-and-adults-2021-to-2026)
- Department of Health & Social Care. (2021). Good for you, good for us, good for everybody: a plan to reduce overprescribing to make patient care better and safer, support the NHS, and reduce carbon emissions. <https://www.gov.uk/government/publications/national-overprescribing-review-report>
- Department of Health & Social Care. (2022). Building the Right Support Action Plan. GOV.UK. <https://www.gov.uk/government/publications/building-the-right-support-for-people-with-a-learning-disability-and-autistic-people/building-the-right-support-action-plan>
- Department of Health & Social Care. (2019). Autism. Health Education England. <https://www.hee.nhs.uk/our-work/autism>
- Department of Health & Social Care, Local Government & Care Partnership Directorate. (2014). Think Autism: Fulfilling and Rewarding Lives, the strategy for adults with autism in



- England: an update. <https://www.gov.uk/government/publications/think-autism-an-update-to-the-government-adult-autism-strategy>
- Department of Health. (2014a). Think Autism: Fulfilling and Rewarding Lives, the strategy for adults with autism in England: An update. Retrieved from HM Government website: <https://www.gov.uk/government/publications/think-autism-an-update-to-the-government-adult-autism-strategy>
- Department of Health. (2014b). Wellbeing: Why it matters to health policy London, UK, Department of Health. [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/277566/Narrative\\_\\_January\\_2014\\_.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/277566/Narrative__January_2014_.pdf)
- Dixon-Woods, M., Cavers, D., Agarwal, S., Annandale, E., Arthur, A., Harvey, J., Hsu, R., Katbamna, S., Olsen, R., Smith, L., Riley, R., & Sutton, A. J. (2006). Conducting a critical interpretive synthesis of the literature on access to healthcare by vulnerable groups. *BMC Medical Research Methodology*, 6(1), 35. <https://doi.org/10.1186/1471-2288-6-35>
- D'Mello, A. M., Frosch, I. R., Li, C. E., Cardinaux, A. L., & Gabrieli, J. D. E. (2022). Exclusion of females in autism research: Empirical evidence for a "leaky" recruitment-to-research pipeline. *Autism Res*, 15(10), 1929-1940. <https://doi.org/10.1002/aur.2795>
- Doherty, M., Haydon, C., & Davidson, I. A. (2021). Recognising autism in healthcare. *British Journal of Hospital Medicine*, 82(12), 1-7. <https://doi.org/10.12968/hmed.2021.0313>
- Doherty, M., O'Sullivan, J. D., & Neilson, S. D. (2020). Barriers to healthcare for autistic adults: Consequences & policy implications. A cross-sectional study. *MedRxiv*, 2020.04.01.20050336. <https://doi.org/10.1101/2020.04.01.20050336>
- Doherty, M., Neilson, S., Carravallah, L., Johnson, M., & Shaw, S. (2022). Barriers to healthcare and self-reported adverse outcomes for autistic adults: a cross-sectional study. *BMJ Open*, 12, 56904. <https://doi.org/10.1136/bmjopen-2021-056904>
- Doyle, N. (2020). Neurodiversity at work: a biopsychosocial model and the impact on working adults. *British Medical Bulletin*, 135(1), 108-125. <https://doi.org/10.1093/bmb/ldaa021>
- Elliott, M., Davies, M., Davies, J., & Wallace, C. (2022). Exploring how and why social prescribing evaluations work: a realist review. *BMJ Open*, 12(4), e057009. <https://doi.org/10.1136/bmjopen-2021-057009>
- Emerson, E., Aitken, Z., Totsika, V., King, T., Stancliffe, R. J., Hatton, C., Llewellyn, G., Hastings, R. P., & Kavanagh, A. (2022). The impact of the COVID pandemic on working age adults with disability: Meta-analysis of evidence from four national surveys. *Health & Social Care in the Community*, 30(6), e4758-e4769. <https://doi.org/10.1111/hsc.13882>
- European Patients Forum. (2016). Defining and Measuring Access to Healthcare: the Patients' Perspective. [https://www.eu-patient.eu/globalassets/policy/access/epf\\_position\\_defining\\_and\\_measuring\\_access\\_010316.pdf](https://www.eu-patient.eu/globalassets/policy/access/epf_position_defining_and_measuring_access_010316.pdf)
- Featherstone, C., Sharpe, R. A., Axford, N., Asthana, S., & Husk, K. (2022). Health and wellbeing outcomes and social prescribing pathways in community-based support for autistic adults: A systematic mapping review of reviews. *Health & Social Care in the Community*, 30(3), e621-e635. <https://doi.org/10.1111/hsc.13635>

- Ferenc, K., Platos, M., Byrka, K., & Krol, M. E. (2023). Looking through rainbow-rimmed glasses: Taking neurodiversity perspective is related to subjective well-being of autistic adults. *Autism*, 27(5), 1348-1361. <https://doi.org/10.1177/13623613221135818>
- Fiene, L., & Brownlow, C. (2015). Investigating interoception and body awareness in adults with and without autism spectrum disorder. *Autism Research*, 8(6), 709-716. <https://doi.org/10.1002/aur.1486>
- Fixsen, A., & Barrett, S. (2022). Challenges and Approaches to Green Social Prescribing During and in the Aftermath of COVID-19: A Qualitative Study. *Frontiers in Psychology*, 13, 861107. <https://doi.org/10.3389/fpsyg.2022.861107>
- Fixsen, A., Seers, H., Polley, M., & Robins, J. (2020). Applying critical systems thinking to social prescribing: a relational model of stakeholder “buy-in”. *BMC Health Services Research*, 20(1), 580. <https://doi.org/10.1186/s12913-020-05443-8>
- Fixsen, D. A., Barrett, D. S., & Shimonovich, M. (2021). Supporting Vulnerable Populations During the Pandemic: Stakeholders’ Experiences and Perceptions of Social Prescribing in Scotland During Covid-19. *Qualitative Health Research*, 10497323211064229. <https://doi.org/10.1177/10497323211064229>
- Forsyth, L., McSorley, M., & Rydzewska, E. (2023). All-cause and cause-specific mortality in people with autism spectrum disorder: A systematic review. *Research in Autism Spectrum Disorders*, 105, 102165. <https://doi.org/10.1016/j.rasd.2023.102165>
- Foster, A., Thompson, J., Holding, E., Ariss, S., Mukuria, C., Jacques, R., Akparido, R., & Haywood, A. (2021). Impact of social prescribing to address loneliness: A mixed methods evaluation of a national social prescribing programme. *Health & Social Care in the Community*, 29(5), 1439-1449. <https://doi.org/10.1111/hsc.13200>
- Gagné, M., & Deci, E. L. (2005). Self-determination theory and work motivation. *Journal of Organizational Behavior*, 26(4), 331-362. <https://doi.org/10.1002/job.322>
- García-Villamizar, D. A., & Dattilo, J. (2010). Effects of a leisure programme on quality of life and stress of individuals with ASD. *Journal of Intellectual Disability Research*, 54(7), 611-619. <https://doi.org/10.1111/j.1365-2788.2010.01289.x>
- Garfinkel, S. N., Tiley, C., O’Keeffe, S., Harrison, N. A., Seth, A. K., & Critchley, H. D. (2016). Discrepancies between dimensions of interoception in autism: Implications for emotion and anxiety. *Biological Psychology*, 114, 117-126. <https://doi.org/10.1016/j.biopsycho.2015.12.003>
- Garg, A., Boynton-Jarrett, R., & Dworkin, P. H. (2016). Avoiding the Unintended Consequences of Screening for Social Determinants of Health. *JAMA*, 316(8), 813-814. <https://doi.org/10.1001/jama.2016.9282>
- Garside, R., Orr, N., Short, R., Lovell, R., Husk, K., McEachan, R., Rashid, R., & Dickie, I. (2020). Therapeutic Nature: Nature-based social prescribing for diagnosed mental health conditions in the UK. Department for Environment, Food and Rural Affairs. <https://randd.defra.gov.uk/ProjectDetails?ProjectId=20263>
- Gernsbacher, M. A. (2017). Editorial Perspective: The use of person-first language in scholarly writing may accentuate stigma. *Journal of child psychology and psychiatry, and allied disciplines*, 58(7), 859-861. <https://doi.org/10.1111/jcpp.12706>

- Gernsbacher, M. A., Dawson, M., & Mottron, L. (2006). Autism: Common, heritable, but not harmful. *The Behavioral and brain sciences*, 29(4), 413-414.  
<https://doi.org/10.1017/S0140525X06319097>
- Ghirardi, L., Brikell, I., Kuja-Halkola, R., Freitag, C. M., Franke, B., Asherson, P., Lichtenstein, P., & Larsson, H. (2018). The familial co-aggregation of ASD and ADHD: a register-based cohort study. *Molecular Psychiatry*, 23(2), 257-262. <https://doi.org/10.1038/mp.2017.17>
- Gibson, K., Pollard, T. M., & Moffatt, S. (2021). Social prescribing and classed inequality: A journey of upward health mobility? *Social Science & Medicine*, 280, 114037.  
<https://doi.org/10.1016/j.socscimed.2021.114037>
- Gillespie-Lynch, K., Kapp, S. K., Brooks, P. J., Pickens, J., & Schwartzman, B. (2017). Whose Expertise Is It? Evidence for Autistic Adults as Critical Autism Experts. *Frontiers in Psychology*, 8. <https://doi.org/10.3389/fpsyg.2017.00438>
- Gillespie-Lynch, K., Kapp, S. K., Shane-Simpson, C., Smith, D. S., & Hutman, T. (2014). Intersections Between the Autism Spectrum and the Internet: Perceived Benefits and Preferred Functions of Computer-Mediated Communication. *Intellectual and Developmental Disabilities*, 52(6), 456-469. <https://doi.org/10.1352/1934-9556-52.6.456>
- Golan, O., & Baron-Cohen, S. (2006). Systemizing empathy: Teaching adults with Asperger syndrome or high-functioning autism to recognize complex emotions using interactive multimedia. *Development and Psychopathology*, 18(2), 591-617.  
 doi:10.1017/S0954579406060305
- Golubinski, V., Wild, E.-M., Winter, V., & Schreyögg, J. (2020). Once is rarely enough: can social prescribing facilitate adherence to non-clinical community and voluntary sector health services? Empirical evidence from Germany. *BMC Public Health*, 20(1), 1827.  
<https://doi.org/10.1186/s12889-020-09927-4>
- Gowen, E., Taylor, R., Bleazard, T., Greenstein, A., Baimbridge, P., & Poole, D. (2019). Guidelines for Conducting Research Studies with the Autism Community | Autism Policy & Practice. *Autism Policy and Practice*, 2(1), 29-45.  
<https://www.openaccessautism.org/index.php/app/article/view/14>
- Gracey, C. D. (2011). ANXIETY AND ASPERGER'S SYNDROME: AN INVESTIGATION INTO THE DELIVERY OF A NOVEL REAL-TIME STRESS MANAGEMENT APPROACH. [Doctoral dissertation, University of Manchester, United Kingdom]. Manchester eScholar Services. Retrieved from  
[https://www.research.manchester.ac.uk/portal/files/54511624/FULL\\_TEXT.PDF](https://www.research.manchester.ac.uk/portal/files/54511624/FULL_TEXT.PDF)
- Gradinger, F., Elston, J., Asthana, S., Myers, C., Wroe, S., & Byng, R. (2020). Integrating the voluntary sector in personalised care: mixed methods study of the outcomes from wellbeing co-ordination for adults with complex needs. *Journal of Integrated Care*, 28(4), 405-418.  
<https://doi.org/10.1108/jica-02-2020-0010>
- Graham-Clarke, E., Rushton, A., Noblet, T., & Marriott, J. (2018). Facilitators and barriers to non-medical prescribing – A systematic review and thematic synthesis. *PLOS ONE*, 13(4), e0196471. <https://doi.org/10.1371/journal.pone.0196471>
- Grant, A., & Kara, H. (2021). Considering the Autistic advantage in qualitative research: the strengths of Autistic researchers. *Contemporary Social Science*, 0(0), 1-15.  
<https://doi.org/10.1080/21582041.2021.1998589>

- Grant, C., Goodenough, T., Harvey, I., & Hine, C. (2000). A randomised controlled trial and economic evaluation of a referrals facilitator between primary care and the voluntary sector. *BMJ*, 320(7232), 419-423. <https://doi.org/10.1136/bmj.320.7232.419>
- Griffith, G. M., Totsika, V., Nash, S., & Hastings, R. P. (2012). 'I just don't fit anywhere': support experiences and future support needs of individuals with Asperger syndrome in middle adulthood. *Autism*, 16(5), 532-546. <https://doi.org/10.1177/1362361311405223>
- Grove, R., Hoekstra, R. A., Wierda, M., & Begeer, S. (2018). Special interests and subjective wellbeing in autistic adults. *Autism Res*, 11(5), 766-775. <https://doi.org/10.1002/aur.1931>
- Grove, R., Roth, I., & Hoekstra, R. A. (2016). The motivation for special interests in individuals with autism and controls: Development and validation of the special interest motivation scale. *Autism Research*, 9(6), 677-688. <https://doi.org/10.1002/aur.1560>
- Guldberg, K., Wallace, S., Bradley, R., Perepa, P., Ellis, L., & MacLeod, A. (2021). Investigation of the causes and implications of exclusion for autistic children and young people. University of Birmingham. [http://pure-oai.bham.ac.uk/ws/portalfiles/portal/156385005/exclusion\\_for\\_autistic\\_children\\_and\\_young\\_people.pdf](http://pure-oai.bham.ac.uk/ws/portalfiles/portal/156385005/exclusion_for_autistic_children_and_young_people.pdf)
- Hall, J. P., Batza, K., Streed, C. G., Jr., Boyd, B. A., & Kurth, N. K. (2020). Health Disparities Among Sexual and Gender Minorities with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, 50(8), 3071-3077. <https://doi.org/10.1007/s10803-020-04399-2>
- Hallett, S., & Crompton, C. J. (2018). Too complicated to treat? Autistic people seeking mental health support in Scotland. *Autistic Mutual Aid Society Edinburgh*. <https://amase.org.uk/resources/mhreport/>
- Hand, B. N., Angell, A. M., Harris, L., & Carpenter, L. A. (2020). Prevalence of physical and mental health conditions in Medicare-enrolled, autistic older adults. *Autism*, 24(3), 755-764. <https://doi.org/10.1177/1362361319890793>
- Hanlon, P., Gray, C. M., Chng, N. R., & Mercer, S. W. (2021). Does Self-Determination Theory help explain the impact of social prescribing? A qualitative analysis of patients' experiences of the Glasgow 'Deep-End' Community Links Worker Intervention. *Chronic Illn*, 17(3), 173-188. <https://doi.org/10.1177/1742395319845427>
- Hassan, S. M., Giebel, C., Morasae, E. K., Rotheram, C., Mathieson, V., Ward, D., Reynolds, V., Price, A., Bristow, K., & Kullu, C. (2020). Social prescribing for people with mental health needs living in disadvantaged communities: the Life Rooms model. *BMC Health Services Research*, 20(1), 19. <https://doi.org/10.1186/s12913-019-4882-7>
- Hazeldine, E., Gowan, G., Wigglesworth, R., Pollard, J., Asthana, S., & Husk, K. (2021). Link worker perspectives of early implementation of social prescribing: A 'Researcher-in-Residence' study. *Health & Social Care in the Community*, 29(6), 1844-1851. <https://doi.org/https://doi.org/10.1111/hsc.13295>
- Health Education England. (2022). The Oliver McGowan Mandatory Training on Learning Disability and Autism. Health Education England. <https://www.hee.nhs.uk/our-work/learning-disability/current-projects/oliver-mcgowan-mandatory-training-learning-disability-autism>

- Heasman, B., Elise, F., Ryan, M., Fletcher-Watson, S., Hughes, C., Davies, B., Kenny, L., & Jones, C. (2020). Can we look forward to a different world after Coronavirus? *Autistica*. <https://www.autistica.org.uk/news/world-after-coronavirus>
- Hedley, D., Hayward, S. M., Denney, K., Uljarevic, M., Bury, S., Sahin, E., Brown, C. M., Clapperton, A., Dissanayake, C., Robinson, J., Trollor, J., & Stokes, M. A. (2021). The association between COVID-19, personal wellbeing, depression, and suicide risk factors in Australian autistic adults. *Autism Res*, 14(12), 2663-2676. <https://doi.org/10.1002/aur.2614>
- Hedley, D., Uljarević, M., Wilmot, M., Richdale, A., & Dissanayake, C. (2017). Brief Report: Social Support, Depression and Suicidal Ideation in Adults with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, 47(11), 3669-3677. <https://doi.org/10.1007/s10803-017-3274-2>
- Higson-Sweeney, N., Mortlock, A., & Neville, F. (2022). A TALE OF TWO HATS: TRANSFORMING FROM THE RESEARCHED TO THE RESEARCHER. *The Open Review*, 7(1), 47-53. <https://doi.org/10.47967/TOR2022TRANS.VOL7.08>
- Hirvikoski, T., Mittendorfer-Rutz, E., Boman, M., Larsson, H., Lichtenstein, P., & Bölte, S. (2016). Premature mortality in autism spectrum disorder. *The British Journal of Psychiatry*, 208(3), 232-238. <https://doi.org/10.1192/bjp.bp.114.160192>
- Hogg-Graham, R., Edwards, K., Ely, T. L., Mochizuki, M., & Varda, D. (2020). Exploring the capacity of community-based organisations to absorb health system patient referrals for unmet social needs. *Health & Social Care in the Community*, 29(2). <https://doi.org/10.1111/hsc.13109>
- Holding, E., Thompson, J., Foster, A., & Haywood, A. (2020). Connecting communities: A qualitative investigation of the challenges in delivering a national social prescribing service to reduce loneliness. *Health & Social Care in the Community*, 28(5), 1535-1543. <https://doi.org/10.1111/hsc.12976>
- Holgate, S. (2012). Perceptions of students with an autism spectrum condition of the value of a CBT intervention to enhance student experience. [Doctoral dissertation, University of Birmingham, United Kingdom]. UBIRA E Theses. Retrieved from <https://etheses.bham.ac.uk/id/eprint/4354/1/Holgate13EdD.pdf>
- Holmes, L. G., Zampella, C. J., Clements, C., McCleery, J. P., Maddox, B. B., Parish-Morris, J., Udhmani, M. D., Schultz, R. T., & Miller, J. S. (2020). A Lifespan Approach to Patient-Reported Outcomes and Quality of Life for People on the Autism Spectrum. *Autism Research*, 13(6), 970-987. <https://doi.org/10.1002/aur.2275>
- Hosozawa, M., Sacker, A., Mandy, W., Midouhas, E., Flouri, E., & Cable, N. (2020). Determinants of an autism spectrum disorder diagnosis in childhood and adolescence: Evidence from the UK Millennium Cohort Study. *Autism*, 24(6), 1557-1565. <https://doi.org/10.1177/1362361320913671>
- Howard, P. L., & Sedgewick, F. (2021). 'Anything but the phone!': Communication mode preferences in the autism community. *Autism*, 25(8), 2265-2278. <https://doi.org/10.1177/13623613211014995>
- Howlin, P. (2021). Adults with Autism: Changes in Understanding Since DSM-111. *Journal of Autism and Developmental Disorders*, 51, 4291-4308. <https://doi.org/10.1007/s10803-020-04847-z>

- Howlin, P., & Yates, P. (1999). The Potential Effectiveness of Social Skills Groups for Adults with Autism. *Autism*, 3(3). <https://doi.org/10.1177/1362361399003003007>
- Howlin, P., Alcock, J., & Burkin, C. (2005). An 8 year follow-up of a specialist supported employment service for high-ability adults with autism or Asperger syndrome. *Autism*, 9(5), 533-549. doi:10.1177/1362361305057871
- Huang, Y., Arnold, S. R. C., Foley, K.-R., & Trollor, J. N. (2020). Diagnosis of autism in adulthood: A scoping review. *Autism*, 24(6), 1311-1327. <https://doi.org/10.1177/1362361320903128>
- Hudry, K., Pellicano, E., Uljarević, M., & Whitehouse, A. J. O. (2020). Setting the research agenda to secure the wellbeing of autistic people. *The Lancet Neurology*, 19(5), 374-376. doi:10.1016/S1474-4422(20)30031-4
- Hudson, C. C., Hall, L., & Harkness, K. L. (2019). Prevalence of Depressive Disorders in Individuals with Autism Spectrum Disorder: a Meta-Analysis. *Journal of Abnormal Child Psychology*, 47(1), 165-175. <https://doi.org/10.1007/s10802-018-0402-1>
- Hughes, J. A. (2021). Does the heterogeneity of autism undermine the neurodiversity paradigm? *Bioethics*, 35(1), 47-60. <https://doi.org/10.1111/bioe.12780>
- Hughes, R. B., Robinson-Whelen, S., Raymaker, D., Lund, E. M., Oschwald, M., Katz, M., Starr, A., Ashkenazy, E., Powers, L. E., Nicolaidis, C., Hughes, R. B., Powers, L. E., Nicolaidis, C., Katz, M., Oschwald, M., Larson, D., Ender, J., Plourde, E., Raymaker, D., Howard, L., Ashkenazy, E., Beers, L., Boatman, M., Gardner, G. B., Gray, N., Grantham, L., Larocque, J., Millin, M., Osburn, S., Salomon, J., Starr, A., Tedlow, A., Wallington, A., Curry, M. A., Robinson-Whelen, S., Allen, P., Goe, R., Leotti, S., & Lund, E. (2019). The relation of abuse to physical and psychological health in adults with developmental disabilities. *Disability and Health Journal*, 12(2), 227-234. <https://doi.org/10.1016/j.dhjo.2018.09.007>
- Hull, L., Petrides, K. V., Allison, C., Smith, P., Baron-Cohen, S., Lai, M.-C., & Mandy, W. (2017). "Putting on My Best Normal": Social Camouflaging in Adults with Autism Spectrum Conditions. *Journal of Autism and Developmental Disorders*, 47(8), 2519-2534. <https://doi.org/10.1007/s10803-017-3166-5>
- Huntley, M. K., Black, M. H., Falkmer, M., Lee, E. A. L., Tan, T., Picen, T., Thompson, M., New, M., Heasman, B., Smith, E., Bolte, S., & Girdler, S. (2019). Action Briefing: Strengths-Based Approaches. <https://www.autistica.org.uk/downloads/files/FINAL-Strengths-Based-Approaches-ActionBriefing.pdf>
- Husk, K., Blockley, K., Lovell, R., Bethel, A., Lang, I., Byng, R., & Garside, R. (2019). What approaches to social prescribing work, for whom, and in what circumstances? A realist review. *Health & Social Care in the Community*, 28(2), 309-324. <https://doi.org/10.1111/hsc.12839>
- Husk, K., Elston, J., Gradinger, F., Callaghan, L., & Asthana, S. (2019). Social prescribing: where is the evidence? *British Journal of General Practice*, 69(678), 6-7. <https://doi.org/10.3399/bjgp19X700325>
- Husk, K., Lovell, R., & Garside, R. (2018). Prescribing gardening and conservation activities for health and wellbeing in older people. *Maturitas*, 110, A1-A2. <https://doi.org/10.1016/j.maturitas.2017.12.013>
- Jaday, N., & Bal, V. H. (2022). Associations between co-occurring conditions and age of autism diagnosis: Implications for mental health training and adult autism research. *Autism Research*, 15(11), 2112-2125. <https://doi.org/10.1002/aur.2808>

- James Lind Alliance. (2016). Autism Top 10 | James Lind Alliance. James Lind Alliance. <https://www.jla.nihr.ac.uk/priority-setting-partnerships/autism/top-10-priorities/>
- James, K. L., Randall, N. P., & Haddaway, N. R. (2016). A methodology for systematic mapping in environmental sciences. *Environmental Evidence*, 5(1), 7. <https://doi.org/10.1186/s13750-016-0059-6>
- Jani, A., Bertotti, M., Lazzari, A., Drinkwater, C., Addarii, F., Conibear, J., & Gray, M. (2020). Investing resources to address social factors affecting health: the essential role of social prescribing. *Journal of the Royal Society of Medicine*, 113(1), 24-27. [doi:10.1177/0141076819865864](https://doi.org/10.1177/0141076819865864)
- Jeanneret, N., Courcy, I., Caron, V., Giroux, M., Guerrero, L., Ouimet, M., d'Arc, B. F., & Soulières, I. (2022). Discrimination and victimization as mediators between social support and psychological distress in autistic adults. *Research in Autism Spectrum Disorders*, 98, 102038. <https://doi.org/10.1016/j.rasd.2022.102038>
- Jellett, R., & Muggleton, J. (2022). Implications of Applying “Clinically Significant Impairment” to Autism Assessment: Commentary on Six Problems Encountered in Clinical Practice. *Journal of Autism and Developmental Disorders*, 52(3), 1412-1421. <https://doi.org/10.1007/s10803-021-04988-9>
- Jenkinson, R., Milne, E., & Thompson, A. (2020). The relationship between intolerance of uncertainty and anxiety in autism: A systematic literature review and meta-analysis. *Autism*, 24(8), 1933-1944. <https://doi.org/10.1177/1362361320932437>
- Jones, S. C. (2022). Measuring the Wrong Thing the Right Way? Time to Rethink Autism Research Tools. *Autism in Adulthood*, 4(2), 104-109. <https://doi.org/10.1089/aut.2021.0050>
- Kapp, S. K., Steward, R., Crane, L., Elliott, D., Elphick, C., Pellicano, E., & Russell, G. (2019). ‘People should be allowed to do what they like’: Autistic adults’ views and experiences of stimming. *Autism*, 23(7), 1782-1792. <https://doi.org/10.1177/1362361319829628>
- Kapp, S. (2023). Profound Concerns about “Profound Autism”: Dangers of Severity Scales and Functioning Labels for Support Needs. *Education Sciences*, 13(2), 106. <https://doi.org/10.3390/educsci13020106>
- Keating, C. T., Hickman, L., Leung, J., Monk, R., Montgomery, A., Heath, H., & Sowden, S. (2023). Autism-related language preferences of English-speaking individuals across the globe: A mixed methods investigation. *Autism Research*, 16(2), 406-428. <https://doi.org/10.1002/aur.2864>
- Kenny, L., Hattersley, C., Molins, B., Buckley, C., Povey, C., & Pellicano, E. (2016). Which terms should be used to describe autism? Perspectives from the UK autism community. *Autism: The International Journal of Research and Practice*, 20(4), 442-462. <https://doi.org/10.1177/1362361315588200>
- Khan, K., Ward, F., Halliday, E., & Holt, V. (2022). Public perspectives of social prescribing. *Journal of Public Health*, 44(2), e227-e233. <https://doi.org/10.1093/pubmed/fdab067>
- Khanna, R., Jariwala-Parikh, K., West-Strum, D., & Mahabaleshwarkar, R. (2014). Health-related quality of life and its determinants among adults with autism. *Research in Autism Spectrum Disorders*, 8(3), 157–167. <https://doi.org/10.1016/j.rasd.2013.11.003>
- Khunti, K., Routen, A., Pareek, M., Treweek, S., & Platt, L. (2020). The language of ethnicity. *BMJ*, 371, m4493. <https://doi.org/10.1136/bmj.m4493>

- Kilgarriff-Foster, A., & O'Cathain, A. (2015). Exploring the components and impact of social prescribing. *Journal of Public Mental Health*, 14(3), 127-134. <https://doi.org/10.1108/jpmh-06-2014-0027>
- Kim, S. Y. (2019). The experiences of adults with autism spectrum disorder: Self-determination and quality of life. *Research in Autism Spectrum Disorders*, 60, 1-15. <https://doi.org/10.1016/j.rasd.2018.12.002>
- Kimberlee, R. (2015). What is social prescribing? *Advances in Social Sciences Research Journal*, 2(1). <https://doi.org/10.14738/assrj.21.808>
- Kimberlee, R. (2016). What is the value of social prescribing? *Advances in Social Sciences Research Journal*, 3(3). <https://doi.org/10.14738/assrj.33.1889>
- Kimberlee, R. H. (2013). Developing a social prescribing approach for Bristol. Retrieved from Bristol, UK: <http://eprints.uwe.ac.uk/23221/1/Social%20Prescribing%20Report-final.pdf>
- Kinnaird, E., Norton, C., Pimblett, C., Stewart, C., & Tchanturia, K. (2019). Eating as an autistic adult: An exploratory qualitative study. *PLOS ONE*, 14(8), e0221937. <https://doi.org/10.1371/journal.pone.0221937>
- Kinnaird, E., Stewart, C., & Tchanturia, K. (2019). Investigating alexithymia in autism: A systematic review and meta-analysis. *European Psychiatry*, 55, 80-89. <https://doi.org/10.1016/j.eurpsy.2018.09.004>
- Kinnear, D., Rydzewska, E., Dunn, K., Hughes-McCormack, L. A., Melville, C., Henderson, A., & Cooper, S.-A. (2019). Relative influence of intellectual disabilities and autism on mental and general health in Scotland: a cross-sectional study of a whole country of 5.3 million children and adults. *BMJ Open*, 9(8), e029040. <https://doi.org/10.1136/bmjopen-2019-029040>
- Kirby, A. V., & McDonald, K. E. (2021). The State of the Science on Autism in Adulthood: Building an Evidence Base for Change. *Autism Adulthood*, 3(1), 2-4. <https://doi.org/10.1089/aut.2020.29018.avk>
- Koch, A. D., Vogel, A., Becker, T., Salize, H.-J., Voss, E., Werner, A., Arnold, K., & Schützwohl, M. (2015). Proxy and self-reported Quality of Life in adults with intellectual disabilities: Impact of psychiatric symptoms, problem behaviour, psychotropic medication and unmet needs. *Research in Developmental Disabilities*, 45-46, 136-146. <https://doi.org/10.1016/j.ridd.2015.07.022>
- Koenig, K. P., & Williams, L. H. (2017). Characterization and Utilization of Preferred Interests: A Survey of Adults on the Autism Spectrum. *Occupational Therapy in Mental Health*, 33(2), 129-140. <https://doi.org/10.1080/0164212X.2016.1248877>
- Koffer Miller, K. H., Cooper, D. S., Song, W., & Shea, L. L. (2022). Self-reported service needs and barriers reported by autistic adults: Differences by gender identity. *Research in Autism Spectrum Disorders*, 92, 101916. <https://doi.org/10.1016/j.rasd.2022.101916>
- Kourti, M. (2021). A Critical Realist Approach on Autism: Ontological and Epistemological Implications for Knowledge Production in Autism Research. *Frontiers in Psychology*, 12, 713423. <https://doi.org/10.3389/fpsyg.2021.713423>
- Lai, M.-C., Anagnostou, E., Wiznitzer, M., Allison, C., & Baron-Cohen, S. (2020). Evidence-based support for autistic people across the lifespan: maximising potential, minimising barriers,



- and optimising the person–environment fit. *The Lancet Neurology*, 19(5), 424-451.  
[https://doi.org/10.1016/S1474-4422\(20\)30034-X](https://doi.org/10.1016/S1474-4422(20)30034-X)
- Lai, M.-C., & Baron-Cohen, S. (2015). Identifying the lost generation of adults with autism spectrum conditions. *The Lancet Psychiatry*, 2(11), 1013-1027.  
[https://doi.org/10.1016/S2215-0366\(15\)00277-1](https://doi.org/10.1016/S2215-0366(15)00277-1)
- Lam, G. Y. H., Holden, E., Fitzpatrick, M., Raffaele Mendez, L., & Berkman, K. (2020). "Different but connected": Participatory action research using Photovoice to explore well-being in autistic young adults. *Autism*, 24(5), 1246-1259.  
<https://doi.org/10.1177/1362361319898961>
- Lam, G. Y. H., Sabnis, S., Migueliz Valcarlos, M., & Wolgemuth, J. R. (2021). A Critical Review of Academic Literature Constructing Well-Being in Autistic Adults. *Autism Adulthood*, 3(1), 61-71. <https://doi.org/10.1089/aut.2020.0053>
- Lambe, S. P. (2015). "Supporting the Transition to University of Students with Autism Spectrum Disorder" (Chapter) In Research Portfolio Submitted in Part Fulfilment of the Requirements for the Degree of Doctorate in Clinical Psychology. [Doctoral dissertation, University of Bath, UK.] Retrieved from  
[https://purehost.bath.ac.uk/ws/portalfiles/portal/187960465/FinalThesisPRINT2\\_1\\_.pdf](https://purehost.bath.ac.uk/ws/portalfiles/portal/187960465/FinalThesisPRINT2_1_.pdf)
- Lawson, Lauren P., Amanda L. Richdale, Alexandra Haschek, Rebecca L. Flower, Josh Vartuli, Samuel R. C. Arnold, and Julian N. Trollor. 2020. "Cross-sectional and longitudinal predictors of quality of life in autistic individuals from adolescence to adulthood: The role of mental health and sleep quality." *Autism* 24 (4):954-967. doi: 10.1177/1362361320908107.
- Leadbitter, K., Buckle, K. L., Ellis, C., & Dekker, M. (2021). Autistic Self-Advocacy and the Neurodiversity Movement: Implications for Autism Early Intervention Research and Practice. *Frontiers in Psychology*, 12. <https://doi.org/10.3389/fpsyg.2021.635690>
- Lee, E., Dobbins, M., DeCorby, K., McRae, L., Tirilis, D., & Husson, H. (2012). An optimal search filter for retrieving systematic reviews and meta-analyses. *BMC Medical Research Methodology*, 12(1), 51. <https://doi.org/10.1186/1471-2288-12-51>
- Legault, M., Bourdon, J.-N., & Poirier, P. (2021). From neurodiversity to neurodivergence: the role of epistemic and cognitive marginalization. *Synthese*, 199(5-6), 12843-12868.  
<https://doi.org/10.1007/s11229-021-03356-5>
- Lei, J., Jones, L., & Brosnan, M. (2021). Exploring an e-learning community's response to the language and terminology use in autism from two massive open online courses on autism education and technology use. *Autism*, 25(5), 1349-1367.  
<https://doi.org/10.1177/1362361320987963>
- Lent, A., Pollard, G., & Studdert, J. (2022). A Community-Powered NHS: Making prevention a reality. <https://www.newlocal.org.uk/wp-content/uploads/2022/07/A-Community-Powered-NHS.pdf>
- Lewis, L. F. (2017). A Mixed Methods Study of Barriers to Formal Diagnosis of Autism Spectrum Disorder in Adults. *Journal of Autism and Developmental Disorders*, 47(8), 2410-2424.  
<https://doi.org/10.1007/s10803-017-3168-3>
- Liberati, E., Richards, N., Parker, J., Willars, J., Scott, D., Boydell, N., Pinfold, V., Martin, G., Jones, P. B., & Dixon-Woods, M. (2022). Qualitative study of candidacy and access to

- secondary mental health services during the COVID-19 pandemic. *Social Science & Medicine*, 296, 114711. <https://doi.org/10.1016/j.socscimed.2022.114711>
- Lilley, R., Lawson, W., Hall, G., Mahony, J., Clapham, H., Heyworth, M., Arnold, S. R., Trollor, J. N., Yudell, M., & Pellicano, E. (2022). 'A way to be me': Autobiographical reflections of autistic adults diagnosed in mid-to-late adulthood. *Autism*, 26(6), 1395-1408. <https://doi.org/10.1177/13623613211050694>
- Linden, A., Best, L., Elise, F., Roberts, D., Branagan, A., Tay, Y. B. E., Crane, L., Cusack, J., Davidson, B., Davidson, I., Hearst, C., Mandy, W., Rai, D., Smith, E., & Gurusamy, K. (2023). Benefits and harms of interventions to improve anxiety, depression, and other mental health outcomes for autistic people: A systematic review and network meta-analysis of randomised controlled trials. *Autism*, 27(1), 7-30. <https://doi.org/10.1177/13623613221117931>
- Lloyd, H. M., Pearson, M., Sheaff, R., Asthana, S., Wheat, H., Sugavanam, T. P., Britten, N., Valderas, J., Bainbridge, M., Witts, L., Westlake, D., Horrell, J., & Byng, R. (2017). Collaborative action for person-centred coordinated care (P3C): an approach to support the development of a comprehensive system-wide solution to fragmented care. *Health Research Policy and Systems*, 15(1), 98. <https://doi.org/10.1186/s12961-017-0263-z>
- Lord, C., Brugha, T. S., Charman, T., Cusack, J., Dumas, G., Frazier, T., Jones, E. J. H., Jones, R. M., Pickles, A., State, M. W., Taylor, J. L., & Veenstra-VanderWeele, J. (2020). Autism spectrum disorder. *Nature Reviews Disease Primers*, 6(1), 1-23. <https://doi.org/10.1038/s41572-019-0138-4>
- Lorenc, T., Rodgers, M., Marshall, D., Melton, H., Rees, R., Wright, K., & Sowden, A. (2018). Support for adults with autism spectrum disorder without intellectual impairment: Systematic review. *Autism*, 22(6), 654–668. <https://doi.org/10.1177/1362361317698939>
- Lounds Taylor, J., McPheeters, M. K., Sathe, N. A., Dove, D., Veenstra-VanderWeele, J., & Warren, Z. (2012). A Systematic Review of Vocational Interventions for Young Adults With Autism Spectrum Disorders. *Pediatrics*, 130(3), 531-538. doi:10.1542/peds.2012-0682
- MacFarlane, A., & Brún, M. O. R.-d. (2011). Using a Theory-Driven Conceptual Framework in Qualitative Health Research. *Qualitative Health Research*. <https://doi.org/10.1177/1049732311431898>
- Mackenzie, M., Conway, E., Hastings, A., Munro, M., & O'Donnell, C. (2013). Is 'Candidacy' a Useful Concept for Understanding Journeys through Public Services? A Critical Interpretive Literature Synthesis. *Social Policy & Administration*, 47(7), 806-825. <https://doi.org/10.1111/j.1467-9515.2012.00864.x>
- Mackenzie, M., Skivington, K., & Fergie, G. (2020). "The state They're in": Unpicking fantasy paradigms of health improvement interventions as tools for addressing health inequalities. *Social Science & Medicine*, 256, 113047. <https://doi.org/10.1016/j.socscimed.2020.113047>
- MacLennan, K., O'Brien, S., & Tavassoli, T. (2022). In Our Own Words: The Complex Sensory Experiences of Autistic Adults. *Journal of Autism and Developmental Disorders*, 52(7), 3061-3075. <https://doi.org/10.1007/s10803-021-05186-3>
- MacLennan, K., Roach, L., & Tavassoli, T. (2020). The Relationship Between Sensory Reactivity Differences and Anxiety Subtypes in Autistic Children. *Autism Research*, 13(5), 785-795. <https://doi.org/10.1002/aur.2259>

- MacLennan, K., Woolley, C., and sensory, E., Heasman, B., Starns, J., George, B., & Manning, C. (2022). "It Is a Big Spider Web of Things": Sensory Experiences of Autistic Adults in Public Spaces. *Autism in Adulthood*. <https://doi.org/10.1089/aut.2022.0024>
- MacLeod, A. (1999). The Birmingham Community Support Scheme for Adults with Asperger Syndrome. *Autism*, 3(2), 177–192. <https://doi.org/10.1177/1362361399003002007>
- MacLeod, A., & Green, S. (2009). Beyond the books: case study of a collaborative and holistic support model for university students with Asperger syndrome. *Studies in Higher Education*, 34(6), 631-646. doi:10.1080/03075070802590643
- MacLeod, A., & Johnston, P. (2007). Standing out and fitting in: a report on a support group for individuals with Asperger syndrome using a personal account. *British Journal of Special Education*, 34(2), 83-88. doi:10.1111/j.1467-8578.2007.00460.x
- Maddox, B. B., Crabbe, S., Beidas, R. S., Brookman-Frazee, L., Cannuscio, C. C., Miller, J. S., Nicolaidis, C., & Mandell, D. S. (2020). "I wouldn't know where to start": Perspectives from clinicians, agency leaders, and autistic adults on improving community mental health services for autistic adults. *Autism*, 24(4), 919-930. <https://doi.org/10.1177/1362361319882227>
- Maenner, M. J., Shaw, K. A., Bakian, A. V., Bilder, D. A., Durkin, M. S., Esler, A., Furnier, S. M., Hallas, L., Hall-Lande, J., Hudson, A., Hughes, M. M., Patrick, M., Pierce, K., Poynter, J. N., Salinas, A. A., Shenouda, J., Verhorn, A., Warren, Z., Constantino, J. N., ... Cogswell, M. E. (2021). Prevalence and Characteristics of Autism Spectrum Disorder Among Children Aged 8 Years—Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2018. *MMWR. Surveillance Summaries*, 70. <https://doi.org/10.15585/mmwr.ss7011a1>
- Maitland, C. A., Rhodes, S., O'Hare, A., & Stewart, M. E. (2021). Social identities and mental well-being in autistic adults. *Autism*, 25(6), 1771-1783. <https://doi.org/10.1177/13623613211004328>
- Malby, R., Boyle, D., Wildman, J., Omar, B. S., & Smith, S. (2019). *The Asset Based Health Inquiry: How best to develop social prescribing [Project report]*. <https://openresearch.lsbu.ac.uk/item/886v8>
- Malone, K. M., Pearson, J. N., Palazzo, K. N., Manns, L. D., Rivera, A. Q., & Mason Martin, D. L. (2022). The Scholarly Neglect of Black Autistic Adults in Autism Research. *Autism in Adulthood*. <https://doi.org/10.1089/aut.2021.0086>
- Mann, F., Bone, J. K., Lloyd-Evans, B., Frerichs, J., Pinfold, V., Ma, R., Wang, J., & Johnson, S. (2017). A life less lonely: the state of the art in interventions to reduce loneliness in people with mental health problems. *Social Psychiatry and Psychiatric Epidemiology*, 52(6), 627-638. <https://doi.org/10.1007/s00127-017-1392-y>
- Marmot, M. (2010). *Fair society, healthy lives: the Marmot Review: strategic review of health inequalities in England post-2010*. <https://www.gov.uk/dfid-research-outputs/fair-society-healthy-lives-the-marmot-review-strategic-review-of-health-inequalities-in-england-post-2010>
- Marmot, M., Allen, J., Boyce, T., Goldblatt, P., & Morrison, J. (2020). *Health Equity in England: The Marmot Review 10 Years On*. <https://www.health.org.uk/publications/reports/the-marmot-review-10-years-on>

- Marocchini, E. (2023). Impairment or difference? The case of Theory of Mind abilities and pragmatic competence in the Autism Spectrum. *Applied Psycholinguistics*, 1-19. <https://doi.org/10.1017/S0142716423000024>
- Marriage, S., Wolverton, A., & Marriage, K. (2009). Autism Spectrum Disorder Grown Up: A Chart Review of Adult Functioning. *Journal of the Canadian Academy of Child and Adolescent Psychiatry*, 18(4), 322–328.
- Marston, C., Renedo, A., & Miles, S. (2020). Community participation is crucial in a pandemic. *The Lancet*, 0(0). [https://doi.org/10.1016/S0140-6736\(20\)31054-0](https://doi.org/10.1016/S0140-6736(20)31054-0)
- Mason, D., Capp, S. J., Stewart, G. R., Kempton, M. J., Glaser, K., Howlin, P., & Happé, F. (2021). A Meta-analysis of Outcome Studies of Autistic Adults: Quantifying Effect Size, Quality, and Meta-regression. *Journal of Autism and Developmental Disorders*, 51(9), 3165-3179. <https://doi.org/10.1007/s10803-020-04763-2>
- Mason, J., Gatineau, M., Beynon, C., Gledhill, R., Clark, R., & Baker, A. (2019). Effectiveness of social prescribing: An evidence synthesis. *Public Health England*. <https://www.scie-socialcareonline.org.uk/effectiveness-of-social-prescribing-an-evidence-synthesis/r/a116f00000Uhql9AAB>
- Mason, D., Ingham, B., Birtles, H., Michael, C., Scarlett, C., James, I. A., Brown, T., Woodbury-Smith, M., Wilson, C., Finch, T., & Parr, J. R. (2021). How to improve healthcare for autistic people: A qualitative study of the views of autistic people and clinicians. *Autism*, 25(3), 774-785. <https://doi.org/10.1177/1362361321993709>
- Mason, D., Ingham, B., Urbanowicz, A., Michael, C., Birtles, H., Woodbury-Smith, M., Brown, T., James, I., Scarlett, C., Nicolaidis, C., & Parr, J. R. (2019). A Systematic Review of What Barriers and Facilitators Prevent and Enable Physical Healthcare Services Access for Autistic Adults. *Journal of Autism and Developmental Disorders*, 49(8), 3387-3400. <https://doi.org/10.1007/s10803-019-04049-2>
- Matias, T., Dominski, F. H., & Marks, D. F. (2020). Human needs in COVID-19 isolation. *J Health Psychol*, 25(7), 871-882. <https://doi.org/10.1177/1359105320925149>
- Mavranouzouli, I., Megnin-Viggars, O., Cheema, N., Howlin, P., Baron-Cohen, S., & Pilling, S. (2014). The cost-effectiveness of supported employment for adults with autism in the United Kingdom. *Autism* 18(8), 975-984. doi:10.1177/1362361313505720
- Mawhood, L., & Howlin, P. (1999). The Outcome of a Supported Employment Scheme for High-Functioning Adults with Autism or Asperger Syndrome. *Autism*, 3(3), 229–254. doi:10.1177/1362361399003003003
- Maye, M., Boyd, B. A., Martinez-Pedraza, F., Halladay, A., Thurm, A., & Mandell, D. S. (2022). Biases, Barriers, and Possible Solutions: Steps Towards Addressing Autism Researchers Under-Engagement with Racially, Ethnically, and Socioeconomically Diverse Communities. *Journal of Autism and Developmental Disorders*, 52(9), 4206-4211. <https://doi.org/10.1007/s10803-021-05250-y>
- McConachie, H., Mason, D., Parr, J. R., Garland, D., Wilson, C., & Rodgers, J. (2018). Enhancing the Validity of a Quality of Life Measure for Autistic People. *Journal of Autism and Developmental Disorders*, 48(5), 1596-1611. doi:10.1007/s10803-017-3402-z
- McCowan, S., Shaw, S. C. K., Doherty, M., Grosjean, B., Blank, P., & Kinnear, M. (2022). A full CIRCLE: inclusion of autistic doctors in the Royal College Of Psychiatrists' values and

- Equality Action Plan. *The British Journal of Psychiatry*, 1-3.  
<https://doi.org/10.1192/bjp.2022.14>
- McDonald, T. A. M. (2020). Autism Identity and the “Lost Generation”: Structural Validation of the Autism Spectrum Identity Scale and Comparison of Diagnosed and Self-Diagnosed Adults on the Autism Spectrum. *Autism in Adulthood*, 2(1), 13-23.  
<https://doi.org/10.1089/aut.2019.0069>
- Mendes, A. (2021). Social prescribing in the community. *British Journal of Community Nursing*, 26(4), 204-205. <https://doi.org/10.12968/bjcn.2021.26.4.204>
- Micai, M., Ciaramella, A., Salvitti, T., Fulceri, F., Fatta, L., Poustka, L., Diehm, R., Iskrov, G., Stefanov, R., Guillon, Q., Rogé, B., Staines, A., Sweeney, M., Boilson, A., Leosdottir, T., Saemundsen, E., Moilanen, I., Ebeling, H., Yliherva, A., & Schendel, D. (2021). Autistic Adult Health and Professional Perceptions of It: Evidence From the ASDEU Project. *Frontiers in Psychiatry*, 12, 614102. <https://doi.org/10.3389/fpsy.2021.614102>
- Michael, C. (2016). Why we need research about autism and ageing. *Autism*, 20(5), 515-516.  
<https://doi.org/10.1177/1362361316647224>
- Michie, S., van Stralen, M. M., & West, R. (2011). The behaviour change wheel: A new method for characterising and designing behaviour change interventions. *Implementation Science*, 6(1), 42. <https://doi.org/10.1186/1748-5908-6-42>
- Miller, R., Glasby, J., & Dickinson, H. (2021). Integrated Health and Social Care in England: Ten Years On. *International Journal of Integrated Care*, 21(4), 6.  
<https://doi.org/https://doi.org/10.5334/ijic.5666>
- Milton, D. E. M. (2012). On the ontological status of autism: the ‘double empathy problem’. *Disability & Society*, 27(6), 883-887. <https://doi.org/10.1080/09687599.2012.710008>
- Milton, D., & Sims, T. (2016). How is a sense of well-being and belonging constructed in the accounts of autistic adults? *Disability & Society*, 31(4), 520-534.  
<https://doi.org/10.1080/09687599.2016.1186529>
- Milton, D., Sims, T., Dawkins, G., Martin, N., & Mills, R. (2017). The development and evaluation of a mentor training programme for those working with autistic adults. *Good Autism Practice*, 18(1), 25–33.
- Ministry of Housing, Communities & Local Government. (2019). English indices of deprivation 2019.  
[https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/835115/IOD2019\\_Statistical\\_Release.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/835115/IOD2019_Statistical_Release.pdf)
- Mitchell, P., Cassidy, S., & Sheppard, E. (2019). The double empathy problem, camouflage, and the value of expertise from experience. *Behavioral and Brain Sciences*, 42.  
<https://doi.org/10.1017/S0140525X18002212>
- Morris, D., Thomas, P., Ridley, J., & Webber, M. (2022). Community-Enhanced Social Prescribing: Integrating Community in Policy and Practice. *Int J Community Wellbeing*, 5(1), 179-195.  
<https://doi.org/10.1007/s42413-020-00080-9>
- Morse, D. F., Sandhu, S., Mulligan, K., Tierney, S., Polley, M., Giurca, B. C., Slade, S., Dias, S., Mahtani, K. R., Wells, L., Wang, H., Bo, Z., Figueiredo, C. E. M. D., Meijs, J. J., Nam, H. K., Lee, K. H., Wallace, C., Elliott, M., Mendive, J. M., Robinson, D., Palo, M., Herrmann,

- W., Nielsen, R. Ø., & Husk, K. (2022). Global developments in social prescribing. *BMJ Global Health*, 7(5), e008524. <https://doi.org/10.1136/bmjgh-2022-008524>
- Mosquera, M. L., Mandy, W., Pavlopoulou, G., & Dimitriou, D. (2021). Autistic adults' personal experiences of navigating a social world prior to and during Covid-19 lockdown in Spain. *Research in Developmental Disabilities*, 117, 104057. <https://doi.org/10.1016/j.ridd.2021.104057>
- Moynihan, R., Sanders, S., Michaleff, Z. A., Scott, A. M., Clark, J., To, E. J., Jones, M., Kitchener, E., Fox, M., Johansson, M., Lang, E., Duggan, A., Scott, I., & Albarqouni, L. (2021). Impact of COVID-19 pandemic on utilisation of healthcare services: a systematic review. *BMJ Open*, 11(3), e045343. <https://doi.org/10.1136/bmjopen-2020-045343>
- Murray, D., Lesser, M., & Lawson, W. (2005). Attention, monotropism and the diagnostic criteria for autism. *Autism : the international journal of research and practice*, 9, 139-156. <https://doi.org/10.1177/1362361305051398>
- National Audit Office (2009). Supporting people with autism through adulthood: report by the Comptroller and Auditor General. London: Stationery Office. Retrieved from: <https://www.nao.org.uk/report/supporting-people-with-autism-through-adulthood/>
- National Autistic Society (2016). Autism employment gap. Retrieved from: <https://www.autism.org.uk/get-involved/media-centre/news/2016-10-27-employment-gap.aspx>
- National Autistic Society. (2020). Left Stranded: The impact of coronavirus on autistic people and their families in the UK. <https://www.autism.org.uk/what-we-do/news/coronavirus-report>
- National Autistic Society. How to talk about autism. Retrieved 19/07/2021 from <https://www.autism.org.uk/what-we-do/help-and-support/how-to-talk-about-autism>
- National Health Service. (2019). The NHS Long Term Plan. <https://www.longtermplan.nhs.uk/publication/nhs-long-term-plan/>
- National Institute for Health & Care Excellence (NICE). (2018). Learning disabilities and behaviour that challenges: service design and delivery. National Institute for Health and Care Excellence. Retrieved from: <https://www.nice.org.uk/guidance/ng93/chapter/recommendations#learning-disability>
- Nesbitt, S. (2000). Why and why not? Factors Influencing Employment for Individuals with Asperger Syndrome. *Autism*, 4(4), 357–369. doi:10.1177/1362361300004004002
- Newey, I. (2002). Evaluating psychological interventions for young men with Asperger's syndrome: cognitive behavioural therapy to address anxiety and teaching theory of mind to address social functioning deficits. [Doctoral dissertation, University of East Anglia, UK]. Europe PMC. Retrieved from <https://europepmc.org/article/eth/246965>
- NHS England. (2019). NHS England » Social prescribing and community-based support: Summary guide. <https://www.england.nhs.uk/publication/social-prescribing-and-community-based-support-summary-guide/>
- NHS England. (2023a). NHS England » Social prescribing: Reference guide and technical annex for primary care networks. NHS England. <https://www.england.nhs.uk/publication/social-prescribing-reference-guide-and-technical-annex-for-primary-care-networks/#annex-c>

- NHS England. (2023b). NHS Long Term Workforce Plan. <https://www.england.nhs.uk/wp-content/uploads/2023/06/nhs-long-term-workforce-plan.pdf>
- NHS England. (a). NHS England » Stopping over medication of people with a learning disability, autism or both (STOMP). <https://www.england.nhs.uk/learning-disabilities/improving-health/stomp/>
- NHS England. (b) NHS England » Making information and the words we use accessible. <https://www.england.nhs.uk/learning-disabilities/about/get-involved/involving-people/making-information-and-the-words-we-use-accessible/#autism>
- NHS England. (c) What are integrated care systems? NHS England. Retrieved 14/06/2023 from <https://www.england.nhs.uk/integratedcare/what-is-integrated-care/>
- Nicolaidis, C., Raymaker, D., Kapp, S. K., Baggs, A., Ashkenazy, E., McDonald, K., Weiner, M., Maslak, J., Hunter, M., & Joyce, A. (2019). The AASPIRE practice-based guidelines for the inclusion of autistic adults in research as co-researchers and study participants. *Autism*, 23(8), 2007-2019. <https://doi.org/10.1177/1362361319830523>
- Oakley, B. F. M., Tillmann, J., Ahmad, J., Crawley, D., San José Cáceres, A., Holt, R., Charman, T., Banaschewski, T., Buitelaar, J., Simonoff, E., Murphy, D., & Loth, E. (2020). How do core autism traits and associated symptoms relate to quality of life? Findings from the Longitudinal European Autism Project. *Autism*, 25(2), 389-404. <https://doi.org/10.1177/1362361320959959>
- Office For National Statistics. (2020a). Coronavirus and the social impacts on disabled people in Great Britain. <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/disability/articles/coronavirusandthesocialimpactsondisabledpeopleingreatbritain/may2020>
- Office for National Statistics. (2020b). Diary of a nation: life in lockdown - Office for National Statistics. Office for National Statistics. <https://www.ons.gov.uk/releases/diaryofanationlifeinlockdown>
- Office for National Statistics. (2022). Outcomes for disabled people in the UK. Office for National Statistics. Retrieved 14/10/2022 from <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/disability/articles/outcomesfordisabledpeopleintheuk/2021>
- Office of Autism Research Coordination, National Institute of Mental Health, Autistica, Canadian Institutes of Health Research, & Macquarie University. (2019). 2016 International Autism Spectrum Disorder Research Portfolio Analysis Report. <https://iacc.hhs.gov/publications/international-portfolio-analysis/2016>
- Ogden, J. (2018). Where next for social prescribing in England? *Prescriber*, 29(5), 31-34. <https://doi.org/10.1002/psb.1674>
- Oliver, M. (1990). *The Politics of Disablement*. Palgrave. <https://doi.org/10.1007/978-1-349-20895-1>
- O'Nions, E., Petersen, I., Buckman, J. E. J., Charlton, R., Cooper, C., Corbett, A., Happé, F., Manthorpe, J., Richards, M., Saunders, R., Zanker, C., Mandy, W., & Stott, J. (2023). Autism in England: assessing underdiagnosis in a population-based cohort study of prospectively collected primary care data. *The Lancet Regional Health - Europe*, 29, 100626. <https://doi.org/10.1016/j.lanepe.2023.100626>

- Orsmond, G. I., Shattuck, P. T., Cooper, B. P., Sterzing, P. R., & Anderson, K. A. (2013). Social Participation Among Young Adults with an Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, 43(11), 2710–2719. <https://doi.org/10.1007/s10803-013-1833-8>
- Ouzzani, M., Hammady, H., Fedorowicz, Z. & Elmagarmid, A. (2016). Rayyan — a web and mobile app for systematic reviews. *Systematic Reviews*, 5, 210. DOI: 10.1186/s13643-016-0384-4.
- Pais, S., & Knapp, M. (2021). The Impact of COVID-19 on Autistic People in the United Kingdom: Final Report. [https://piru.ac.uk/assets/files/The\\_Impact\\_of\\_COVID-19\\_on\\_Autistic\\_People\\_in\\_the\\_United\\_Kingdom\\_Final\\_Report.pdf](https://piru.ac.uk/assets/files/The_Impact_of_COVID-19_on_Autistic_People_in_the_United_Kingdom_Final_Report.pdf)
- Parkinson, A., Buttrick, J., & Butler, O. (2015). The Role of Advice Services in Health Outcomes: Evidence Review and Mapping Study. <https://www.thelegaeducationfoundation.org/wp-content/uploads/2015/06/Role-of-Advice-Services-in-Health-Outcomes.pdf>
- Pavlopoulou, G., Wood, R., & Papadopoulos, C. (2020). Impact of Covid-19 on the experiences of parents and family carers of autistic children and young people in the UK [Report]. [https://discovery.ucl.ac.uk/id/eprint/10101297/3/Pavlopoulou\\_COVID19%20AUTISM%20FINAL%20GP.pdf](https://discovery.ucl.ac.uk/id/eprint/10101297/3/Pavlopoulou_COVID19%20AUTISM%20FINAL%20GP.pdf)
- Pearson, A., & Rose, K. (2021). A Conceptual Analysis of Autistic Masking: Understanding the Narrative of Stigma and the Illusion of Choice. *Autism in Adulthood*, 3(1), 52-60. <https://doi.org/10.1089/aut.2020.0043>
- Pellicano, E., Brett, S., Den Houting, J., Heyworth, M., Magiati, I., Steward, R., Urbanowicz, A., & Stears, M. (2020). "I want to see my friends": The everyday experiences of autistic people and their families during COVID-19. <https://www.sydney.edu.au/content/dam/corporate/documents/sydney-policy-lab/everyday-experiences-of-autistic-people-during-covid-19---report---july-2020.pdf>
- Pellicano, E., Dinsmore, A., & Charman, T. (2014). What should autism research focus upon? Community views and priorities from the United Kingdom. *Autism*, 18(7), 756-770. <https://doi.org/10.1177/1362361314529627>
- Pellicano, E., Fatima, U., Hall, G., Heyworth, M., Lawson, W., Lilley, R., Mahony, J., & Stears, M. (2022). A capabilities approach to understanding and supporting autistic adulthood. *Nature Reviews Psychology*, 1, 624-639. <https://doi.org/10.1038/s44159-022-00099-z>
- Pelton, M. K., Crawford, H., Robertson, A. E., Rodgers, J., Baron-Cohen, S., & Cassidy, S. (2020). Understanding Suicide Risk in Autistic Adults: Comparing the Interpersonal Theory of Suicide in Autistic and Non-autistic Samples. *Journal of Autism and Developmental Disorders*, 50(10), 3620-3637. <https://doi.org/10.1007/s10803-020-04393-8>
- Perepa, P. (2014). Cultural basis of social ‘deficits’ in autism spectrum disorders. *European Journal of Special Needs Education*, 29(3), 313-326. <https://doi.org/https://doi.org/10.1080/08856257.2014.908024>
- Perepa, P., Wallace, S., & Guldberg, K. (2023). The experiences of marginalised families with autistic children. <https://www.birmingham.ac.uk/documents/college-social-sciences/education/publications/marginalised-families-with-autistic-children.pdf.pdf>
- Peschery, J. V., Pappas, Y., & Randhawa, G. (2018a). Evaluating the Implementation and Delivery of a Social Prescribing Intervention: A Research Protocol. *International Journal of Integrated Care*, 18(1), 13. <https://doi.org/10.5334/ijic.3087>



- Pescheny, J. V., Pappas, Y., & Randhawa, G. (2018b). Facilitators and barriers of implementing and delivering social prescribing services: a systematic review. *BMC Health Services Research*, 18(1), 86. <https://doi.org/10.1186/s12913-018-2893-4>
- Polley, M., Bertotti, M., Kimberlee, R., Pilkington, K., & Refsum, C. (2017). A review of the evidence assessing impact of social prescribing on healthcare demand and cost implications. <https://westminsterresearch.westminster.ac.uk/item/q1455/a-review-of-the-evidence-assessing-impact-of-social-prescribing-on-healthcare-demand-and-cost-implications>
- Polley, M., Dixon, M., Pilkington, K., Ridge, D., Herbert, N., Drinkwater, C., Fleming, J., McGregor, A., Bertotti, M., Frostick, C., Hopewell, D., Kimberlee, R., & Pedro, L. (2016). Report of the Annual Social Prescribing Network Conference. [https://docs.wixstatic.com/ugd/14f499\\_9ba1233600eb454ab836b1c6424feed3.pdf](https://docs.wixstatic.com/ugd/14f499_9ba1233600eb454ab836b1c6424feed3.pdf)
- Polley, M., Fleming, J., Anfilogoff, T., & Carpenter, A. (2017). Making Sense of Social Prescribing. [https://docs.wixstatic.com/ugd/14f499\\_816dc79e160a4e77991599a74236d0d4.pdf](https://docs.wixstatic.com/ugd/14f499_816dc79e160a4e77991599a74236d0d4.pdf)
- Polley, M., Whiteside, J., Elnaschie, S., & Fixsen, A. (2020). What does successful social prescribing look like? Mapping meaningful outcomes. University of Westminster. <https://westminsterresearch.westminster.ac.uk/item/qyz67/what-does-successful-social-prescribing-look-like-mapping-meaningful-outcomes>
- Popay, J., Kowarzik, U., Mallinson, S., Mackian, S., & Barker, J. (2007). Social problems, primary care and pathways to help and support: addressing health inequalities at the individual level. Part I: the GP perspective. *Journal of Epidemiology & Community Health*, 61(11), 966-971. <https://doi.org/10.1136/jech.2007.061937>
- Prentice-Dunn, S., & Rogers, R. W. (1986). Protection Motivation Theory and preventive health: beyond the Health Belief Model. *Health Education Research*, 1(3), 153-161. <https://doi.org/10.1093/her/1.3.153>
- Provenzani, U., Fusar-Poli, L., Brondino, N., Damiani, S., Vercesi, M., Meyer, N., Rocchetti, M., & Politi, P. (2020). What are we targeting when we treat autism spectrum disorder? A systematic review of 406 clinical trials. *Autism*, 24(2), 274-284. <https://doi.org/10.1177/1362361319854641>
- Putnam, O. C., Eddy, G., Goldblum, J., Swisher, M., & Harrop, C. (2023). How autistic adults' priorities for autism research differ by gender identity: A mixed-methods study. *Women's Health*, 19, 17455057231160342. <https://doi.org/10.1177/17455057231160342>
- Rast, J. E., Fernandes, S. J., Schott, W., & Shea, L. L. (2023). Disparities by Race and Ethnicity in Inpatient Hospitalizations Among Autistic Adults. *Journal of Autism and Developmental Disorders*. <https://doi.org/10.1007/s10803-023-05911-0>
- Raymaker, D. M., McDonald, K. E., Ashkenazy, E., Gerrity, M., Baggs, A. M., Kripke, C., ... Nicolaidis, C. (2017). Barriers to healthcare: Instrument development and comparison between autistic adults and adults with and without other disabilities. *Autism*, 21(8), 972-984. <https://doi.org/10.1177/1362361316661261>
- Raymaker, D. M., Teo, A. R., Steckler, N. A., Lentz, B., Scharer, M., Delos Santos, A., Kapp, S. K., Hunter, M., Joyce, A., & Nicolaidis, C. (2020). "Having All of Your Internal Resources Exhausted Beyond Measure and Being Left with No Clean-Up Crew": Defining Autistic Burnout. *Autism in Adulthood*, 2(2). <https://doi.org/10.1089/aut.2019.0079>
- Rayner, J., Muldoon, L., Bayoumi, I., McMurchy, D., Mulligan, K., & Tharao, W. (2018). Delivering primary health care as envisioned: A model of health and well-being guiding

- community-governed primary care organizations. *Journal of Integrated Care*, 26(3), 231-241. <https://doi.org/10.1108/JICA-02-2018-0014>
- Rhodes, J., & Bell, S. (2021). "It sounded a lot simpler on the job description": A qualitative study exploring the role of social prescribing link workers and their training and support needs (2020). *Health & Social Care in the Community*, 29(6), e338-e347. <https://doi.org/10.1111/hsc.13358>
- Richards, H. M., & Schwartz, L. J. (2002). Ethics of qualitative research: are there special issues for health services research? *Family Practice*, 19(2), 135-139. <https://doi.org/10.1093/fampra/19.2.135>
- Richards, J. (2012). Examining the exclusion of employees with Asperger syndrome from the workplace. *Personnel Review*, 41(5), 630-646. doi:10.1108/00483481211249148
- Ridout S., Guldberg K. & Macleod A. (2011) Hear me out! Supporting young people (16-18) on the Autism Spectrum living in Warwickshire: an evaluation of the adult model. Birmingham: Autism Centre for Education and Research. Retrieved from: <https://www.researchgate.net/publication/272348268>
- Roche, L., Adams, D., & Clark, M. (2021). Research priorities of the autism community: A systematic review of key stakeholder perspectives. *Autism*, 25(2), 336-348. <https://doi.org/10.1177/1362361320967790>
- Roman-Urrestarazu, A., van Kessel, R., Allison, C., Matthews, F. E., Brayne, C., & Baron-Cohen, S. (2021). Association of Race/Ethnicity and Social Disadvantage With Autism Prevalence in 7 Million School Children in England. *JAMA Pediatrics*, 175(6), e210054. <https://doi.org/10.1001/jamapediatrics.2021.0054>
- Rosqvist, H. B., Botha, M., Hens, K., O'Donoghue, S., Pearson, A., & Stenning, A. (2023). Being, Knowing, and Doing: Importing Theoretical Toolboxes for Autism Studies. *Autism Adulthood*, 5(1), 15-23. <https://doi.org/10.1089/aut.2022.0021>
- Rothwell, C. (2020). Select literature review: Autism and its economic costs. <http://www.niassembly.gov.uk/globalassets/documents/raise/publications/2017-2022/2021/finance/0821.pdf>
- Royal College of Psychiatrists. (2020). The psychiatric management of autism in adults (CR228). <https://www.rcpsych.ac.uk/improving-care/campaigning-for-better-mental-health-policy/college-reports/2020-college-reports/cr228>
- Rubenstein, E., & Furnier, S. (2020). #Bias: The Opportunities and Challenges of Surveys That Recruit and Collect Data of Autistic Adults Online. *Autism in Adulthood*. <https://doi.org/10.1089/aut.2020.0031>
- Rumball, F., Happe, F., & Grey, N. (2020). Experience of Trauma and PTSD Symptoms in Autistic Adults: Risk of PTSD Development Following DSM-5 and Non-DSM-5 Traumatic Life Events. *Autism Res*, 13(12), 2122-2132. <https://doi.org/10.1002/aur.2306>
- Russell, A. J., Jassi, A., Fullana, M. A., Mack, H., Johnston, K., Heyman, I., Murphy, D. G., & Mataix-Cols, D. (2013). Cognitive Behavior Therapy for Comorbid Obsessive-Compulsive Disorder in High-Functioning Autism Spectrum Disorders: A Randomized Controlled Trial. *Depression and Anxiety*, 30(8), 697-708. <https://doi.org/10.1002/da.22053>

- Russell, G., Kapp, S. K., Elliott, D., Elphick, C., Gwernan-Jones, R., & Owens, C. (2019). Mapping the Autistic Advantage from the Accounts of Adults Diagnosed with Autism: A Qualitative Study. *Autism in Adulthood*, 1(2), 124-133. <https://doi.org/10.1089/aut.2018.0035>
- Russell, G., Mandy, W., Elliott, D., White, R., Pittwood, T., & Ford, T. (2019). Selection bias on intellectual ability in autism research: a cross-sectional review and meta-analysis. *Molecular Autism*, 10(1), 9. <https://doi.org/10.1186/s13229-019-0260-x>
- Russell, G., Stapley, S., Newlove-Delgado, T., Salmon, A., White, R., Warren, F., Pearson, A., & Ford, T. (2022). Time trends in autism diagnosis over 20 years: a UK population-based cohort study. *Journal of child psychology and psychiatry, and allied disciplines*, 63(6), 674-682. <https://doi.org/10.1111/jcpp.13505>
- Ryan Idriss, C. (2021). Invisible Autistic Infrastructure: Ethnographic Reflections on an Autistic Community. *Med Anthropol*, 40(2), 129-140. <https://doi.org/10.1080/01459740.2020.1849185>
- Ryan, R. M., Patrick, H., Deci, E. L., & Williams, G. C. (2008). Facilitating health behaviour change and its maintenance: Interventions based on Self-Determination Theory. *European Psychologist*, 10, 2-5. <https://acuresearchbank.acu.edu.au/item/86yww/facilitating-health-behaviour-change-and-its-maintenance-interventions-based-on-self-determination-theory>
- Ryan, R. M., & Deci, E. L. (2000). Intrinsic and Extrinsic Motivations: Classic Definitions and New Directions. *Contemporary Educational Psychology*, 25(1), 54-67. <https://doi.org/10.1006/ceps.1999.1020>
- Saldaña, J. (2021). *The Coding Manual for Qualitative Researchers* (4 ed.). Sage.
- Sandhu, S., Lian, T., Drake, C., Moffatt, S., Wildman, J., & Wildman, J. (2022). Intervention components of link worker social prescribing programmes: A scoping review. *Health & Social Care in the Community*, 30(6), e3761-e3774. <https://doi.org/10.1111/hsc.14056>
- Saqr, Y., Braun, E., Porter, K., Barnette, D., & Hanks, C. (2018). Addressing medical needs of adolescents and adults with autism spectrum disorders in a primary care setting. *Autism*, 22(1), 51-61. <https://doi.org/10.1177/1362361317709970>
- Scartazza, A., Mancini, M. L., Proietti, S., Moscatello, S., Mattioni, C., Costantini, F., Di Baccio, D., Villani, F., & Massacci, A. (2020). Caring local biodiversity in a healing garden: Therapeutic benefits in young subjects with autism. *Urban Forestry & Urban Greening*, 47, 126511. <https://doi.org/10.1016/j.ufug.2019.126511>
- Schall, C., Wehman, P., Avellone, L., & Taylor, J. P. (2020). Competitive Integrated Employment for Youth and Adults with Autism: Findings from a Scoping Review. *Psychiatric Clinics of North America*, 43(4), 701–722. <https://doi.org/10.1016/j.psc.2020.08.007>
- Schalock, R. L. (2000). Three Decades of Quality of Life. *Focus on Autism and Other Developmental Disabilities*, 15(2), 116–127. <https://doi.org/10.1177/108835760001500207>
- Scheeren, Anke M., Patricia Howlin, Meike Bartels, Lydia Krabbendam, and Sander Begeer. 2021. "The importance of home: Satisfaction with accommodation, neighborhood, and life in adults with autism." *Autism Research* 15 (3):519-530. doi: 10.1002/aur.2653.
- Schleien, S. J., Rynders, J. E., Mustonen, T., Heyne, L. A., & Kaase, S. J. (1991). TEACHING HORTICULTURE SKILLS TO ADULTS WITH AUTISM: A REPLICATED CASE STUDY. *Journal of Therapeutic Horticulture*, 6, 21-37. <https://www.jstor.org/stable/44024960>

- Schott, W., Nonnemacher, S., & Shea, L. (2021). Service Use and Unmet Needs Among Adults with Autism Awaiting Home- and Community-Based Medicaid Services. *Journal of Autism and Developmental Disorders*, 51(4), 1188-1200. <https://doi.org/10.1007/s10803-020-04593-2>
- Schott, W., Tao, S., & Shea, L. (2022). COVID-19 risk: Adult Medicaid beneficiaries with autism, intellectual disability, and mental health conditions. *Autism*, 26(4), 975-987. <https://doi.org/10.1177/13623613211039662>
- Scott, M., Jacob, A., Hendrie, D., Parsons, R., Girdler, S., Falkmer, T., & Falkmer, M. (2017). Employers' perception of the costs and the benefits of hiring individuals with autism spectrum disorder in open employment in Australia. *PLOS ONE*, 12(5), e0177607. <https://doi.org/10.1371/journal.pone.0177607>
- Scott, M., Milbourn, B., Falkmer, M., Black, M., Bölte, S., Halladay, A., Lerner, M., Taylor, J. L., & Girdler, S. (2019). Factors impacting employment for people with autism spectrum disorder: A scoping review. *Autism*, 23(4), 869-901. <https://doi.org/10.1177/1362361318787789>
- Shakespeare, T. (2016). The Social Model of Disability. In *The Disability Studies Reader* (5 ed., pp. 195-203). Routledge. <https://books.google.co.uk/books?id=aiQIDwAAQBAJ>
- Shakespeare, T. (2013). Critical realist approaches to disability. In *Disability Rights and Wrongs Revisited* (2 ed.). Routledge.
- Shannon-Baker, P. (2016). Making Paradigms Meaningful in Mixed Methods Research. *Journal of Mixed Methods Research*, 10(4), 319-334. <https://doi.org/10.1177/1558689815575861>
- Sharpe, R. A., Curry, W., Brown, R., & Shankar, R. (2019). A public health approach to reducing health inequalities among adults with autism. *British Journal of General Practice*, 69(688), 534-535. <https://doi.org/10.3399/bjgp19X706133>
- Shattuck, P. T., Garfield, T., Roux, A. M., Rast, J. E., Anderson, K., Hassrick, E. M., & Kuo, A. (2020). Services for Adults With Autism Spectrum Disorder: A Systems Perspective. *Current Psychiatry Reports*, 22(3), 13. <https://doi.org/10.1007/s11920-020-1136-7>
- Shattuck, P. T., Roux, A. M., Hudson, L. E., Taylor, J. L., Maenner, M. J., & Trani, J.-F. (2012). Services for Adults with an Autism Spectrum Disorder. *The Canadian Journal of Psychiatry*, 57(5), 284-291. <https://doi.org/10.1177/070674371205700503>
- Shaw, S. C., Davis, L. J., & Doherty, M. (2022). Considering autistic patients in the era of telemedicine: the need for an adaptable, equitable, and compassionate approach. *BJGP Open*, 6(1), BJGPO.2021.0174. <https://doi.org/10.3399/BJGPO.2021.0174>
- Shea, L. L., Verstrete, K., Nonnemacher, S., Song, W., & Salzer, M. S. (2021). Self-reported community participation experiences and preferences of autistic adults. *Autism*, 25(5), 1295-1306. <https://doi.org/10.1177/1362361320987682>
- Sinclair, J. (1993). Don't mourn for us. Retrieved 12 June 2023 from [http://www.autreat.com/dont\\_mourn.html](http://www.autreat.com/dont_mourn.html)
- Sinclair, J. (2013). Why I dislike "person first" Language. *Autonomy, the Critical Journal of Interdisciplinary Autism Studies*, 1(2). <http://www.larry-arnold.net/Autonomy/index.php/autonomy/article/view/OP1>
- Smart, J. (2006). Challenges to the Biomedical Model of Disability. *Advances in Medical Psychotherapy and Psychodiagnosis*, 12, 41-44. <files/1839/summary.html>

- Smith, J., & Firth, J. (2011). Qualitative data analysis: the framework approach. *Nurse Researcher*, 18(2). <https://doi.org/10.7748/nr2011.01.18.2.52.c8284>
- Smith, W. G. (2008). Does Gender Influence Online Survey Participation? A Record-Linkage Analysis of University Faculty Online Survey Response Behavior. <https://eric.ed.gov/?id=ED501717>
- Snilstveit, B., Vojtkova, M., Bhavsar, A., Stevenson, J., & Gaarder, M. (2016). Evidence & Gap Maps: A tool for promoting evidence informed policy and strategic research agendas. *Journal of Clinical Epidemiology*, 79, 120-129. doi:10.1016/j.jclinepi.2016.05.015
- South, J., Higgins, T., Woodall, J., & White, S. M. (2008). Can social prescribing provide the missing link. *Primary Health Care Research & Development*, 9, 310-318. <https://doi.org/10.1017/s146342360800087x>
- Southby, K., & Robinson, O. (2018). Information, Advocacy and Signposting as a Low-Level Support for Adults with High-Functioning Autism Spectrum Disorder: An Example from the UK. *Journal of Autism and Developmental Disorders*, 48(2), 511-519. <https://doi.org/10.1007/s10803-017-3331-x>
- Spain, D., & Blainey, S. H. (2015). Group social skills interventions for adults with high-functioning autism spectrum disorders: A systematic review. *Autism*, 19(7), 874–886. <https://doi.org/10.1177/1362361315587659>
- Spain, D., Blainey, S. H., & Vaillancourt, K. (2017). Group cognitive behaviour therapy (CBT) for social interaction anxiety in adults with autism spectrum disorders (ASD). *Research in Autism Spectrum Disorders*, 41–42, 20–30. <https://doi.org/10.1016/j.rasd.2017.07.005>
- Steadman, K., Thomas, R., & Donnalaja, V. (2017). Social prescribing: A pathway to work? [http://www.theworkfoundation.com/wp-content/uploads/2017/02/412\\_Social\\_prescribing.pdf](http://www.theworkfoundation.com/wp-content/uploads/2017/02/412_Social_prescribing.pdf)
- Stenning, A., & Rosqvist, H. B. (2021). Neurodiversity studies: mapping out possibilities of a new critical paradigm. *Disability & Society*, 0(0), 1-6. <https://doi.org/10.1080/09687599.2021.1919503>
- Stuart, A., Stevenson, C., Koschate, M., Cohen, J., & Levine, M. (2022). 'Oh no, not a group!' The factors that lonely or isolated people report as barriers to joining groups for health and well-being. *Br J Health Psychol*, 27(1), 179-193. <https://doi.org/10.1111/bjhp.12536>
- Taboas, A., Doepke, K., & Zimmerman, C. (2023). Preferences for identity-first versus person-first language in a US sample of autism stakeholders. *Autism*, 27(2), 565-570. <https://doi.org/10.1177/13623613221130845>
- Taylor, H., Ingham, B., Mason, D., Finch, T., Wilson, C., Scarlett, C., Moss, S., Buckley, C., Urbanowicz, A., Raymaker, D., Seiboth, C., Lees, R., Garland, D., Osbourne, M., Lennox, N., Cooper, S. A., Nicolaidis, C., & Parr, J. R. (2023). Co-design of an NHS primary care health check for autistic adults. *Autism*, 27(4), 1079-1091. <https://doi.org/10.1177/13623613221132921>
- Taylor, J. L., & Henninger, N. A. (2015). Frequency and Correlates of Service Access Among Youth with Autism Transitioning to Adulthood. *Journal of Autism and Developmental Disorders*, 45(1), 179-191. <https://doi.org/10.1007/s10803-014-2203-x>
- Taylor, J. L., & Seltzer, M. M. (2011). Employment and Post-Secondary Educational Activities for Young Adults with Autism Spectrum Disorders During the Transition to Adulthood. *Journal*

of Autism and Developmental Disorders, 41(5), 566-574. <https://doi.org/10.1007/s10803-010-1070-3>

- Tester-Jones, M., White, M. P., Elliott, L. R., Weinstein, N., Grellier, J., Economou, T., Bratman, G. N., Cleary, A., Gascon, M., Korpela, K. M., Nieuwenhuijsen, M., O'Connor, A., Ojala, A., van den Bosch, M., & Fleming, L. E. (2020). Results from an 18 country cross-sectional study examining experiences of nature for people with common mental health disorders. *Scientific Reports*, 10(1), 19408. <https://doi.org/10.1038/s41598-020-75825-9>
- Thomas, G., Lynch, M., & Spencer, L. H. (2021). A Systematic Review to Examine the Evidence in Developing Social Prescribing Interventions That Apply a Co-Productive, Co-Designed Approach to Improve Well-Being Outcomes in a Community Setting. *International Journal of Environmental Research and Public Health*, 18(8), 3896. <https://doi.org/10.3390/ijerph18083896>
- Tierney, S., Cartwright, L., Akinyemi, O., Carder-Gilbert, H., Burns, L., Dayson, C., & Chatterjee, H. (2022). What does the evidence tell us about accessibility of social prescribing schemes in England to people from black and ethnic minority backgrounds? <https://socialprescribingacademy.org.uk/media/mkptzvz/evidence-review-accessibility-for-black-and-ethnic-minority-backgrounds.pdf>
- Tierney, S., Libert, S., Gorenberg, J., Wong, G., Turk, A., Husk, K., Chatterjee, H. J., Eccles, K., Potter, C., Webster, E., McDougall, B., Warburton, H., Shaw, L., Roberts, N., & Mahtani, K. R. (2022). Tailoring cultural offers to meet the needs of older people during uncertain times: a rapid realist review. *BMC Medicine*, 20(1), 260. <https://doi.org/10.1186/s12916-022-02464-4>
- Tierney, S., Mahtani, K. R., Wong, G., Todd, J., Roberts, N., Akinyemi, O., Howes, S., & Turk, A. (2022). The role of volunteering in supporting well-being - What might this mean for social prescribing? A best-fit framework synthesis of qualitative research. *Health & Social Care in the Community*, 30(2), e325-e346. <https://doi.org/10.1111/hsc.13516>
- Tierney, S., Potter, C., Eccles, K., Akinyemi, O., Gorenberg, J., Libert, S., Wong, G., Turk, A., Husk, K., Chatterjee, H. J., Webster, E., McDougall, B., Warburton, H., Shaw, L., & Mahtani, K. R. (2022). Social prescribing for older people and the role of the cultural sector during the COVID-19 pandemic: What are link workers' views and experiences? *Health & Social Care in the Community*, 30(6), e5305-e5313. <https://doi.org/10.1111/hsc.13949>
- Tierney, S., Wong, G., Roberts, N., Boylan, A.-M., Park, S., Abrams, R., Reeve, J., Williams, V., & Mahtani, K. R. (2020). Supporting social prescribing in primary care by linking people to local assets: a realist review. *BMC Medicine*, 18(1), 49. <https://doi.org/10.1186/s12916-020-1510-7>
- Tiner, S., Cunningham, G. B., & Pittman, A. (2021). "Physical activity is beneficial to anyone, including those with ASD": Antecedents of nurses recommending physical activity for people with autism spectrum disorder. *Autism*, 25(2), 576-587. <https://doi.org/10.1177/1362361320970082>
- Tookey, S., Renzi, C., Waller, J., von Wagner, C., & Whitaker, K. L. (2018). Using the candidacy framework to understand how doctor-patient interactions influence perceived eligibility to seek help for cancer alarm symptoms: a qualitative interview study. *BMC Health Services Research*, 18(1), 937. <https://doi.org/10.1186/s12913-018-3730-5>
- Torquati, B., Stefani, G., Massini, G., Cecchini, L., Chiorri, M., & Paffarini, C. (2019). Social farming and work inclusion initiatives for adults with autism spectrum disorders: A pilot

- study. *NJAS - Wageningen Journal of Life Sciences*, 88, 10-20.  
<https://doi.org/10.1016/j.njas.2019.02.001>
- Tsatsou, P. (2020). Is digital inclusion fighting disability stigma? Opportunities, barriers, and recommendations. *Disability & Society*, 36(5), 702-729.  
<https://doi.org/10.1080/09687599.2020.1749563>
- Valderrama, A., Martinez, A., Charlebois, K., Guerrero, L., & Forgeot d'Arc, B. (2023). For autistic persons by autistic persons: Acceptability of a structured peer support service according to key stakeholders. *Health Expect*, 26(1), 463-475. <https://doi.org/10.1111/hex.13680>
- Wallis, K. E., Adebajo, T., Bennett, A. E., Drye, M., Gerdes, M., Miller, J. S., & Guthrie, W. (2023). Short report: Prevalence of autism spectrum disorder in a large pediatric primary care network. *Autism*, 13623613221147396. <https://doi.org/10.1177/13623613221147396>
- Walsh, E., Holloway, J., McCoy, A., & Lydon, H. (2017). Technology-Aided Interventions for Employment Skills in Adults with Autism Spectrum Disorder: A Systematic Review. *Review Journal of Autism and Developmental Disorders*, 4(1), 12–25.  
<https://doi.org/10.1007/s40489-016-0093-x>
- Wang, M., Chen, R. C., Usinger, D. S., & Reeve, B. B. (2017). Evaluating measurement invariance across assessment modes of phone interview and computer self-administered survey for the PROMIS measures in a population-based cohort of localized prostate cancer survivors. *Quality of Life Research*, 26(11), 2973-2985. <https://doi.org/10.1007/s11136-017-1640-3>
- Warner, G., Parr, J. R., & Cusack, J. (2019). Workshop Report: Establishing Priority Research Areas to Improve the Physical Health and Well-Being of Autistic Adults and Older People. *Autism in Adulthood*, 1(1), 20-26. <https://doi.org/10.1089/aut.2018.0003>
- Warren, N., Eatchel, B., Kirby, A. V., Diener, M., Wright, C., & D'Astous, V. (2021). Parent-identified strengths of autistic youth. *Autism*, 25(1), 79-89.  
<https://doi.org/10.1177/1362361320945556>
- Webster, A. A., & Garvis, S. (2020). What does success mean for autistic men? A narrative exploration of self-determination. *Autism & Developmental Language Impairments*, 5, 2396941520945522. <https://doi.org/10.1177/2396941520945522>
- Webster, P. (2020). Virtual health care in the era of COVID-19. *The Lancet*, 395(10231), 1180-1181. [https://doi.org/10.1016/S0140-6736\(20\)30818-7](https://doi.org/10.1016/S0140-6736(20)30818-7)
- Welch, C., Cameron, D., Fitch, M., & Polatajko, H. (2020). From “since” to “if”: using blogs to explore an insider-informed framing of autism. *Disability & Society*, 37(4), 638-661.  
<https://doi.org/10.1080/09687599.2020.1836479>
- Welch, C., Cameron, D., Fitch, M., & Polatajko, H. (2021). Living in autistic bodies: bloggers discuss movement control and arousal regulation. *Disabil Rehabil*, 43(22), 3159-3167.  
<https://doi.org/10.1080/09638288.2020.1729872>
- Welch, C., Polatajko, H., Rigby, P., & Fitch, M. (2019). Autism inside out: lessons from the memoirs of three minimally verbal youths. *Disability and Rehabilitation*, 41(19), 2308-2316. <https://doi.org/10.1080/09638288.2018.1465133>
- Westlake, D., Ekman, I., Britten, N., & Lloyd, H. (2022). Terms of engagement for working with patients in a person-centred partnership: A secondary analysis of qualitative data. *Health & Social Care in the Community*, 30(1), 330-340. <https://doi.org/10.1111/hsc.13406>

- Westlake, D., Elston, J., Gude, A., Gradinger, F., Husk, K., & Asthana, S. (2022). Impact of COVID-19 on social prescribing across an Integrated Care System: A Researcher in Residence study. *Health & Social Care in the Community*, 30(6), e4086-e4094. <https://doi.org/10.1111/hsc.13802>
- Whelpley, C. E., & May, C. P. (2023). Seeing is Disliking: Evidence of Bias Against Individuals with Autism Spectrum Disorder in Traditional Job Interviews. *Journal of Autism and Developmental Disorders*, 53(4), 1363-1374. <https://doi.org/10.1007/s10803-022-05432-2>
- White, C., Bell, J., Reid, M., & Dyson, J. (2022). More than signposting: Findings from an evaluation of a social prescribing service. *Health & Social Care in the Community*, 30(6), e5105-e5114. <https://doi.org/10.1111/hsc.13925>
- White, K., Flanagan, T. D., & Nadig, A. (2018). Examining the Relationship Between Self-Determination and Quality of Life in Young Adults with Autism Spectrum Disorder. *Journal of Developmental and Physical Disabilities*, 30(6), 735-754. <https://doi.org/10.1007/s10882-018-9616-y>
- Wildman, J. M., Moffatt, S., Penn, L., O'Brien, N., Steer, M., & Hill, C. (2019). Link workers' perspectives on factors enabling and preventing client engagement with social prescribing. *Health & Social Care in the Community*, 27(4), 991-998. <https://doi.org/10.1111/hsc.12716>
- Wilkenfeld, D. A., & McCarthy, A. M. (2020). Ethical Concerns with Applied Behavior Analysis for Autism Spectrum "Disorder". *Kennedy Institute of Ethics Journal*, 30(1), 31-69. Retrieved from <https://muse.jhu.edu/article/753840>
- Wilkerson, J. M., Iantaffi, A., Grey, J. A., Bockting, W. O., & Rosser, B. R. (2014). Recommendations for internet-based qualitative health research with hard-to-reach populations. *Qual Health Res*, 24(4), 561-574. <https://doi.org/10.1177/1049732314524635>
- Wilkie, S., & Davinson, N. (2021). Prevalence and effectiveness of nature-based interventions to impact adult health-related behaviours and outcomes: A scoping review. *Landscape and Urban Planning*, 214, 104166. <https://doi.org/10.1016/j.landurbplan.2021.104166>
- Williams, M., 2003. *Making Sense of Social Research*. SAGE Publications, Limited, London, UNITED KINGDOM.
- Wood, E., Ohlsen, S., Fenton, S.-J., Connell, J., & Weich, S. (2021). Social prescribing for people with complex needs: a realist evaluation. *BMC Family Practice*, 22(1), 53. <https://doi.org/10.1186/s12875-021-01407-x>
- Woods, R. (2017). Exploring how the social model of disability can be re-invigorated for autism: in response to Jonathan Levitt. *Disability & Society*, 32(7), 1090-1095. <https://doi.org/10.1080/09687599.2017.1328157>
- Woods, R., Milton, D., Arnold, L., & Graby, S. (2018). Redefining Critical Autism Studies: a more inclusive interpretation. *Disability & Society*, 33(6), 974-979. <https://doi.org/10.1080/09687599.2018.1454380>
- Woolfenden, S., Sarkozy, V., Ridley, G., Coory, M., & Williams, K. (2012). A systematic review of two outcomes in autism spectrum disorder – epilepsy and mortality. *Developmental Medicine & Child Neurology*, 54(4), 306-312. <https://doi.org/10.1111/j.1469-8749.2012.04223.x>
- World Health Organization. (2017). Human rights and health. <https://www.who.int/news-room/factsheets/detail/human-rights-and-health>



- World Health Organization. (2018). International classification of diseases for mortality and morbidity statistics (11th Revision ed.). <https://icd.who.int/browse11/1-m/en>
- Yelin, D., Wirtheim, E., Vetter, P., Kalil, A. C., Bruchfeld, J., Runold, M., Guaraldi, G., Mussini, C., Gudiol, C., Pujol, M., Bandera, A., Scudeller, L., Paul, M., Kaiser, L., & Leibovici, L. (2020). Long-term consequences of COVID-19: research needs. *The Lancet Infectious Diseases*, 20(10), 1115-1117. [https://doi.org/10.1016/S1473-3099\(20\)30701-5](https://doi.org/10.1016/S1473-3099(20)30701-5)
- Younan, H. C., Junghans, C., Harris, M., Majeed, A., & Gnani, S. (2020). Maximising the impact of social prescribing on population health in the era of COVID-19. *Journal of the Royal Society of Medicine*, 113(10), 377-382. <https://doi.org/10.1177/0141076820947057>
- Zheng, L., Foley, K. R., Grove, R., Elley, K., Brown, S. A., Leong, D. J., Li, X., Pellicano, E., Trollor, J. N., & Hwang, Y. I. J. (2022). The use of everyday and assistive technology in the lives of older autistic adults. *Autism*, 26(6), 1550-1562. <https://doi.org/10.1177/13623613211058519>

## **List of Appendices**

1. Ethical approval letter dated 27/08/2020
2. Approval for ethical amendment dated 01/09/2021
3. Survey information sheet
4. Survey debrief form
5. Interview information sheet
6. Interview consent form
7. Interview debrief form
8. Survey questionnaire
9. Stage 1 interview schedules
10. Follow-up interview schedule
11. Mapping review search strategy
12. Mapping review table of studies identified
13. Mapping review qualitative analysis
14. Survey recruitment strategy
15. Autistica Social Care Seed Funding report



27<sup>th</sup> August 2020

Charlotte Featherstone  
Faculty of Health  
University of Plymouth  
Phase 1 Building, Plymouth Science Park  
Plymouth  
PL6 8BU

Dear Charlotte

**Application for Approval by Faculty Research Ethics and Integrity  
Committee**

***Amendment Reference Number:* 19/20-1311**  
***Application Title:* A mixed methods study  
exploring the impact of COVID-19 lockdowns on wellbeing, healthcare  
and access to communities for autistic adults.**

The Committee has granted ethical approval to conduct this research.

Please note that this approval is for the duration requested on your application, until 30<sup>th</sup> September 2022, after which you will be required to seek an extension of existing approval.

Please note that if you wish to make any MAJOR changes to your research you must inform the Committee. Please contact the Faculty Research Administrator, Maurice Bottomley (email [hhsethics@plymouth.ac.uk](mailto:hhsethics@plymouth.ac.uk)).

Yours sincerely



**Professor Sarah Neill,**  
**PhD, PGD Res. Deg. Sup., PGDE, MSc, BSc(Hons), RGN, RSCN, RNT**  
Professor of Nursing  
Co-Chair, Research Ethics and Integrity Committee - Faculty of Health



# UNIVERSITY OF PLYMOUTH

01/09/2021

**Confidential**

Miss Charlotte Featherstone

Dear Miss Charlotte Featherstone

**Research Ethics Application Approval - Faculty Research Ethics and Integrity Committee:**

2908

Application of ethical amendment for 19/20-1311: A mixed methods study exploring the impact of COVID-19 lockdowns on wellbeing, healthcare and access to communities for autistic adults

The committee has considered your application and has granted ethical approval to conduct this research.

Approval is for the duration of the project. If you wish to continue beyond this date, you will need to seek an extension.

Please note that if you wish to make any minor changes to your research, you must complete an amendment form or major changes you will need to resubmit an application.

Yours sincerely

Dr Daniela Oehring

Chair, Faculty of Health Staff Research Ethics and Integrity Committee



## **Participant Information Sheet (Version 1.2 - 04/08/2020)**

**Project:** *A survey study exploring wellbeing, healthcare and access to communities for autistic adults*

### **Project Invite**

We would like to invite you to take part in a research study as part of a PhD research project. Please read the following information carefully in order to decide if this study is suitable for you.

### **Why am I being invited to take part?**

You can take part in this study if you are an autistic adult over the age of 18 living in the UK. You can take part if you have a diagnosis of autism or if you suspect that you may be autistic but do not have a formal diagnosis.

### **What is this project about?**

This study will involve taking an online survey about your experiences during the COVID-19 lockdown. The responses to this survey will be used to find out the problems autistic people have when trying to use health services and community spaces and how these might have changed during lockdown. We will also look at how lockdown has affected mental wellbeing.

We would like to hear about your experiences, both good and bad. The results of the research will help to identify opportunities for services to learn and improve to support autistic people more effectively in future.

### **What will you have to do if you agree to take part?**

This study will involve taking an online survey about your experiences during the COVID-19 lockdown. The survey will take approximately 30-40 minutes to complete. You will be asked some questions about yourself, your living arrangements, access to outdoor areas and healthcare, and emotional wellbeing. Questions will relate to different time points in the past year. Please answer these questions as best you can, but don't worry if your memory is not completely accurate.

If you think you will need help completing the survey, or require a printable version, please email [charlotte.featherstone@plymouth.ac.uk](mailto:charlotte.featherstone@plymouth.ac.uk).

### **Informed consent**

This survey is voluntary and it is up to you whether you wish to take part. You will not be at any disadvantage if you decide not to take part. You will need to agree with all the statements on the next page in order to take part.

### **Right to withdraw**

If you change your mind about taking part, you can withdraw any data you have submitted within 2 weeks of taking the survey. After that time it will not be possible to withdraw your data, but it will not be possible to identify you from data which has been analysed. You will not have to give a reason for withdrawing from the study and withdrawing will not affect any planned or existing care you are receiving.

You can withdraw from the study by contacting Charlotte Featherstone (PhD student) at [charlotte.featherstone@plymouth.ac.uk](mailto:charlotte.featherstone@plymouth.ac.uk) and we will delete your responses from the survey.



### **What are the advantages of taking part?**

You may find the project interesting and enjoy answering questions about the research. The results will help to inform research about what contributes to good quality of life for autistic people and how barriers to accessing healthcare and communities can be reduced to support wellbeing.

### **Are there any disadvantages of taking part?**

You may not want to take part in this study if you are not comfortable answering brief questions about your emotional wellbeing, such as feelings related to anxiety and depression.

### **Planned Outputs**

When we have collected enough responses, we will analyse them to look for patterns. We hope to publish the results in scientific journals related to the topics covered by the survey. We will follow up this study with interviews and other qualitative methods to find out more about these experiences in depth. Outcomes from the research, such as recommendations for health services, will therefore be informed by the lived experiences of autistic people.

If you would like to be added to a mailing list to receive updates on the study and information about follow-up studies you can take part in, there will be an opportunity to give your email address at the end of the survey. This is optional and your email address will not be linked to your answers to the survey so we will not be able to identify your answers from your email address. Your email address will not be shared outside the research team or used for any other purpose.

### **Confidentiality<sup>1</sup>**

Sensitive data will be handled and stored in line with data protection laws that apply in the UK and Europe (GDPR and the UK Data Protection Act) and will not be used for any purpose other than analysis of the results of this survey. Data will be stored securely on a private University of Plymouth network drive. Data that is shared in publications or data repositories will not contain names or other information that could be used to identify you.

As part of NIHR funded research, your data will be handled in accordance with the NHS UK Policy Framework for Health and Social Care Research <https://www.hra.nhs.uk/planning-and-improving-research/policies-standards-legislation/uk-policy-framework-health-social-care-research/>, the General Data Protection Regulation (GDPR) 2018 and the Data Protection Act 2018.

Your information will be retained for at least 10 years in case of the need to contact you and in compliance with the University of Plymouth's Research Data Policy. After 10 years, your data may no longer be available. Anonymous research results stored in online repositories which allow future researchers to use the study data will be stored indefinitely in accordance with GDPR.

### **Questions**

If you have any questions about taking part that have not been answered by this information sheet, you can email Charlotte Featherstone (PhD student) at [charlotte.featherstone@plymouth.ac.uk](mailto:charlotte.featherstone@plymouth.ac.uk).

### **Project contact details:**

If you have any questions or concerns, please contact the student or supervisory team in the first instance using the details below.

Name of student: Charlotte Featherstone

Contact details: [charlotte.featherstone@plymouth.ac.uk](mailto:charlotte.featherstone@plymouth.ac.uk)

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<sup>1</sup> In accordance with [Plymouth University Ethics Policy](#)



**Supervisory team:**

Dr Kerry Husk (University of Plymouth); Dr Richard Sharpe (Public Health, Cornwall Council); Dr Nick Axford (University of Plymouth); Professor Sheena Asthana (University of Plymouth)

Contact details of Primary Supervisor: [kerryn.husk@plymouth.ac.uk](mailto:kerryn.husk@plymouth.ac.uk)

Research Group: The National Institute for Health Research (NIHR) Applied Research Collaboration (ARC) South West Peninsula have funded this research. Contact options are available at:

<https://www.arc-swp.nihr.ac.uk/contact> (Tel: 01392 726055)

With Autistica (<https://www.autistica.org.uk/>)



**To make a complaint:**

If your concerns have not been addressed to your satisfaction by the research team, you can make a complaint to the University of Plymouth health research ethics committee:

[HHSEthics@plymouth.ac.uk](mailto:HHSEthics@plymouth.ac.uk)

Tel: 01752 586992

**Consent Statements**

*(Project: A survey study exploring wellbeing, healthcare and access to communities for autistic adults)*

<b>Please read each statement carefully and tick the box if you agree.</b>	
I confirm I have read and understood the study information sheet (version 1.2, 04/08/2020) for the above study	
I confirm I have been given the opportunity to ask questions about the survey if needed and that I am satisfied with the answers I have been given	
I confirm that I understand that my participation in this research is voluntary and that I have a right to withdraw up to two weeks after taking part.	
I confirm that the use of the data that I provide has been clearly explained	
I consent to my anonymised data being used for the purposes of this research	
I consent to the processes around storage, publication, sharing, archiving and destruction of the data I provide	
I confirm I am over 18 years old	
I agree to take part in the above study	



## **Participant Debrief Sheet (Version 1.2 – 04/08/2020)**

**Project:** *A survey exploring wellbeing, healthcare and access to communities for autistic adults*

Thank you for taking part in this study and sharing your experiences of your wellbeing during lockdown to support our research.

You may want to print this page or make a note of the unique ID number you have been given (shown above) and the researcher contact details below for future reference.

If you would like to, you may share this survey with other autistic people that you know who have not yet completed it, which will help us to reach a larger sample of people.

### **What happens now?**

When we have collected enough responses, we will analyse them to look for patterns. The results will help to inform research about what contributes to good quality of life for autistic people and how barriers to accessing healthcare and communities can be reduced to support wellbeing.

If you have provided an email address, you will hear from us again in future with updates about the survey and information about follow-up studies you can take part in.

We hope to publish the studies in scientific journals related to the topics covered by the survey and to share results as appropriate at conferences, presentations, webinars and on social media/blogs. In line with guidelines for NIHR funded research, publications will be made Open Access wherever possible so that they are free to read. Where this may not be possible, a copy of the final PhD thesis will be available on Plymouth University's online repository (PEARL) and pre-print versions of journal articles will also be available by contacting the researchers.

Your data will be retained for at least 10 years in line with the University of Plymouth's Research Data Policy.

### **What if I have concerns from taking part in this survey or want to withdraw from the research?**

If you need further advice about managing your wellbeing, these organisations are able to provide support:

- Samaritans (<http://samaritans.org>) Phone 116 123. Advice hotline for emotional distress.
- Mind (<http://mind.org.uk>) Mental health support.
- National Autistic Society (<http://autism.org.uk>) and Autistica (<http://autistica.org.uk>) Advice and support about autism, including information about managing during the coronavirus pandemic. You may be able to find details of local support groups for autistic adults through the National Autistic Society's website.

You can also get support with wellbeing from your GP and by visiting <http://nhs.uk>.

If you change your mind about taking part, you can withdraw your data up to 2 weeks after taking the survey. After this time it will not be possible to withdraw your data. You can withdraw your data by emailing [charlotte.featherstone@plymouth.ac.uk](mailto:charlotte.featherstone@plymouth.ac.uk).





You may also contact the researcher if you provided an email address for future contact but no longer wish to be contacted, and we can remove your email address from the mailing list.

If any parts of this survey caused you concerns with regard to your wellbeing or the wellbeing of others, or there is anything else you are not satisfied with, please contact the researcher in the first instance at [charlotte.featherstone@plymouth.ac.uk](mailto:charlotte.featherstone@plymouth.ac.uk) or the academic supervisor Kerry Husk at [Kerry.husk@plymouth.ac.uk](mailto:Kerry.husk@plymouth.ac.uk)

If your concerns have not been resolved to your satisfaction, you can contact the University of Plymouth's health research ethics committee at [HHSEthics@plymouth.ac.uk](mailto:HHSEthics@plymouth.ac.uk) Tel: 01752 586992

**Project details:**

Name of student: Charlotte Featherstone

Contact details: [charlotte.featherstone@plymouth.ac.uk](mailto:charlotte.featherstone@plymouth.ac.uk)

Supervisory team:

Dr Kerry Husk (University of Plymouth); Dr Richard Sharpe (Public Health, Cornwall Council); Dr Nick Axford (University of Plymouth); Professor Sheena Asthana (University of Plymouth)

Contact details of Primary Supervisor: [kerry.husk@plymouth.ac.uk](mailto:kerry.husk@plymouth.ac.uk)

Research Group: The National Institute for Health Research (NIHR) Applied Research Collaboration (ARC) South West Peninsula have funded this research. Contact options are available at: <https://www.arc-swp.nihr.ac.uk/contact> (Tel: 01392 726055)



## **Participant Information Sheet (Version 2 – 06/08/2021)**

**Project:** *An interview study exploring wellbeing, healthcare and access to communities for autistic adults*

### **Project Invite**

We would like to invite you to take part in a research study as part of a PhD research project. Please read the following information carefully in order to decide if this study is suitable for you.

### **Why am I being invited to take part?**

You can take part in this study if you are an autistic adult over the age of 18 living in the UK. You can take part if you have a diagnosis of autism or if you suspect that you may be autistic but do not have a formal diagnosis.

### **What is this project about?**

We are a research team comprised of an autistic and non-autistic researchers, interested in exploring the potential for improving health and wellbeing outcomes for autistic adults through community-based social prescribing services. The aim of this study is to carry out web-based interviews to find out about autistic adults' experiences of managing wellbeing and accessing services, including social prescribing, although you don't have to have experience of social prescribing to take part in the study. (If you're not sure what social prescribing is, you can read more about it [here](#)).

We would like to hear about your experiences, both good and bad. There are no right or wrong answers. The results of the research will help to identify opportunities for services to learn and improve to support autistic people more effectively in future. By conducting interviews, this will ensure that recommendations are informed by the lived experiences of real people, as well as providing rich information to learn about how autistic adults manage wellbeing, an area that is under-explored. We are really keen to hear from a range of people, especially those who don't usually take part in research. For example, we can discuss options to help you take part if you find speaking difficult some or all of the time.

### **How do you take part?**

To take part you will need to complete the expression of interest form or email [charlotte.featherstone@plymouth.ac.uk](mailto:charlotte.featherstone@plymouth.ac.uk). You will then be contacted to arrange a date for your interview that works for both you and the researcher – weekends and evenings are available if you are usually busy during weekdays.

### **What will you have to do if you agree to take part?**

This study will involve taking part in an interview with a research student (Charlotte Featherstone, photo below), which will be carried out using Zoom or by phone call (via Zoom) whichever is your preference. Zoom includes many accessibility options which can be used to help you take part in a way that is comfortable for you and suitable for your needs, such as live captioning and the ability to use text to communicate, so if you are interested in taking part please get in touch even if a standard interview would be difficult for you, as we can work together to find ways to accommodate you. If you are unable to use Zoom, you may also take part in an interview by email.

We will first contact you with a form to complete with your contact details and preferences and to arrange an interview date.



You will be sent a copy of the interview questions before taking part so you will know what to expect and can prepare some answers. In the interview, the researcher may ask extra questions in response to your answers, or ask questions in a slightly different order to what you have seen previously. The interview will take 1-2 hours and, with your permission, will be recorded if you are taking part in a video or audio-based interview – this ensures we can use your answers accurately. You will be asked to consent to the recording and data collection processes before taking part in the study and will need to confirm this verbally (for a video or audio interview) or in writing for a text-based interview. If you need the support of a family member, friend or carer to take part, they will also need to complete a consent form. You can take a break at any time during the interview and you can also skip any question that you do not want to answer.

### **What happens after the interview?**

After the interview, we will store the video/audio/text file of your interview and type it up into a transcript. We may contact you again by email if there is anything you said in the interview which we are not sure about and would need more detail on. In some cases we might want to carry out a second interview if there are areas that we would like to explore in more detail, but this would be your choice.

The interview transcript will be analysed with the transcripts of other people's interviews and we will look for themes that link responses together. We will change your name and remove any other identifying information about you or other people that might be mentioned in your interview so that people will not be able to identify you from the transcript or information about this study.

You will be sent a summary of the study results after your interview and you can give your feedback and views on this (more information on what feedback would be helpful will be included at the time).

### **Informed consent**

This study is voluntary and it is up to you whether you wish to take part. You will not be at any disadvantage if you decide not to take part. You will need to agree with all the statements on the next page in order to take part.

### **Right to withdraw**

If you change your mind about taking part during the interview, you can ask to end the interview at any time. You can choose whether or not to withdraw your data. You can also drop out after the interview if you decide you would not like us to keep your data after taking part. You will have 2 weeks after your interview to let us know if you want to withdraw. After that time it will not be possible to withdraw your data, but it will not be possible to identify you from data which has been analysed. You will not have to give a reason for withdrawing from the study and withdrawing will not affect any planned or existing care you are receiving.

You can withdraw from the study by contacting Charlotte Featherstone (PhD student) at [charlotte.featherstone@plymouth.ac.uk](mailto:charlotte.featherstone@plymouth.ac.uk) and we will delete your data permanently.

### **What are the advantages of taking part?**

You may find the project interesting and enjoy answering questions about the research. The results will help to inform research about how autistic adults manage wellbeing and where there are gaps in service provision, so that these can be addressed in a way that is relevant and responsive to the strengths, interests and needs of autistic people. The interview has been developed and will be analysed by a researcher who is on the autism spectrum.



### **Are there any disadvantages of taking part?**

You may not want to take part in this study if you are not comfortable answering questions about your mental health or experiences of accessing health services. If you do experience any distress during the interview, you can ask to stop at any time and you will be given details of services which offer support. However, it is unlikely that the interview will cause distress and you can view the interview questions beforehand to help plan your answers and decide if the interview is right for you.

### **Planned Outputs**

We hope to publish the results in scientific journals related to autism, public health or delivering health services. We are also planning to do further work to co-produce a resource for providers of social prescribing (community-based activities intended to improve wellbeing) on providing a service which is accessible and inclusive to autistic adults. The research outputs will also be shared with the public in a number of formats, and it is best to follow our Twitter account at [@SPAA\\_Project](#) to keep up to date.

### **Confidentiality<sup>2</sup>**

Sensitive data will be handled and stored in line with data protection laws that apply in the UK and Europe (GDPR and the UK Data Protection Act) and will not be used for any purpose other than analysis of the results of this survey. Data will be stored securely on a private University of Plymouth network drive. Data that is shared in publications or data repositories will not contain names or other information that could be used to identify you.

As part of NIHR funded research, your data will be handled in accordance with the NHS UK Policy Framework for Health and Social Care Research <https://www.hra.nhs.uk/planning-and-improving-research/policies-standards-legislation/uk-policy-framework-health-social-care-research/>, the General Data Protection Regulation (GDPR) 2018 and the Data Protection Act 2018.

Your information will be retained for at least 10 years in case of the need to contact you and in compliance with the University of Plymouth's Research Data Policy. After 10 years, your data may no longer be available. Anonymous research results stored in online repositories which allow future researchers to use the study data will be stored indefinitely in accordance with GDPR.

### **Questions**

If you have any questions about taking part that have not been answered by this information sheet, you can email Charlotte Featherstone (PhD student) at [charlotte.featherstone@plymouth.ac.uk](mailto:charlotte.featherstone@plymouth.ac.uk).

### **Project contact details:**

If you have any questions or concerns, please contact the student or supervisory team in the first instance using the details below.

Name of student (carrying out interviews): Charlotte Featherstone

Contact details: [charlotte.featherstone@plymouth.ac.uk](mailto:charlotte.featherstone@plymouth.ac.uk)

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<sup>2</sup> In accordance with [Plymouth University Ethics Policy](#)



**UNIVERSITY OF  
PLYMOUTH**

Faculty of Health: Medicine,  
Dentistry & Human Sciences

**NIHR** | Applied Research Collaboration  
South West Peninsula



**Supervisory team:**

Dr Kerryn Husk (University of Plymouth); Dr Richard Sharpe (Public Health, Cornwall Council); Dr Nick Axford (University of Plymouth); Professor Sheena Asthana (University of Plymouth)

Contact details of Primary Supervisor: [kerryn.husk@plymouth.ac.uk](mailto:kerryn.husk@plymouth.ac.uk)

Research Group: The National Institute for Health Research (NIHR) Applied Research Collaboration (ARC) South West Peninsula have funded this research. Contact options are available at:

<https://www.arc-swp.nihr.ac.uk/contact> (Tel: 01392 726055)

**NIHR** | Applied Research Collaboration  
South West Peninsula

The project is supported by Autistica (<https://www.autistica.org.uk/>) and Cornwall Council



**Please note no personal information is shared with funders/partner organisations.**

**To make a complaint:**

If your concerns have not been addressed to your satisfaction by the research team, you can make a complaint to the University of Plymouth health research ethics committee:

[HHSEthics@plymouth.ac.uk](mailto:HHSEthics@plymouth.ac.uk)

Tel: 01752 586992

**Reference number: 19/20-1311**



**Consent Statements**

(Project: *An interview study exploring wellbeing, healthcare and access to communities for autistic adults*)

<b>Please read each statement carefully and tick the box if you agree.</b>	
I confirm I have read and understood the study information sheet (version 2, 06/08/2021) for the above study	
I confirm I have been given the opportunity to ask questions about the study if needed and that I am satisfied with the answers I have been given	
I confirm that I understand that my participation in this research is voluntary and that I have a right to withdraw up to two weeks after taking part.	
I consent to the interview being recorded for the purposes of audio transcription (not applicable for text-based interviews)	
I confirm that the use of the data that I provide has been clearly explained	
I consent to my anonymised data being used for the purposes of this research	
I consent to the processes around storage, publication, sharing, archiving and destruction of the data I provide	
I confirm I am over 18 years old	
I agree to take part in the above study	

Name (IN CAPITALS): .....

Signature: .....

Date: .....

Name of researcher: .....

Signature: .....

Date: .....



## **Participant Debrief Sheet (Version 1 – 24/05/2021)**

**Project:** *Project: An interview study exploring wellbeing, healthcare and access to communities for autistic adults*

Thank you for taking part in this study and sharing your experiences of managing your wellbeing and accessing services.

### **What happens now?**

After your interview, you will be sent a transcript (text) of the interview to review. We will let you know what type of feedback we need from you at the time (for example, we might ask you to correct any errors or clarify something that was mentioned in the interview).

When we have carried out enough interviews, we will analyse them to look for patterns called themes. The results will help to inform research about what contributes to good quality of life for autistic people and how services, particularly social prescribing, can be provided in ways that are accessible and inclusive to autistic adults. Your interview will help to make sure recommendations have been informed by the lived experience of autistic adults. You can find out more about social prescribing [here](#), and you can speak to your GP or local voluntary sector to find out if social prescribing is available in your local area if you would like to take part in a community-based activity to manage your wellbeing.

We hope to publish the studies in scientific journals related to the topics covered by the interview and to share results as appropriate at conferences, presentations, webinars and on social media/blogs. In line with guidelines for NIHR funded research, publications will be made Open Access wherever possible so that they are free to read. Where this may not be possible, a copy of the final PhD thesis will be available on Plymouth University's online repository (PEARL) and pre-print versions of journal articles will also be available by contacting the researchers. You can also follow our Twitter account [@SPAA\\_Project](#) for updates about the studies and results.

Your data will be retained for at least 10 years in line with the University of Plymouth's Research Data Policy.

### **What if I have concerns from taking part in this survey or want to withdraw from the research?**

If you need further advice about managing your wellbeing, these organisations may be able to provide support:

- Samaritans (<http://samaritans.org>) Phone 116 123. Advice hotline for emotional distress.
- Shout (<https://giveusashout.org/>) Text SHOUT to 85258. Service offering mental health support by text messaging.
- Mind (<http://mind.org.uk>) Mental health support.
- National Autistic Society (<http://autism.org.uk>) and Autistica (<http://autistica.org.uk>) Advice and support about autism, including information about managing during the coronavirus pandemic. You may be able to find details of local support groups for autistic adults through the National Autistic Society's website.



You may also be able to get support with wellbeing from your GP and by visiting <http://nhs.uk>.

If you change your mind about taking part, you can withdraw your data up to 2 weeks after taking the interview. After this time it will not be possible to withdraw your data. You can withdraw your data by emailing [charlotte.featherstone@plymouth.ac.uk](mailto:charlotte.featherstone@plymouth.ac.uk).

If any parts of this interview caused you concerns with regard to your wellbeing or the wellbeing of others, or there is anything else you are not satisfied with, please contact the researcher in the first instance at [charlotte.featherstone@plymouth.ac.uk](mailto:charlotte.featherstone@plymouth.ac.uk) or the academic supervisor Kerryn Husk at [Kerryn.husk@plymouth.ac.uk](mailto:Kerryn.husk@plymouth.ac.uk)

If your concerns have not been resolved to your satisfaction, you can contact the University of Plymouth's health research ethics committee at [HHSEthics@plymouth.ac.uk](mailto:HHSEthics@plymouth.ac.uk) Tel: 01752 586992. The reference number for this study is 19/20-1311.

**Project details:**

Name of student: Charlotte Featherstone

Contact details: [charlotte.featherstone@plymouth.ac.uk](mailto:charlotte.featherstone@plymouth.ac.uk)

Supervisory team:

Dr Kerryn Husk (University of Plymouth); Dr Richard Sharpe (Public Health, Cornwall Council); Dr Nick Axford (University of Plymouth); Professor Sheena Asthana (University of Plymouth)

Contact details of Primary Supervisor: [kerryn.husk@plymouth.ac.uk](mailto:kerryn.husk@plymouth.ac.uk)

Research Group: The National Institute for Health Research (NIHR) Applied Research Collaboration (ARC) South West Peninsula have funded this research. Contact options are available at: <https://www.arc-swp.nihr.ac.uk/contact> (Tel: 01392 726055)





**UNIVERSITY OF  
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# Exploring wellbeing, healthcare and access to communities for autistic adults

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## About this survey

### **Participant Information Sheet (Version 1.3 – 01/09/2020)**

**Project:** *A survey exploring wellbeing, healthcare and access to communities for autistic adults*

### **Project Invite**

We would like to invite you to take part in a survey as part of a PhD research project. Please read the following information carefully to decide if this research is suitable for you.

### **You can take part in this study if you are:**

- An autistic adult over the age of 18, living in the UK.
- You can take part if you have a diagnosis of autism or if you suspect that you may be on the autism spectrum but do not have a formal diagnosis.

### **About the survey**

- The survey is voluntary and it is up to you whether you wish to take part.
- The survey will take approximately 30-60 minutes to complete.
- You will be asked some questions about yourself, your living arrangements, access to outdoor areas and healthcare, and emotional wellbeing. Questions will relate to different time points in the past year. Please answer these questions as best you can, but don't worry if your memory is not completely accurate.

- The results will help to inform research about what contributes to good quality of life for autistic people and how barriers to accessing healthcare and communities can be reduced to support wellbeing.
- **If you think you will need help completing the survey, or require a printable version, please email [charlotte.featherstone@plymouth.ac.uk](mailto:charlotte.featherstone@plymouth.ac.uk).**

### **Are there any disadvantages of taking part?**

- You may not want to take part in this study if you are not comfortable answering brief questions about your emotional wellbeing, such as feelings related to anxiety and depression.

Click next to continue to information about survey ethics.

# Ethics information

This page outlines the ethical procedures used in this survey. Please read the information then **complete the form at the bottom of the page to proceed to the survey.**

## What will happen to your data?

Sensitive data will be handled and stored in line with data protection laws that apply in the UK and Europe (GDPR and the UK Data Protection Act) and will not be used for any purpose other than analysis of the results of this survey. Data will be stored securely on a private University of Plymouth network drive. Data that is shared in publications or data repositories will not contain names or other information that could be used to identify you. Data will be handled in accordance with the NHS UK Policy Framework for Health and Social Care Research <https://www.hra.nhs.uk/planning-and-improving-research/policies-standards-legislation/uk-policy-framework-health-social-care-research/>, the General Data Protection Regulation (GDPR) 2018 and the Data Protection Act 2018. Your information will be retained for at least 10 years in case of the need to contact you and in compliance with the University of Plymouth's Research Data Policy. After 10 years, your data may no longer be available. Anonymous research results stored in online repositories which allow future researchers to use the study data will be stored indefinitely in accordance with GDPR. In accordance with [Plymouth University Ethics Policy](#)

## Follow-up studies

If you would like to be added to a mailing list to receive updates on the study and information about follow-up studies you can take part in, there will be an opportunity to give your email address at the end of the survey. This is optional and your email address will not be linked to your answers to the survey. Your email address will not be shared outside the research team or used for any other purpose.

## Right to withdraw:

If you change your mind about taking part once started, you can withdraw any data you have submitted within 2 weeks of taking the survey by contacting Charlotte Featherstone (PhD student) at [charlotte.featherstone@plymouth.ac.uk](mailto:charlotte.featherstone@plymouth.ac.uk). You will not have to give a reason for withdrawing from the study and withdrawing will not affect any planned or existing care you are receiving.

This study was approved by the University of Plymouth health research ethics committee on 27<sup>th</sup> August 2020.

[HHSEthics@plymouth.ac.uk](mailto:HHSEthics@plymouth.ac.uk)

Tel: 01752 586992

**Ethical approval reference number: 19/20-1311**

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## Questions

If you have any questions about taking part that have not been answered by this information sheet, you can email Charlotte Featherstone (PhD student) at [charlotte.featherstone@plymouth.ac.uk](mailto:charlotte.featherstone@plymouth.ac.uk).

Supervisory team:

Dr Kerryn Husk (University of Plymouth); Dr Richard Sharpe (Public Health, Cornwall Council); Dr Nick Axford (University of Plymouth); Professor Sheena Asthana (University of Plymouth)

Contact details of Primary Supervisor: [kerryn.husk@plymouth.ac.uk](mailto:kerryn.husk@plymouth.ac.uk)

Research Group: The National Institute for Health Research (NIHR) Applied Research Collaboration (ARC) South West Peninsula have funded this research. Contact options are available at: <https://www.arc-swp.nihr.ac.uk/contact> (Tel: 01392 726055)

**NIHR** | Applied Research Collaboration  
South West Peninsula

With Autistica (<https://www.autistica.org.uk/>)



**Consent Statements: Please read each statement carefully and tick the box if you agree.**

	* <i>Required</i>
	Agree
I confirm I have read and understood the study information	<input type="radio"/>
I confirm I have been given the opportunity to ask questions about the survey if needed and that I am satisfied with the answers I have been given	<input type="radio"/>
I confirm that I understand that my participation in this research is voluntary and that I have a right to withdraw from the research up to two weeks after taking part	<input type="radio"/>
I confirm that the use of the data that I provide has been clearly explained	<input type="radio"/>
I consent to my anonymised data being used for the purposes of this research	<input type="radio"/>
I consent to the processes around storage, publication, sharing, archiving and destruction of the data I provide	<input type="radio"/>
I confirm I am over 18 years old	<input type="radio"/>
I agree to take part in the above study	<input type="radio"/>

# Screening Questions

Do you live in the UK? \* *Required*

# Screening Questions

Did you live outside the UK for any period since March 2020? \* *Required*

# Screening Questions

Do you have a clinical diagnosis of autism? (including Autism Spectrum Disorder; Asperger's syndrome; High Functioning Autism; Atypical autism) \* *Required*



# Screening Questions

Do you believe yourself to be on the autism spectrum? \* *Required*

- Yes
- No
- Maybe

## Your autism diagnosis

What diagnosis were you given? (e.g. Autism Spectrum Disorder; Asperger's syndrome; High Functioning Autism)

If you don't know your diagnosis, please select "Don't know" below:

In what year (approximately) did you receive your diagnosis? \* *Required*

Please enter a whole number (integer).

What was the role of the professional who diagnosed you? \* *Required*

- Psychiatrist
- Psychologist
- Paediatrician
- Not sure
- Other

If you selected Other, please specify:

# AQ-10

Please tick one option per question only.

	<i>* Required</i>			
	Definitely agree	Slightly agree	Slightly disagree	Definitely disagree
I often notice small sounds when others do not	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I usually concentrate on the whole picture rather than the small details	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I find it easy to do more than one thing at once	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
If there is an interruption, I can switch back to what I was doing very quickly	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I find it easy to 'read between the lines' when someone is talking to me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I know how to tell if someone listening to me is getting bored	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When reading a story I find it difficult to work out the characters' intentions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I like to collect information about categories of things (e.g. types of car, types of bird, types of train, types of plant etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I find it easy to work out what someone is thinking or feeling just by looking at their face	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I find it difficult to work out people's intentions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

# Demographics

Please answer these questions about yourself. If you do not wish to answer a question, you may select 'Prefer not to say'.

What is your age?

- Prefer not to say
- 18-25
- 26-35
- 36-45
- 46-55
- 56-65
- 65+

What is your gender?

- Prefer not to say
- Male
- Female
- Non-binary/Other

What is your ethnic background?

- Prefer not to say
- White & Black Caribbean
- White & Black African
- White & Asian

- Any other mixed background
- Chinese
- Bangladeshi
- Indian
- Pakistani
- Any other Asian background
- African
- Caribbean
- Any other Black background
- White British
- White Irish
- Any other white background
- Other

What is your level of education?

- Prefer not to say
- No formal education
- GCSEs/NVQ Level 1-2
- A Level/NVQ Level 3
- Foundation/Undergraduate Degree/Diploma/Higher Education Certificate/BTEC/NVQ Lv4-5
- Postgraduate Degree

What is your employment status? (note "employed" includes self-employment)

- Prefer not to say
- Employed full time (30 or more hours per week)
- Employed part time (Less than 30 hours per week)

- Retired
- Student
- Volunteer
- Not currently in employment

What is your annual household income before tax?

- Prefer not to say
- Under £10,000
- £10,000-£19,999
- £20,000-£29,999
- £30,000-£39,999
- £40,000+
- Don't know

What is the first part of your postcode? (e.g. PL6) This will be used to compare responses from different areas.

Your answer should be no more than 6 characters long.

## Questions about disability

Do you consider yourself to have any disabilities other than autism? Select all that apply.

- No other disabilities
- Visual (e.g. blindness or partial sight)
- Hearing (e.g. deafness or partial hearing)
- Mobility (e.g. walking short distances or climbing stairs)
- Dexterity (e.g. lifting or carrying objects or using a keyboard)
- Learning disability or difficulty
- Memory
- Mental health
- Stamina, breathing or fatigue
- ADHD
- Other

If you selected Other, please specify:

	Very good	Good	Fair	Bad	Very bad	Don't know
How would you rate your general health at the moment?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

What is your usual method of communicating your needs to others?

- Verbally (talking)
- Using a communication device (AAC)

- Through writing
- Visual communication methods (e.g. picture exchange system)
- Sign language (BSL; Makaton)
- Another way or a mixture of ways

Do you mask (camouflage) your autism in social situations to fit in with other people? (e.g. using scripts to make conversation; copying body language and facial expressions of others; feeling like you're performing in social situations rather than being yourself)

- Always or usually
- Sometimes
- No
- Not sure



# Questions about your living arrangements

The questions in this survey will ask about your life last year (2019), during lockdown and in the past month.

Where we say "During lockdown", we are talking about the full national lockdown where most people were instructed to stay at home, which was brought in on 23 March 2020.

Lockdown restrictions began easing on 13 May in England and slightly later in Scotland, Wales and Northern Ireland. "During lockdown" refers to that period from March to May.

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What type of accommodation were you living in during 2020? Select all that apply.

- Living alone in private owned/rented accommodation
- Living with others (e.g. partner, family, housemates) in private owned/rented accommodation
- Supported accommodation
- University halls of residence
- Inpatient unit
- Residential care home
- Other

If you selected more than one type of accommodation, please give details (e.g. dates when your accommodation changed)

What did you do during the lockdown period in the UK (23 March - 13 May)?

- I stayed at home throughout lockdown and did not go out at all (e.g. shielding)
- I went out at least some of the time (e.g. for exercise, work or grocery shopping)

In the last month:

- I stayed at home and did not go out at all
- I went out at least some of the time (e.g. for exercise, work, grocery shopping)

At any time in the past year, did you receive payments from the government to support you? (e.g. personal independence payment (PIP); employment support allowance (ESA); disabled students' allowance (DSA); universal credit; housing benefit; carer's allowance)

- Yes
- No
- Not sure
- Prefer not to say

Did you have support from adult social care (or have the opportunity to access support from adult social care if needed) at any time in the past year?

- Yes
- No
- Not sure
- Prefer not to say

Did you have help from your community at any time in the past year? (e.g. volunteers helped you with shopping).

- Yes
- No
- Prefer not to say

# Healthcare requirements

Did you have any health problems that required support from health services...

	Yes	No
During lockdown?	<input type="radio"/>	<input type="radio"/>
In the past month?	<input type="radio"/>	<input type="radio"/>

Were you offered any virtual healthcare (e.g. video/phone calls)...

	Yes	No
In 2019 or before?	<input type="radio"/>	<input type="radio"/>
During lockdown?	<input type="radio"/>	<input type="radio"/>
In the past month?	<input type="radio"/>	<input type="radio"/>

## Barriers to healthcare

In this section you will be asked about your experiences of using health services in the past, during the full UK lockdown, and in the last month. You will need to select whether you agree or disagree with the statements. If you did not need to use health services in the specified time period, please select 'disagree'.

	In 2019 or before		During lockdown		In the past month	
	Agree	Disagree	Agree	Disagree	Agree	Disagree
Fear, anxiety, embarrassment or frustration kept me from getting to primary care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I had trouble following up on care (e.g. going to the pharmacy, taking prescribed drugs at the right time, or making a follow-up appointment)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I had difficulty understanding how to translate medical information into concrete steps that I could take to improve my health.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt that I don't understand the healthcare system	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I found it too difficult to make appointments	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I had problems filling out paperwork	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

My behaviours were misinterpreted by my provider or the staff	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My providers or the staff did not take my communications seriously.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	In 2019 or before		During lockdown		In the past month	
	Agree	Disagree	Agree	Disagree	Agree	Disagree
I could not find a healthcare provider who would accommodate my needs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My providers or the staff did not include me in discussions about my health.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Communication with my healthcare provider or the staff was too difficult.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When I experienced pain and/or other physical symptoms, I had difficulties identifying them and reporting them to my healthcare provider.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sensory discomforts (e.g. the lights, smells, or sounds) got in the way of my healthcare.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I did not have a way to get to my doctor's surgery	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

I had inadequate social, family or caregiver support	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I found it hard to handle the waiting room	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

## Use of outdoor spaces

The following questions ask about your use of outdoor green spaces such as parks and gardens during lockdown (including your private garden if you have one).

Did you access any of the following? (Select all that apply)

	In 2019	During lockdown	In the past 2 weeks
Private garden	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other private outdoor space (e.g. balcony)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Public outdoor/green space (e.g. park; communal garden; nature reserve)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

How frequently did you use your garden/private outdoor space?

	More than once a day	Once a day	Several times a week	Once a week	Less often	Not applicable
In 2019	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
During lockdown	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
In the past 2 weeks	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Private outdoor space: What activities did you use your garden or private outdoor space for? (Select all that apply) If you did not access a private outdoor space during the specified time period, you can skip this question.



	In 2019	During lockdown	Last 2 weeks
Gardening (including growing vegetables to eat)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sitting and relaxing or socialising	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Exercise	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Watching/caring for wildlife	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other (e.g. household chores)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## Use of outdoor spaces

These questions ask about your use of public green spaces. Examples of public green spaces include: parks; allotments; coast; nature reserves; woodlands; rivers

How frequently did you access a public green space?

	More than once a day	Once a day	Several times a week	Once a week	Less often	Not applicable
In 2019	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
During lockdown	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
In the past 2 weeks	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

What activities did you typically use public green space for? (Select all that apply) If you did not access a public green space during the specified time period, select 'Not applicable'.

	<i>Optional</i>		
	In 2019	During lockdown	Last 2 weeks
Exercise (e.g. alone; with others; walking a dog)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Relaxation and recreation (e.g. watching wildlife; getting some fresh air; visiting an attraction)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Socialising (e.g. spending time with family/friends; outdoor dining with others)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Working outdoors (including volunteering)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Passing through on the way to somewhere else	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

How satisfied were you with your amount of access to public green spaces?

	1 - Very dissatisfied	2	3	4	5 - Very satisfied	Don't know
In 2019	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
During lockdown	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Last 2 weeks	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

## Access to outdoor spaces

Did any of the following problems prevent you spending more time in public green spaces in the past year? (Select all that apply)

- Bad/poor weather
- Old age
- Poor health/a physical disability
- Pregnancy
- I have young children
- I have other caring responsibilities
- I am too busy at home
- I am too busy at work
- I am not interested in visiting public green spaces
- Visiting public green spaces is not something for people like me
- I don't like going to public green spaces on my own
- I don't have access to a car
- Lack of public transport prevents me from visiting green spaces
- It's too expensive to visit green spaces
- I prefer to do other leisure activities
- I don't feel safe in public green spaces
- I have concerns about where I am allowed to go/trespassing
- I don't feel welcome or feel out of place
- There is a lack of a suitable place to go or lack of suitable paths
- I don't know where to go or lack information about green spaces in my area

Do you agree with any of the following statements about your experiences of accessing public green spaces? (Select all that apply)

In 2019	During lockdown	Last 2 weeks
---------	-----------------	--------------

I felt anxious in public green spaces	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
When I accessed green spaces, there was wildlife to see and enjoy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The areas were free of litter and vandalism	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
There were good facilities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I felt safe in public green spaces	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I found visits to public green spaces worthwhile	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I was satisfied with my visits to public green spaces	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Going to public green spaces helped me get away from it all and clear my head	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

# PROMIS Support Questions

Please rate your agreement with the following questions

	Never	Rarely	Sometimes	Usually	Always
Do you have someone to help you if you are confined to bed?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Do you have someone to take you to the doctor if you need it?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Do you have someone to help with your daily chores if you are sick?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Do you have someone to run errands if you need it?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Do you have someone to prepare your meals if you are unable to do it yourself?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Do you have someone to take over all of your responsibilities at home if you need it?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Is someone available to help you if you need it?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Do you have someone to help you clean up around the home if you need it?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Never	Rarely	Sometimes	Usually	Always
I have someone who will listen to me when I need to talk	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have someone to confide in or talk to about myself or my problems	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

I have someone who makes me feel appreciated	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have someone to talk with when I have a bad day	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have someone who understands my problems	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have someone I trust to talk with about my feelings	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have someone with whom to share my most private worries and fears	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have someone I trust to talk with about my problems	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

# PROMIS Wellbeing Questions

Please rate your agreement with the following statements

---

**In the past 7 days...**

	Never	Rarely	Sometimes	Often	Always
I felt fearful	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I found it hard to focus on anything other than my anxiety	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My worries overwhelmed me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt uneasy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt nervous	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt like I needed help for my anxiety	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt anxious	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt tense	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Thinking about feelings of anxiety, do you think you have felt better or worse this year than you did last year?

- Better
- About the same
- Worse

**In the past 7 days...**



	Never	Rarely	Sometimes	Often	Always
I felt worthless	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt helpless	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt depressed	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt hopeless	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt like a failure	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt unhappy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt that I had nothing to look forward to	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt that nothing could cheer me up	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Thinking about feelings of depression or low mood, do you think you have felt better or worse this year than you did last year?

Better  
 About the same  
 Worse

**In the past 7 days...**

	Not at all	A little bit	Somewhat	Quite a bit	Very much
I had a hard time getting things done because I was sleepy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt alert when I woke up	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt tired	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I had problems during the day because of poor sleep	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

I had a hard time concentrating because of poor sleep	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt irritable because of poor sleep	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was sleepy during the daytime	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I had trouble staying awake during the day	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Do you think your sleep has been better or worse this year than it was last year?

Better

About the same

Worse

# PROMIS Questions

Please rate your agreement with the following statements

---

## Over the past 7 days...

	Not at all	A little bit	Somewhat	Quite a bit	Very much	Not applicable
I was satisfied with how much work I could do (including work at home)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was satisfied with my ability to work	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was satisfied with my ability to do regular personal and household responsibilities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was satisfied with my ability to perform my daily routines	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was satisfied with my ability to meet the needs of those who depend on me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was satisfied with my ability to do household chores/tasks	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was satisfied with my ability to do things for my family	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was satisfied with the amount of time I spent performing my daily routines	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

# PROMIS Support Questions

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For these questions, we would like you to think about your life **during the initial COVID-19 lockdown (23 March - 13 May)**.

---

Please rate your agreement with the following questions

---

## During lockdown...

	Never	Rarely	Sometimes	Usually	Always
Did you have someone to help you if you were confined to bed?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Did you have someone to take you to the doctor if you needed it?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Did you have someone to help with your daily chores if you were sick?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Did you have someone to run errands if you needed it?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Did you have someone to prepare your meals if you were unable to do it yourself?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Did you have someone to take over all of your responsibilities at home if you needed it?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Was someone available to help you if you needed it?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Did you have someone to help you clean up around the home if you needed it?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
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**During lockdown...**

	Never	Rarely	Sometimes	Usually	Always
I had someone who listened to me when I needed to talk	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I had someone to confide in or talk to about myself or my problems	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I had someone who made me feel appreciated	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I had someone to talk with when I had a bad day	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I had someone who understood my problems	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I had someone I trust to talk with about my feelings	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I had someone with whom to share my most private worries and fears	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I had someone I trust to talk with about my problems	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**During lockdown...**

	Not at all	A little bit	Somewhat	Quite a bit	Very much	Not applicable
I was satisfied with how much work I could do (including work at home)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

I was satisfied with my ability to work	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was satisfied with my ability to do regular personal and household responsibilities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was satisfied with my ability to perform my daily routines	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was satisfied with my ability to meet the needs of those who depend on me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was satisfied with my ability to do household chores/tasks	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was satisfied with my ability to do things for my family	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was satisfied with the amount of time I spent performing my daily routines	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

# PROMIS Wellbeing Questions

For these questions, please continue to think about your life **during lockdown**. Please rate your agreement with the following statements

## During lockdown...

	Never	Rarely	Sometimes	Often	Always
I felt fearful	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I found it hard to focus on anything other than my anxiety	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My worries overwhelmed me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt uneasy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt nervous	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt like I needed help for my anxiety	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt anxious	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt tense	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

## During lockdown...

	Never	Rarely	Sometimes	Often	Always
I felt worthless	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt helpless	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt depressed	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt hopeless	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt like a failure	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

I felt unhappy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt that I had nothing to look forward to	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt that nothing could cheer me up	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**During lockdown...**

	Not at all	A little bit	Somewhat	Quite a bit	Very much
I had a hard time getting things done because I was sleepy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt alert when I woke up	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt tired	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I had problems during the day because of poor sleep	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I had a hard time concentrating because of poor sleep	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt irritable because of poor sleep	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was sleepy during the daytime	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I had trouble staying awake during the day	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



# PROMIS Support Questions

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For these final sets of questions, we would like you to think about your life **last year, in 2019**.

---

Please rate your agreement with the following questions

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**In 2019...**

	Never	Rarely	Sometimes	Usually	Always
Did you have someone to help you if you were confined to bed?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Did you have someone to take you to the doctor if you needed it?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Did you have someone to help with your daily chores if you were sick?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Did you have someone to run errands if you needed it?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Did you have someone to prepare your meals if you were unable to do it yourself?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Did you have someone to take over all of your responsibilities at home if you needed it?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Was someone available to help you if you needed it?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Did you have someone to help you clean up around the home if you needed it?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
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**In 2019...**

	Never	Rarely	Sometimes	Usually	Always
I had someone who listened to me when I needed to talk	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I had someone to confide in or talk to about myself or my problems	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I had someone who made me feel appreciated	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I had someone to talk with when I had a bad day	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I had someone who understood my problems	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I had someone I trust to talk with about my feelings	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I had someone with whom to share my most private worries and fears	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I had someone I trust to talk with about my problems	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**In 2019...**

	Not at all	A little bit	Somewhat	Quite a bit	Very much	Not applicable
I was satisfied with how much work I could do (including work at home)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

I was satisfied with my ability to work	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was satisfied with my ability to do regular personal and household responsibilities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was satisfied with my ability to perform my daily routines	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was satisfied with my ability to meet the needs of those who depend on me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was satisfied with my ability to do household chores/tasks	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was satisfied with my ability to do things for my family	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was satisfied with the amount of time I spent performing my daily routines	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

## Additional questions

If you have time, we would like to ask you some additional questions about the effect of lockdown on being able to take part in your usual interests, hobbies and activities. These will take a maximum of 10 minutes to complete.

- Yes, I will answer some more questions
- No, I'd like to finish the survey now

## Other activities

During lockdown, did you do **more** of any of the following activities than before? (Select all that apply)

- Exercising (indoor or outdoor)
- Exercise classes (including virtual)
- Socialising
- Spending time with pets
- Spending time with family
- Gardening
- Cooking
- Arts/crafts
- Reading/writing (e.g. novels, blogs, academic writing)
- Attending events (including virtual events)
- Noticing/watching wildlife
- Gaming (electronic)
- Board games/quizzes
- Meditation/mindfulness
- Playing/listening to music
- Learning a skill/adult education
- Another hobby or activity
- None of these

During lockdown, did you do **less** of any of the following activities than before? (Select all that apply)

- Exercising (indoor or outdoor)
- Exercise classes (including virtual)
- Socialising
- Spending time with pets

- Spending time with family
- Gardening
- Cooking
- Arts/crafts
- Reading/writing (e.g. novels, blogs, academic writing)
- Attending events (including virtual events)
- Noticing/watching wildlife
- Gaming (electronic)
- Board games/quizzes
- Meditation/mindfulness
- Playing/listening to music
- Learning a skill/adult education
- Another hobby or activity
- None of these

Which, if any, of the following activities do you think helped you to cope with lockdown most of all? (Select all that apply)

- Exercising (indoor or outdoor)
- Exercise classes (including virtual)
- Socialising
- Spending time with pets
- Spending time with family
- Gardening
- Cooking
- Arts/crafts
- Reading/writing (e.g. novels, blogs, academic writing)
- Attending events (including virtual events)
- Noticing/watching wildlife
- Gaming (electronic)

- Board games/quizzes
- Meditation/mindfulness
- Playing/listening to music
- Learning a skill/adult education
- Another hobby or activity
- None - I didn't do any of these activities
- I did some of these activities but they didn't help me to cope
- Not sure

## Follow up

Thank you for taking part in this survey. We would like to contact you again in future to share the results of the study with you and invite you to take part in follow up studies. If this is of interest to you, please provide an **email address**. (By showing an interest this does not mean you must take part in follow-up activities, as there will be a new consent form to sign at the time and you will have a choice whether or not to take part. By providing an email address you confirm that you consent to being re-contacted by researchers.)

Please enter a valid email address.



# Final page

## Participant Debrief Sheet (Version 1.3 - 01/09/2020)

**Project:** *A survey exploring wellbeing, healthcare and access to communities for autistic adults*

Thank you for taking the time to take part in this survey.

You may want to print this page or make a note of the receipt number you have been given (shown above) and the researcher contact details below for future reference.

If you would like to, you may share this survey with other people that you know who have not yet completed it, which will help us to reach a larger sample of people.

You can also follow and retweet information about the project on Twitter [@SPAA\\_Project](#).

### What happens now?

When we have collected enough responses to the full survey, we will analyse them to look for patterns. The results will help to inform research about what contributes to good quality of life for autistic people and how barriers to accessing healthcare and communities can be reduced to support wellbeing.

We will follow up this study with interviews and other qualitative methods to find out more about these experiences in depth. Outcomes from the research, such as recommendations for health services, will therefore be informed by the lived experiences of autistic people.

If you have provided an email address, you will hear from us again in future with updates about the survey and information about follow-up studies you can take part in.

We hope to publish the studies in scientific journals related to the topics covered by the survey and to share results as appropriate at conferences, presentations, webinars and on social media/blogs. In line with guidelines for NIHR funded research, publications will be made Open Access wherever possible so that they are free to read. Where this may not be possible, a copy of the final PhD thesis will be available on Plymouth University's online repository (PEARL) and pre-print versions of journal articles will also be available by contacting the researchers.

Your data will be retained for at least 10 years in line with the University of Plymouth's

Research Data Policy.

## What if I have concerns from taking part in this survey or want to withdraw from the research?

If you need further advice about managing your wellbeing, these organisations are able to provide support:

- Samaritans (<http://samaritans.org>) Phone 116 123. Advice hotline for emotional distress.
- Mind (<http://mind.org.uk>) Mental health support.
- National Autistic Society (<http://autism.org.uk>) and Autistica (<http://autistica.org.uk>) Advice and support about autism, including information about managing during the coronavirus pandemic. You may be able to find details of local support groups for autistic adults through the National Autistic Society's website.

You can also get support with wellbeing from your GP and by visiting <http://nhs.uk>.

If you change your mind about taking part, you can withdraw your data up to 2 weeks after taking the survey. After this time it will not be possible to withdraw your data.

You can withdraw your data by emailing [charlotte.featherstone@plymouth.ac.uk](mailto:charlotte.featherstone@plymouth.ac.uk) and quoting the receipt number shown at the top of this page. You may also contact the researcher if you provided an email address for future contact but no longer wish to be contacted, and we can remove your email address from the mailing list.

If any parts of this survey caused you concerns with regard to your wellbeing or the wellbeing of others, or there is anything else you are not satisfied with, please contact the researcher in the first instance at [charlotte.featherstone@plymouth.ac.uk](mailto:charlotte.featherstone@plymouth.ac.uk) or the academic supervisor Kerryn Husk at [Kerryn.husk@plymouth.ac.uk](mailto:Kerryn.husk@plymouth.ac.uk).

If your concerns have not been resolved to your satisfaction, you can contact the University of Plymouth's health research ethics committee at [HHSEthics@plymouth.ac.uk](mailto:HHSEthics@plymouth.ac.uk) Tel: 01752 586992 **Ethical approval reference number: 19/20-1311**

### Project details:

Name of student: Charlotte Featherstone

Contact details: [charlotte.featherstone@plymouth.ac.uk](mailto:charlotte.featherstone@plymouth.ac.uk)

Supervisory team:

Dr Kerryn Husk (University of Plymouth); Dr Richard Sharpe (Public Health, Cornwall Council); Dr Nick Axford (University of Plymouth); Professor Sheena Asthana (University of Plymouth)

Contact details of Primary Supervisor: [kerryn.husk@plymouth.ac.uk](mailto:kerryn.husk@plymouth.ac.uk)

Research Group: The National Institute for Health Research (NIHR) Applied Research Collaboration (ARC) South West Peninsula have funded this research. Contact options are available at: <https://www.arc-swp.nihr.ac.uk/contact> (Tel: 01392 726055)

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## Key for selection options

### 2 - Do you live in the UK?

Yes

No

### 3 - Did you live outside the UK for any period since March 2020?

Yes

No

### 4 - Do you have a clinical diagnosis of autism? (including Autism Spectrum Disorder; Asperger's syndrome; High Functioning Autism; Atypical autism)

Yes

No

### 6.a - If you don't know your diagnosis, please select "Don't know" below:

Don't know

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## Appendix 9 Stage 1 interview schedules

### **Interview Schedule Stage 1 – Participant with social prescribing experience**

The interview will be based on the following questions. There is space below them in case you want to plan out some answers before the interview and bring these along, but please note that this is a loose script, so you might be asked the questions in a different order, be asked extra questions or skip some questions depending on your answers or the time available.

#### **Questions**

What does wellbeing mean to you?

- What does it mean to feel at your best?
- What do you do to keep mentally and physically healthy?
- Have there been any differences in how you are able to keep well during the Covid pandemic compared to before?

When you have a health concern (physical or mental health) that you can't manage by yourself, what steps do you typically take to get support?

- When do you decide to seek support?
- What would put you off getting support?
- What other difficulties might you have?

How have you found accessing support for your health?

- What types of support do you feel have helped you most?
- Do you disclose your autism diagnosis in a healthcare environment? Why/why not?
- In what ways have health services adapted for you to support your needs?
- Have you had any challenges or difficult experiences with getting support for your health or wellbeing?

You've indicated that you have experience with a social prescribing referral. Can you tell me more about that?

- What was the reason for the referral?
- What did you expect from it?
- Did you have an appointment with a link worker or community connector?
- What type(s) of prescription (activity/service) did you end up getting through social prescribing? What did you think of it?
- Has it had any effect on your wellbeing?
- If you dropped out at any point or didn't take up the referral: What wasn't working for you?

If you could design the perfect service to support your wellbeing, what would it be like?

How do you feel about the local community in your area?

- Do you feel a part of that community?
- Can you give me an example of a community you feel that you a part of?
- How has COVID-19 affected your experience of belonging to communities? What impact has this had on your life?

How do different places and environments around you affect your wellbeing?

- Where do you feel at your best?
- Are there any environments that you don't like? How do these make you feel?
- How do you feel about nature and green spaces?
- How has COVID-19 affected how you experience different places and environments? Has anything about the experience changed?

## **Stage 1 Interview Schedule – Participant with no social prescribing experience**

The interview will be based on the following questions. There is space below them in case you want to plan out some answers before the interview and bring these along, but please note that this is a loose script, so you might be asked the questions in a different order, be asked extra questions or skip some questions depending on your answers or the time available.

### **Questions**

1. What does wellbeing mean to you?
  - What does it mean to feel at your best?
  - What do you do to keep mentally and physically healthy?
  - Have there been any differences in how you are able to keep well during the Covid pandemic compared to before?
  
2. When you have a health concern (physical or mental health) that you can't manage by yourself, what steps do you typically take to get support?
  - When do you decide to seek support?
  - What would put you off getting support?
  - What other difficulties might you have?
  
3. How have you found accessing support for your health?
  - What types of support do you feel have helped you most?
  - Do you disclose your autism diagnosis in a healthcare environment? Why/why not?
  - In what ways have health services adapted for you to support your needs?
  - Have you had any challenges or difficult experiences with getting support for your health or wellbeing?
  
4. How do different places and environments around you affect your wellbeing?
  - Where do you feel at your best?

- Are there any environments that you don't like? How do these make you feel?
- How do you feel about nature and green spaces?
- How has COVID-19 affected how you experience different places and environments? Has anything about the experience changed?

5. Have you heard of green social prescribing or nature on prescription? What do you think it is?
- How would you feel about being given a referral by your doctor to access groups and activities in local green spaces as a way of managing your wellbeing?
  - How would this compare to other types of healthcare that are available?
  - Is there anything you don't like about the idea?
  - Do you know if social prescribing is available in your area?

6. If you could design a service to support your wellbeing, what would it be like?

7. How do you feel about the local community in your area?
- Do you feel a part of that community?
  - Can you give me an example of a community you feel that you are a part of?
  - How has COVID-19 affected your experience of belonging to communities? What impact has this had on your life?



## Appendix 10 Follow-up interview schedule

### **Follow-up interviews – Leaders/providers/organisers of autistic community-led services to support wellbeing of autistic adults**

Tell me about the service that you provide/lead on:

- How long have you been involved?
- Who is it for?
- What area do you cover?
- What are its aims?
- What does it offer?
- How do people find out about it?
- What setting does it take place in?
- What is your role in the service?

How did the service come about? What resources were needed to start the service? / (If not involved from the start: How did you come to get involved in leading the service?)

Tell me about some of your experiences within the service – for example, what has been a positive experience or something that has gone well?

Have there been any challenges or anything that has not gone so well? What have you learnt from this?

Is there anything the service doesn't currently do that you'd like to do? What resources would you need to achieve this?

How has Covid-19 affected how you've been able to deliver your service?

**In your experience/opinion what are the most important issues affecting autistic adults in your locality? Do you think your service plays any role in addressing these? In what ways?**

How does your service fit in with other autism support in your area? What does it do differently to other services? Do you ever work with other services in the area?

How do you take account of the variety of support needs that present across the autism spectrum? What levels of support needs do you tend to see? How does this affect how you engage people with the service?

What sort of feedback have you received from people who use your service? Who does it work best for?

Does providing your service have any impact on your own wellbeing?

**What could adult autism services in the health or social care sectors learn from your service?**

Is there anything else you would like to add that hasn't been covered by the questions?

Would you like the name of the service to be mentioned in communication/publications about this research?

**Appendices 11, 12 and 13 contain supplementary material from Featherstone, C., Sharpe, R. A., Axford, N., Asthana, S., & Husk, K. (2022). Health and wellbeing outcomes and social prescribing pathways in community-based support for autistic adults: A systematic mapping review of reviews. *Health & Social Care in the Community*, 30(3), e621-e635. <https://doi.org/10.1111/hsc.13635>**

### **Appendix 11: Embase Search Strategy**

1	exp autism/	69285
2	exp "pervasive developmental disorder"/	69285
3	autis*.ti,ab,kw.	63548
4	asperger*.ti,ab,kw.	3406
5	"pervasive development* disorder*".ti,ab,kw.	3195
6	1 or 2 or 3 or 4 or 5	80024
7	adults/	6277617
8	adults.ti,ab,kw.	748353
9	7 or 8	6633693
10	6 and 9	17179
11	MEDLINE.tw.	145386
12	exp systematic review/ or systematic review.tw.	298415
13	meta-analysis/	189080
14	intervention\$.ti.	198525
15	or/11-14	613835
16	((systematic or rapid or mapping or scoping or realist or exploratory) adj (review\$1 or overview\$1)).tw.	218920
17	15 or 16	625469
18	10 and 17	682
19	communit*.ti,ab,kw.	692254
20	(community adj3 intervention*).ti,ab,kw.	12588
21	community care/	53995
22	"social prescri*".ti,ab,kw.	179
23	(communit* adj3 refer*).ti,ab,kw.	4113
24	"non-medical".ti,ab,kw.	9053
25	"link worker".ti,ab,kw.	47
26	exp voluntary worker/	5053
27	exp public sector/	2051
28	exp non-profit organization/	34230
29	"non-profit".ti,ab,kw.	3705
30	"local government".ti,ab,kw.	4642
31	"peer group"/	23214
32	(peer adj3 (led or run)).ti,ab,kw.	1672
33	(lay adj3 (led or run)).ti,ab,kw.	159
34	(user adj3 (led or run)).ti,ab,kw.	345
35	mentors/	4583
36	mentor*.ti,ab,kw.	21089
37	"support group".ti,ab,kw.	5770
38	support*.ti,ab,kw.	1973041
39	program development/	23942
40	program evaluation/	14713
41	"advice service".ti,ab,kw.	179
42	(advice or advis*).ti,ab,kw.	166648
43	exp wellbeing/	82371
44	wellbeing.ti,ab,kw.	25267
45	exp lifestyle/	129219
46	lifestyle.ti,ab,kw.	128703
47	creative.ti,ab,kw.	17797
48	art therapy/	3889
49	music therapy/	6917
50	music.ti,ab,kw.	20427
51	sensory.ti,ab,kw.	222331
52	bibliotherapy/	243
53	exp occupational therapy/	21552

54	(nature adj3 based).ti,ab,kw.	2465
55	(conservation adj3 activit*).ti,ab,kw.	503
56	animal-assisted therapy/	559
57	(animal adj3 therap*).ti,ab,kw.	3390
58	outdoor\$.ti,ab,kw.	30087
59	gardening/	1640
60	horticultural therapy/	108
61	garden*.ti,ab,kw.	14225
62	exercise.ti,ab,kw.	355959
63	exercise therapy/	29285
64	sports/	45073
65	(team adj3 sport*).ti,ab,kw.	3039
66	cooking.ti,ab,kw.	17054
67	(health* adj2 eating).ti,ab,kw.	11580
68	employment.ti,ab,kw.	71099
69	mindfulness.ti,ab,kw.	10111
70	meditation.ti,ab,kw.	7057
71	yoga.ti,ab,kw.	6885
72	exp mind-body therapies/	57202
73	group therapy/	18815
74	club.ti,ab,kw.	12957
75	class.ti,ab,kw.	521398
76	exp health education/	320382
77	hobbies/	33149
78	adult education/	271
79	advoca*.ti,ab,kw.	94322
80	coach*.ti,ab,kw.	18800
81	games.ti,ab,kw.	18608
82	gaming.ti,ab,kw.	4371
83	fitness.ti,ab,kw.	84911
84	wellness.ti,ab,kw.	13999
85	intervention study/	45384
86	vocational.ti,ab,kw.	14103
87	holistic.ti,ab,kw.	30472
88	service.ti,ab,kw.	345389
89	befriend*.ti,ab,kw.	399
90	"drop in".ti,ab,kw.	34992
91	"drop-in".ti,ab,kw.	34992
92	"low level".ti,ab,kw.	77760
93	"low-level".ti,ab,kw.	77760
94	leisure.ti,ab,kw.	20299
95	recreation*.ti,ab,kw.	34116
96	"community-based".ti,ab,kw.	76448
97	exp health program/	131193
98	group.ti,kw.	174612
99	psychosocial.ti,ab,kw.	131511
100	exp social competence/	4452
101	*social interaction/	6800
102	"social skills".ti,ab,kw.	7102
103	(social adj3 skills).ti,ab,kw.	10047
104	or/19-103	5172968
105	18 and 104	355

## Appendix 12:

### Identification of Reviews and Studies

Author(s)	Category/Title	Number of studies included	Appraisal tools used (where stated)	UK studies identified/ Author-rated appraisal (where stated)	Number of UK studies included in mapping review	Reasons for exclusion of UK studies
<b>Anderson et al. (2018)</b>	Academic: “A Systematic Literature Review of Empirical Research on Postsecondary Students with Autism Spectrum Disorder”	24	RCTs: Leong, Carter & Stephenson (2015) checklist Quasi-experimental designs: Preston & Carter checklist (2009)	Holgate (2012) Lambe (2015)	2	
<b>Atkinson-Jones et al. (2008)</b>	Psychosocial: “Do group interventions help people with autism spectrum disorder to develop better relationships with others? A critical review of the literature”	9		Ashman et al. (2017) Howlin & Yates (1999)	2	
<b>Balderaz et al. (2020)</b>	Psychosocial: “Social Skills Interventions for Adults with ASD: A Review of the Literature”	6		Ashman et al. (2017) Spain et al. (2017)	2	
<b>Benevides, Shore, Andresen</b>	General: “Interventions to address health outcomes among	19	Cochrane criteria	Russell et al. (2013) (6/7	1	

<b>et al. (2020)</b>	autistic adults: A systematic review”			criteria met for low risk of bias)		
<b>Bishop-Fitzpatrick et al. (2013)</b>	Psychosocial: “A Systematic Review of Psychosocial Interventions for Adults with Autism Spectrum Disorders”	14		Golan & Baron Cohen (2006)	1	
<b>DeJesus et al. (2020)</b>	Exercise: “Dance promotes positive benefits for negative symptoms in autism spectrum disorder (ASD): A systematic review”	5				
<b>Hedley et al. (2017)</b>	Vocational: “Employment programmes and interventions targeting adults with autism spectrum disorder: A systematic review of the literature”	60		Howlin et al. (2005) Mawhood & Howlin (1999)	2	
<b>Hendricks (2010)</b>	Vocational: “Employment and adults with autism spectrum disorders: Challenges and strategies for success”	Not stated		Howlin et al. (2005) Mawhood & Howlin (1999)	2	
<b>Ke et al. (2018)</b>	Psychosocial: “Social Skill Interventions for Youth and Adults With Autism Spectrum Disorder: A Systematic Review”	42	Cooper (2017) guidelines Evaluative method for determining evidence-based practices in autism (Reichow, 2011)	Golan & Baron-Cohen (2006) Mitchell et al. (2006)	1	Participants under 16 (Mitchell et al., 2006)
<b>Lorenc et al. (2018)</b>	General: “Support for adults with autism spectrum disorder	32	EPHPP Quality Assessment Tool	Howlin & Yates (1999)	4	

	without intellectual impairment: Systematic review”			Mawhood & Howlin (1999) Gracey (2011) Newey (2002)		
<b>Lorenc et al. (2016)</b>	General: “Preventative co-ordinated low-level support for adults with high-functioning autism”	37	Quantitative: EPHPP Quality Assessment Tool Economic: CRD handbook Qualitative: Hawker et al. (2002)	Howlin & Yates (1999) (Low quality) Mawhood & Howlin (1999) (High quality) Macleod & Johnston (2007) (Poor) Ridout et al. (2011) (Fair) National Audit Office (2009) (Not rated) Marwick & Tait (2007) (Poor)	5	Unobtainable (Marwick & Tait, 2007)
<b>Lounds Taylor et al. (2012)</b>	Vocational: “A Systematic Review of Vocational Interventions for Young Adults With Autism Spectrum Disorders”	5	Agency for Healthcare Research and Quality Effective Health Care Program’s Methods Guide for Effectiveness and Comparative Effectiveness Reviews	Howlin et al. (2005) (Poor) Mawhood & Howlin (1999) (Poor)	2	

<b>Nicholas et al. (2015)</b>	Vocational: “Vocational support approaches in autism spectrum disorder: A synthesis review of the literature”	10		Howlin et al. (2005) Mawhood & Howlin (1999)	2
<b>Pallathra et al. (2019)</b>	Psychosocial: “Psychosocial Interventions Targeting Social Functioning in Adults on the Autism Spectrum: a Literature Review”	41	RCTs: American Academy of Cerebral Palsy and Developmental Medicine scale Quasi-experimental designs: Gersten et al. (2005) quality indicators Non-controlled experiments: Sackett (1989) scale	Howlin & Yates (1999) (Weak) Spain et al. (2017) (Weak)	2
<b>Robertson &amp; Emerson (2006)</b>	Vocational: “A Systematic Review of the Comparative Benefits and Costs of Models of Providing Residential and Vocational Supports to Adults with Autistic Spectrum Disorder”	Not stated		Howlin et al. (2005)	1
<b>Schall et al. (2020)</b>	Vocational: Competitive integrated employment for youth and adults with autism: findings from a scoping review	25	Johns Hopkins Nursing Evidence Based Practice Rating Scale 2005	Howlin et al. (2005) (Level 2 research – medium quality)	1



<b>Scott et al. (2019)</b>	Vocational: “Factors impacting employment for people with autism spectrum disorder: A scoping review”	134	Standard Quality Assessment Criteria for Evaluating Primary Research Papers from a Variety of Fields (Kmet et al., 2004) Joanna Briggs Institute (2014) JBI levels of evidence and grades of recommendation	Griffith et al. (2011) (Good) Howlin (2000) (Limited) Howlin et al. (2004) (Strong) Howlin et al. (2005) (Strong) Howlin & Moss (2012) (Limited) Lopez & Keenan (2014) (Adequate) Mavranouzouli et al. (2014) (Strong) Nesbitt (2000) (Adequate) Richards (2012) (Adequate) Walsh & Hall (2012) (Limited)	7	Review article (Howlin, 2000; Howlin & Moss, 2012; Walsh & Hall, 2012)  Phenomenological qualitative study (Griffith et al., 2011; Richards, 2012)  Survey/cohort study (Howlin et al., 2004; Lopez & Keenan, 2014)
<b>Seaman et al. (2016)</b>	Vocational: “Vocational Skills Interventions for Adults with Autism Spectrum Disorder: A Review of the Literature”	20				
<b>Shattuck et al. (2012)</b>	General: “Services for Adults With an Autism Spectrum Disorder”	23		Howlin et al. (2005) Macleod & Green (2009)	2	
<b>Shattuck et al. (2020)</b>	General: “Services for Adults With Autism Spectrum Disorder: A Systems Perspective”	52		Mavranouzouli et al. (2014)	2	Secondary analysis/ cohort study (Mukherjee et al., 2018)

				Milton et al. (2017) Mukherjee et al. (2018)	
<b>SIGN (2016)</b>	Psychosocial: “SIGN 145 • Assessment, diagnosis and interventions for autism spectrum disorders”	Not stated	NICE Levels of evidence	Russell et al. (2013) (Low risk of bias)	1
<b>Spain &amp; Blainey (2015)</b>	Psychosocial: “Group social skills interventions for adults with high-functioning autism spectrum disorders: A systematic review”	5		Howlin & Yates (1999)	1
<b>Tobin et al. (2014)</b>	Psychosocial: “A systematic review of social participation for adults with autism spectrum disorders: Support, social functioning, and quality of life”	13	What Works Clearinghouse Single Case Design evidence standards (Kratochwill et al. 2010)	Howlin & Yates (1999) (Poor)	1
<b>Wilson et al. (2019)</b>	Psychosocial: “Interventions Targeting Expressive Communication in Adults With Autism Spectrum Disorders: A Systematic Review”	22	What Works Clearinghouse Single Case Design evidence standards (Kratochwill et al. 2010)		

### Appendix 13: Qualitative Synthesis of Service Pathway Data

Stage of Pathway	Facilitating Mechanisms	Example Supporting Quotes	Barriers	Example Supporting Quotes
Enrolment	Identification of needs	<p><i>“The Liverpool Asperger Syndrome service was set up in 2003 so that people with Asperger Syndrome who were not eligible for either Learning Disability or Mental Health services would have specialised support and a direct route into multi-disciplinary services.”</i> (National Audit Office, 2009, p.37)</p> <p><i>“Andrew’s family contacted the support team directly to request support”</i> (Macleod &amp; Green, 2009, p.635).</p> <p><i>“An age range of 18 to 24 years was identified for mentees but the upper age limit was dropped because the team received enquiries from autistic people of 25 and over”</i> (Milton et al., 2017)</p>	Lack of ability to identify needs in time	<p><i>“In both of the illustrations given here, students had initially not accessed the support they needed. [...] Although they did declare their disabilities, both were initially confident that they had no additional support needs”</i> (Macleod &amp; Green, 2009, p.639).</p> <p><i>“Participants tended to deny their difficulties: this was especially noticeable in Participant 4.”</i> (Newey, 2002, p.143)</p> <p><i>“There was clear indication that intervention at an earlier stage with young people would be more cost-effective in the long-term”</i> (Ridout et al., 2011, p.9)</p>
	Managing expectations	<p><i>“Individuals that met with the researcher for the initial meeting to discuss what participation would involve, were more likely to continue with the study”</i> (Gracey, 2011, p.106).</p> <p><i>“Prior to the group, we offered each patient an individual 30 min meeting with one or all of the group facilitators to confirm presenting difficulties and risk issues, and also, to allay potential anticipatory anxiety</i></p>	Unrealistic expectations of service users or partner organisations	<p><i>“Other line managers suggested (somewhat unrealistically given the technical nature of many of the jobs) that the support worker should learn more about the specific job requirements; others wanted support sessions to be held outside working hours”</i> (Howlin et al., 2005, p.543).</p> <p><i>“Another difficulty involved clients’ employment goals. Nine support workers noted that ‘job preferences were not</i></p>

		<i>about joining or participating in a group.”</i> (Spain et al., 2017, p.24)		<i>always realistic’”</i> (Howlin et al., 2005, p.545).
Engagement	Collaboration	<p><i>“The collaborative nature of the model has been critical in this respect. As a specialist organisation, the support team was well placed to predict changing needs, and their infrastructure was designed to offer a flexible model of support, to an extent that the Disability Team could not have done.”</i> (McLeod &amp; Green, 2009, p.639)</p> <p><i>“The benefit of having training designed and delivered with significant input from autistic people was consistently highlighted and has been adopted as an underpinning principle for all future training”</i> (Milton et al., 2017)</p>	Collaboration barriers	<i>“Both teams were extremely committed, yet encountered considerable difficulties as colleagues in other key services are not sufficiently trained in autism awareness.”</i> (Ridout et al., 2011)
	Opportunities for social interaction	<p><i>“I am usually uncomfortable in group situations. [...] But this was different. There was something reassuringly familiar about these people’.”</i> (MacLeod &amp; Johnston, 2007, p.85)</p> <p><i>“The group discussion sections were helpful because they make me realise that I am not the only one like me”</i> (Lambe, 2015, p.51).</p> <p><i>“Results suggest that attendance at the group led to a reduction in anxiety about, and avoidance of, social situations”</i> (Spain et al., 2017, p.26)</p>	Challenges of social interaction	<p><i>“Two participants dropped out after one session because they found the group environment overwhelming and felt too anxious to continue”</i> (Spain et al., 2017, p.25).</p> <p><i>“One person said that he had not enjoyed mixing with the other group members”</i> (Howlin &amp; Yates, 1999, p.302)</p>
	Accessibility	<i>“Various mentoring arrangements were implemented, including face-to-face and email based interactions depending on the</i>	Accessibility issues	<i>“Potential participants were not obliged to say why they declined to attend, but we noted that this was largely due to difficulties travelling to the hospital,</i>

		<i>preferences of the mentees.” (Milton et al., 2017)</i>		<i>conflicts with other commitments, or a preference not to engage in a group.” (Spain, 2017) “Participants failed to think of calling the researcher to explain that they were unable to attend.” (Newey, 2002, p.164)</i>
			Low acceptability or engagement	<i>“All of them related dropping out/not completing their work to being too busy and not getting to do the required amount of work.” (Golan &amp; Baron-Cohen, 2006, p.597) “All of the participants who responded felt that the PDA interfered with their daily lives to some degree and more than half reported the PDA increased their anxiety. Only one participant reported finding the strategies helpful” (Gracey, 2011, p.92).</i>
Adherence	Staff skills	<i>“The lack of prominence of the co-ordinators [...] is worthy of consideration. This is not to suggest that the co-ordinators were unnecessary, it may in fact highlight the success of the co-ordinators in providing a consistent but unobtrusive framework and ensuring a balance of contributions.” (MacLeod &amp; Johnston, 2007, p.87) “Supervision by the project team was valued by mentors and thought to be crucial to the success of the project.” (Milton et al., 2017) “Both of the qualified staff had experience of developing and running therapy groups with young people and adults with and without ASD.” (Spain et al., 2017, p.25)</i>	Lack of training	<i>“None of the student ambassadors had any health or social care training or specialist expertise in working with people with ASD. [...] ‘Sometimes seemed ambassadors didn’t know what to do’ ([Participant 2])” (Lambe, 2015, pp.46-51) “There is [...] no precedent for this unusual partnership and no formal protocol to follow.” (MacLeod, 2009, p.642) “During the mentoring program it was found that, disappointingly, the reliability of mentors was variable. Whilst the vast majority were reliable, when mentors were unreliable this clearly impacted negatively</i>

				<i>on the quality of the mentoring relationship.” (Milton et al., 2017)</i>
	Reinforcement	<p><i>“Paula’s description does not reflect a traditional teacher– learner intervention. It is apparent that she learnt about herself by observing other participants.” (MacLeod &amp; Johnston, 2007, p.87).</i></p> <p><i>“Provision of written information and visual materials may help to overcome possible impairments in memory or attention” (Spain, 2017, p.28)</i></p> <p><i>“This suggests that longer use of the software leads to improved generalization” (Golan &amp; Baron-Cohen, 2006, p.612)</i></p>	Lack of reinforcement opportunities	<i>“The brevity of the interventions in the current study may have played a role in the lack of meaningful change in the progress measures.” (Newey, 2002, p.151)</i>
	Resources	<p><i>“Acting as a central point of access from assessment and diagnosis, the team provides its clients with ongoing care management and co-ordinates a range of other services, including employment support, education, service-user and carer groups, mental health, criminal justice liaison and alcohol/substance misuse services.” (National Audit Office, 2009, p.37)</i></p> <p><i>“Participants [...] were asked to use the software (provided free of charge) at home” (Golan &amp; Baron-Cohen, 2006, p.597)</i></p>	Lack of resources	<p><i>“There was a general feeling of ‘running against the tide’ in terms of never having enough time, money, or other necessary resources in order fully to meet the needs of their clients. The financial costs of running the programme also remain high.” (Howlin et al., 2005, p.547).</i></p> <p><i>“The ability to be responsive when needed can be subject to practical restrictions [...] Often, we do not know if the student will definitely be taking up a place until a few weeks beforehand, and, until that time, funding remains uncertain. There may be a waiting list for support from the voluntary sector team, who are tied by their own resource limitations” (MacLeod &amp; Green, 2009, p.642)</i></p>

	Tailoring	<p><i>“A great deal of time was spent collecting information on both clients and potential jobs so that these could be carefully matched, and individuals’ strengths, interests, weaknesses and previous experience taken into account.” (Mawhood &amp; Howlin, 1999, p.248)</i></p> <p><i>“In the first meeting the agenda for the year as a whole was agreed, taking major issues that were raised by the group members themselves.” (Howlin &amp; Yates, 1999, p.300)</i></p> <p><i>“Session duration was negotiable in line with student participants’ preference, tolerance and concentration span” (Holgate, 2012, p.95)</i></p>	Problems outside intervention remit	<p><i>“Freddie: ...the CBT sessions themselves, they were alright, because we simply tried to save the situation: it didn’t work because of circumstances, not the therapy.” (Holgate, 2012, p.142)</i></p> <p><i>“There was some indication that family factors (family accommodation) were associated with treatment outcome” (Russell et al., 2013, p.706)</i></p>
All stages	Individual differences	<p><i>“It is possible that those who have higher verbal IQ coped better with the tasks, as they were less distracted and stressed by the need to use the handouts”(Golan &amp; Baron-Cohen, 2006, p.612)</i></p> <p><i>“The other individual, who had seemed to be coping well and enjoying his work, left suddenly without warning [...] It appeared he and his family found it difficult (probably for cultural reasons) to accept help from an outside agency.” (Mawhood &amp; Howlin, 1999, p.246).</i></p> <p><i>“Ben was able and prepared to take risks in terms of social activities [...] Not all students with Asperger syndrome can do this, even with support” (Macleod &amp; Green, 2009, p. 638)</i></p>		

Appendix 14 contains supplementary material from Featherstone, C., Sharpe, R. A., Axford, N., Asthana, S., Ball, S., & Husk, K. (2022). Barriers to healthcare and their relationship to well-being and social support for autistic adults during COVID-19. *Primary Health Care Research & Development*, 23, e79. <https://doi.org/10.1017/S1463423622000755>

#### Appendix 14: Recruitment strategy

Organisations	Actions	Total organisations contacted	Total organisations distributing survey	Reasons for not sharing (if given/applicable)
Autistica Discover Network	All members of network mailing list emailed	1	1	N/a
Autism support groups and charities	Organisations identified through National Autistic Society directory Shared study invite and information with group members and clients Some groups requested additional actions e.g. first author spoke to group over web call to explain more; authors sent blank PDF of survey to group in advance	79	17	<ul style="list-style-type: none"> <li>• Did not respond</li> <li>• One organisation felt autism research did not lead to tangible benefit so did not share with members</li> </ul>
Mind branches	All identifiable local branches on Mind directory contacted with request to share study invitation and information with service users.	146	2	<ul style="list-style-type: none"> <li>• Did not respond</li> <li>• Against policy to share research requests</li> <li>• Did not have adequate resources</li> </ul>
Autism partnership boards	Google search for “Autism” on sites ending “.gov.uk” All identifiable boards contacted with request to share study invitation and information with board members	22	7	<ul style="list-style-type: none"> <li>• Did not respond</li> </ul>
University disability representatives	Google searches for “Disability” on sites ending “.ac.uk”	22	3	<ul style="list-style-type: none"> <li>• Did not respond</li> <li>• Against policy to share research requests</li> </ul>



	Disability support services, societies and student representatives on disability contacted with request to share study invitation and information to students and staff.			<ul style="list-style-type: none"> <li>• Did not have adequate resources</li> </ul>
SMARTEN (student mental health research website)	Shared study invite on public website	1	1	N/a
National Police Autism Association	Shared study invite on closed forum	1	1	N/a
Self-Care Forum (mental health website)	Shared study invite on public website	1	1	N/a
Healthwatch (regional patient involvement groups)	Shared study invite on closed intranet with instruction for regional groups to forward to relevant members	152 regional groups (via intranet)	Unknown	N/a
Social media	2 public posts on Twitter account	N/a	29 retweets	N/a
National Autistic Society	Information sent to personal contact	1	0	<ul style="list-style-type: none"> <li>• Already shared similar research</li> </ul>
Special education colleges (natspec.org.uk)	Invite sent to central email address	1	0	<ul style="list-style-type: none"> <li>• Did not have adequate resources and had many similar requests</li> </ul>
Asian People's Disability Alliance	Invite sent to contact email address	1	0	<ul style="list-style-type: none"> <li>• Did not respond</li> </ul>
Voiceability.org (advocacy service)	Invite sent to contact email address	1	0	<ul style="list-style-type: none"> <li>• Did not respond</li> </ul>

# SOCIAL PRESCRIBING SOLUTIONS TO SUPPORT THE SOCIAL CARE NEEDS OF AUTISTIC ADULTS: FINDINGS OF A STAKEHOLDER INVOLVEMENT PROJECT

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Report by Charlotte Featherstone, University of Plymouth/NIHR PenARC

February 2022



## IN BRIEF

### ABOUT THIS PROJECT

This project explored stakeholders' views on a social prescribing approach to improve wellbeing for autistic adults using patient and public involvement and engagement (PPIE) workshops with community partners.

Project Team:

PPIE organisation, scoping meetings and reporting:

Charlotte Featherstone, PhD student, University of Plymouth/NIHR PenARC

7 PPIE community partners including:

Heather Davison, Lynn Tatnell, and five group members who preferred to remain anonymous

Supervisors:

Dr Kerry Husk, Senior Research Fellow, University of Plymouth/NIHR PenARC

Dr Richard Sharpe, Public Health Practitioner, Cornwall Council

Dr Nick Axford, Associate Professor, University of Plymouth/NIHR PenARC

Prof. Sheena Asthana, Professor of Health Policy, University of Plymouth

Funder:

Autistica

### BACKGROUND

Autistic adults experience poor health and wellbeing and barriers accessing healthcare. Many aspects of adult social care provision are inadequate for autistic people. Autistic people with lower level support needs may not be eligible for many services but continue to experience poor mental wellbeing and may need low level support to prevent needs escalating.

Social prescribing differs from medical care by connecting people with services and support in the community, which can help improve people's wellbeing. Social prescriptions are not based on diagnoses but on working closely with people to identify their individual wellbeing goals and come up with a personalised prescription.

### AIMS AND OBJECTIVES

The project had two main aims:

1. Understand the capacity for a social prescribing solution for autistic adults to be embedded in Adult Social Care.
2. Gather views and ideas to inform future research on a social prescribing solution to respond to the wellbeing needs of autistic adults

The objective of the project was to carry out meetings with professionals and a public and patient involvement and engagement (PPIE) group over a six month period to achieve the aims above. Autistica provided funding to support these activities.

### FINDINGS

Over 6 months I (CF) met with stakeholders including local authorities, service providers, commissioners and expert researchers and led the PPIE group.

Findings from discussions could be organised into three themes. The first theme explored the current reality of adult autism service pathways. This theme covered people's views on issues comprising availability of appropriate services, eligibility for a service, referrals and access to services, needs which were not being met by services, and the capacity and resources within existing services.

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#### KEY POINTS

*Autistic adults experience a loss of services after transitioning out of education, and services such as mental health services and learning disability services are not always appropriate. There is a lack of low level support and opportunities to connect with and get support from peers. Some autistic people may experience exclusion from digital spaces. Services were difficult to navigate, especially for autistic people who are also carers. GPs often provide access to other services but are hard to access. Covid-19 had led to closure and prioritisation of services which left some people with unmet needs. Labelling people as high- or low-functioning also led to unmet needs. Services such as social care are strained, with a lack of resources to introduce new supports and cannot cover all support needs. Waiting lists for specialist services can be very long.*

The second theme comprised people's attitudes towards social prescribing as a solution to the issues. People considered what role social prescribing could play in managing autistic adults' wellbeing, which models of social prescribing might work best, and how feasible social prescribing was as a solution given the capacity and resources of services.

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#### KEY POINTS

*Social prescribing was sometimes perceived as a service to 'hold' people while awaiting other services or as a last resort. Positively, social prescribing could provide an alternative to more medical models of support and opportunities to access lower level, holistic and person-centred support. There are many ways social prescribing could be delivered which may help people, such as through community hubs, community connectors, nature-based solutions and digitally. Autistic community connectors could be a way of sharing expertise in the autistic community. Issues for social prescribing include demand outstripping resources and unequal provision of services across different areas.*

The final theme sets out stakeholders' vision of the ideal service: an autism community hub and online network. The theme explores what would be included and how this could be achieved through coproduction and collaboration. It also briefly includes ways the service might be evaluated by researchers.

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#### KEY POINTS

*Stakeholders favoured a hybrid service with physical drop-in hubs and online resources and communities. There was a view that the service should be led by or include a very high level of involvement of autistic adults to ensure it was as relevant and inclusive as possible.*

## RECOMMENDATIONS

The overall vision from this research may require a lot of resources and many sources of funding. We suggest in the interim that research could look at upskilling existing community hub services to be better adapted to accommodate autistic adults. This could include holding autism 'pop-up shops' in community hubs, such as having set days where autism-specific services, activities and information are offered to autistic members of the community. Involving autistic adults in training and providing services at hubs would also be an advantage.

Research could also investigate issues of digital exclusion for autistic adults, especially those with learning disabilities or higher support needs.

Researchers also need to review existing autism and generic hub models to identify gaps in geographical spread of hubs, assess involvement of the autism community, evaluate which hub models work best and for whom, and estimate the social value that community hubs provide.

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## INTRODUCTION

Social prescribing describes a personalised healthcare pathway which connects people from primary care services to support in communities provided by the voluntary, community and social enterprise (VCSE) sector. The approach aims to address chronic and socially determined health and wellbeing concerns holistically through these connections, where the medical approach may be insufficient to address complex health issues and promote quality of life.

Models of social prescribing [1] can include: signposting only; referral from a GP or other professional to a link worker, who provides consultation around specific or holistic individual wellbeing needs and support to identify and access community-based support to address these; collaborative community connector models such as the Frome model [see 2]; and community wellbeing hubs such as the Bromley-By-Bow centre that offer a holistic model. The most holistic models of social prescribing provide a range of services and activities, allow multiple referral pathways and rely on multiple sources of funding [3]. Some key mechanisms of social prescribing include its holistic, tailored and person-centred model and collaboration between patients, providers and VCSE services [4, 5]. Additionally, the model relies on secure funding and resource allocation, effective leadership and training, and mutual buy-in and trust [4, 6-8]. Social prescribing has been linked to improvements in psychological, emotional, interpersonal and physical wellbeing as well as skill development and reduced use of health services [9].

Autistic adults are a population who experience disadvantages in physical and mental health [10], and social conditions such as housing, education and employment [11]. Despite their prevalence in funding allocation for autism research, medical, behavioural and cognitive treatments for autistic people have shown little large scale success in improving and sustaining quality of life outcomes [12]. There is also a lack of evidence about which models of social care work best for autistic adults and outcomes are poor compared to the amount of funding spent on providing care [13]. Statutory services are also unable to support autistic adults who fail to meet thresholds of support [14], even though health disparities pervade all levels of support needs [10]. Furthermore, existing community-based care models show a preference for using targeted approaches to treat specific behaviours than attending to holistic health and wellbeing needs [15]. Autistica has recommended the building of capacity in adult social care to better support autistic adults, including through upskilling services and trialling innovative and low support models [13].

So far there has been little research attention given to whether social prescribing could help to address health inequalities affecting autistic adults. The personalised approach of social prescribing reflects recommendations for autism services to focus on individual interests and strengths to promote quality of life [16]. Furthermore, autistic community priorities show a preference for low-level, community-based support models and increasing research funding for services [17, 18]. Policies including the Care Act 2014 [19] and Autism Strategy [20] also recommend community-based provision to reduce unnecessary, costly and harmful use of overmedicalisation and institutionalisation of autistic adults. However, little is known about the feasibility, acceptability and effectiveness of social prescribing for autistic adults as a distinct group or how autistic adults currently use social prescribing services [21].

This report describes the methods and findings of development work funded by Autistica from 2021-22, which aimed to develop a proposal for further research around embedding social prescribing into adult social care (ASC) to benefit the health and wellbeing of autistic adults. The first objective was to scope the potential for social care to provide access to social prescribing by meeting with people who had professional expertise in adult social care. The second objective was to conduct a public and patient involvement and engagement (PPIE) group with autistic adults and parent/carers to identify their priorities for research in this area. These interactions with stakeholders would then lead to the development of research questions for a future grant proposal.



The activities aimed to address questions including:

- Understanding the needs of autistic adults not accessing adult social care (ASC)
- Embedding social prescribing into ASC to help address those needs
- Consulting with stakeholders to plan research around embedding social prescribing into ASC which could focus on:
  - Upskilling staff such as link workers (e.g. trialling a link worker within an ASC service)
  - Connecting ASC to VCSE sector to create a referral pathway
  - Assessing if social prescribing is useful for autistic adults within ASC services
  - Creating an identification route to help autistic adults not currently known to ASC access social prescribing via ASC as an alternative to the medical route (including identifying issues with access to ASC such as the criteria for referral)
  - Assessing whether access to social prescribing via ASC decreases suicide risk and other areas of priority for autistic people
  - Assessing the impact of embedding social prescribing on ASC services (e.g. financial constraints and social return on investment).

## METHODS

### STAKEHOLDERS AND PROCEDURES

All meetings were conducted by one researcher (CF) using Zoom, with administrative support in the PPIE meetings. From July 2021 until January 2022, I identified and met with professionals representing local authorities, health services, charities and community support groups, and with researchers who had expertise in research areas including social care, primary care, education, psychology and computing. Some of the providers and researchers consulted were themselves autistic adults or parent/carers. Discussions included research aims, possible collaborations and the current landscape of service provision. Two local authorities - Devon County Council and Plymouth City Council - invited me to attend their autism involvement groups to discuss views with a group representing the autistic community locally.

The PPIE group was made up of seven autistic adults, two of whom were also parent/carers to autistic adults, and one parent/carer who did not identify as being on the autistic spectrum. Contributors were identified from participants of a research study on autism and social prescribing conducted by the same research team, PenARC's PPIE contacts and a local patient partnership group based in Cornwall. Although the research would be based in the South West of England, some contributors were based in London. The PPIE group was held across one full day and two half-day meetings and contributors were paid for their time. Some tasks were completed between meetings and payments also covered the additional time.

### TRAINING

Throughout the process I attended NIHR training seminars and met with the south west regional design service to ensure understanding of the requirements for an NIHR grant application.

### PPIE MEETING CONTENT

Meeting 1:

- Group introductions and deciding on terms of reference
- 15 minute group discussion on adult social care using prompts
- Introduction to models of social prescribing and breakout room discussions followed by whole group discussion of following points:

- Completely online or in-person or both?
- Who gets to access the service and how?
- How to measure success and usefulness?
- Safety and how to minimise harm - what are potential harms?
- Based on research evidence or lived experience?
- Improve one thing (e.g. loneliness) or have many possible outcomes?
- Could apps/digital solutions fit in with the service?
- How can autistic skills and expertise best be used?
- How can it be funded long-term?

Between meetings 1 & 2:

- PPIE group read and approved meeting notes
- I generated six main ideas based on re-reading the notes from the group discussion and identifying key ideas:
  1. A service or app to help navigate services and systems
  2. Social networking or virtual community specifically for autistic adults
  3. Community autism hub with physical and remote access options
  4. Virtual link worker/community navigator to connect people to community-based support/advice services
  5. Access to group-based activities to improve wellbeing and social connections
  6. Practical advice sessions with experts in different areas of wellbeing
- PPIE contributors were sent the 6 ideas and asked to complete a prioritisation task

Meeting 2:

- Results of prioritisation task into a poll
- Breakout rooms to discuss the two highest ranked ideas and what would need to be included
- Whole group discussion of action planning questions:
  - What do we need to do next?
  - Who do we need to make contact with?
  - What services might we need to work with?
  - What materials and resources do we need?
  - Whose expertise do we need?
  - How can we raise awareness of the service?
  - How can service user involvement be done better?
  - Access to any research needed?

Between meetings 2&3:

I generated some suggestions for research questions around the hub idea:

- **Co-designing the prototype** for a hub or interim service, and planning how to test how well it could be delivered
- **Joining up with another service** to adapt the way they work to a more coproduced approach or adding our priorities to theirs
- **Reviewing the evidence in published research** for autism hubs/apps/support groups, so that recommendations can be made for future planning
- **Testing the social value** of existing autism hubs/apps/support groups to make a case for having something similar in the South West
- Investigating **digital exclusion** in the autistic community and how to resolve this in remote areas

### Meeting 3:

- Summary of vision so far
- Breakout room discussions on suggested research questions, considering:
  - What problems does it answer?
  - How could we put the question into action?
  - How can we make it SMART? (Specific, Measurable, Achievable, Relevant, Time-Bound)
  - How would the research lead to improvements? What steps would it provide towards achieving the community hub vision?
- Research impact discussion - participants were asked to consider what changes they would most want to see in the following areas as a result of this work:
  - Changes to services/support - especially adult social care
  - Changes to health/wellbeing of yourself/your family and people like you
  - Changes at a local level
  - Changes at a wider level (e.g. country-wide; wider attitudes in society)
  - Changes to future research
  - If you could choose 1 main issue to address, what would it be?
  - What would a service/research question need to do to address this issue?

## FINDINGS

Findings have been generated from notes taken in meetings with all stakeholders and organising discussion points into themes.

### REALITY OF ADULT AUTISM SERVICE PATHWAYS

#### AVAILABILITY OF SERVICES AND ELIGIBILITY

Autistic adults and parent/carers felt that support from adult social care was often only available once a person reached a certain threshold of need and there was a lack of lower level support to prevent people reaching a point of crisis. Researchers with expertise in adult social care reported that this is due to the tightening of adult social care budgets, placing limitations on services. Autistic adults and parent/carers also felt there was a lack of support available for autistic people without a learning disability. They also felt that the availability of services and support also dropped off once a person transitioned out of education. Providers of services reported that an autism diagnosis is often required to access a specialised autism service in order to manage demand, but some services were flexible with this, particularly around older adults and people estranged from their family, who may find it harder to access a diagnosis. They also felt that mental health support represented a substantial gap in care.

Autistic adults and parent/carers felt that more peer support would be beneficial but current services did not offer many opportunities for peer support. For example, one person reported that although they had access to PA services funded through direct payments, this form of support only offered a one-to-one model devoid of opportunities that would support people to build social networks with peers. Sometimes people had access to online communities for peer support but lacked 'real life' communities.

A further challenge was the geography of an area. As this research was carried out in the west of England, some people in the group lived in remote areas of Devon and Cornwall. They were often poorly served by public transport and did not always have access to a car. Accessing online services and remote healthcare during Covid-19 has also been difficult due to costs and availability of a strong Wi-Fi connection in these remote regions. Locations of services can present challenges as

buildings in cities do not always have disabled parking nearby, but buildings outside of large towns may not have good public transport services.

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## REFERRAL AND ACCESS TO SERVICES

Parents and carers who were also on the autistic spectrum themselves felt that navigating services on behalf of someone else whilst managing their own needs was difficult and needed to be supported.

Autistic adults and parent/carers reported how GPs were often gatekeepers to other services, including the diagnostic pathway, but they were difficult to access and poorly trained around autism. They also felt that information given out by services was often scant, inadequate and disempowering, presenting medical model views of autism that did not recognise their lived experience or offer advice regarding quality of life for adults on the autism spectrum.

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## UNMET NEEDS

Autistic adults and parent/carers discussed whether services were currently capable of meeting the needs of autistic service users. They felt that residential services in particular were inadequate. A carer with experience of residential care felt residents were not given enough encouragement or resources to look after themselves or their environment, and had a poor quality of life as a result. One contributor to the group who had used residential services through the local council said they had felt bullied and reported a lack of responsiveness when in need of repairs to their accommodation. Furthermore, another contributor felt that services were knowingly not following the guidance set out by the Autism Act 2009.

During Covid-19 many forms of support such as day services and PA support were paused but did not resume after restrictions eased and were still on hold over a year after the first lockdown started. During Covid-19 some councils used a traffic light system to prioritise people for support, but a carer in the group felt that it did not accurately represent the level of need required by her family member and she had been left to manage their care unsupported by services. However, in another family, spending more time with family was found to be beneficial compared to formal support services, leading to achieving wellbeing goals that had not been achieved with support from services alone. These two accounts demonstrate the differences in resources available to families and how Covid-19 has impacted families in different ways.

Some people felt that being given unhelpful labels by services contributed to unmet needs. Being labelled as 'high-functioning' was seen as a dismissive action that assumed a level of independence or lack of need inconsistent with the person's experience of their own needs. Autistic people are often given a 'mental health' label leading to inappropriate referrals to mental health services not equipped to accommodate their needs.

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## SERVICE CAPACITY AND RESOURCES

A provider of a psychology-led, post-diagnostic autism service reported that the greatest areas of need for autistic adults appeared to be housing, benefits, mental health and employment. Post-diagnostic autism services had less provision for activity-based, community-based and social activities, compared to other areas of support such as therapies. There was a lack of places to signpost people to for these types of support. The service maintained a directory of community-based support, but found they did not always have the capacity to keep this up to date.

There is often a long wait for autism diagnosis, and service providers felt that there is a need for pre-diagnostic support but a lack of funding for these types of services. In the Plymouth area, there

has not been a diagnostic pathway at all until recently, meaning a backlog of people who could benefit from pre-diagnostic support.

Researchers with expertise in social care stated that the sector is overwhelmed by demand and understaffed, so there is a low level of capacity to introduce new services or ways of working, to carry out research, or to test out new referral pathways.

## ATTITUDES TOWARDS INTRODUCING A SOCIAL PRESCRIBING TYPE SOLUTION TO ADDRESS INEQUALITIES IN HEALTH AND WELLBEING FOR AUTISTIC ADULTS

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### ROLE OF SOCIAL PRESCRIBING

Some autistic adults and parent/carers had experience of being referred through the social prescribing pathway to improve their wellbeing. In some cases there was a lack of personalisation and tailoring to the person, despite these being important mechanisms and aims of social prescribing models. For example, a person who had a physical disability had received an exercise referral that was not accessible to them. People also found that it could be hard to maintain an activity such as going to the gym, when vouchers they had been given to enable this activity had been used up. It was also notable that, for this group, social prescriptions often appeared to have centred around exercise as the main goal.

Service providers and researchers felt that the positioning of social prescribing and link workers within primary care networks sometimes led to a model that was overly health-driven and did not always consider social care needs. They felt there was a need for more collaboration with the VCSE and social care sectors to incorporate the context of social care and community-focused approaches. However, researchers also highlighted that the new integrated care systems intend to increase collaboration with the social care sector.

Some autistic adults and parent/carers were concerned that social prescribing might be offered as a ‘stop gap’ when more appropriate services could not be found or had long waits to access. Providers of services including local authority services and charity sector support groups reported that people who were suspected of being on the autism spectrum and had raised this with their GP were sometimes referred to social prescribing due to a lack of knowledge about the autism diagnostic pathway by clinicians. Social prescribers sometimes provided signposting to autism support groups in the interim while a person was awaiting autism diagnosis. It was also felt that undiagnosed autistic people often ended up in the social prescribing pathway due to having complex presentations or after being ‘passed around’ between other unsuitable services. In some cases researchers and providers felt this may be a better alternative than medical care and could fulfil a role of offering low-level support to people who ‘fall through the gaps’ of services to avoid escalation of need. One local council’s autism involvement group was considering the role of social prescribers as advocates for improving access to GP surgeries for autistic people through personalisation of reasonable adjustments.

Researchers and providers also emphasised how social prescribing aims to view people beyond medical labels, focusing instead on personal wellbeing goals. The idea of providing a social prescribing solution to a specific cohort, such as autistic adults, may therefore be incompatible with this ethos. However, they also acknowledged that autistic people have specific needs and face inequalities in health outcomes, and as a diverse group could benefit from a more tailored approach. In some areas they may currently be excluded from being offered a social prescription due to a perception of complexity. Researchers considered how link workers could provide an enabling role helping autistic adults to identify their own wellbeing goals, as opposed to services imposing ideals of quality of life on autistic people.

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## MODELS OF SOCIAL PRESCRIBING

Researchers and service providers emphasised the need to scope out existing provision to ensure a social prescribing solution would not replicate the efforts of other services. They reported that some post-diagnostic services operate community hub models in collaboration with charities, with post diagnostic services providing support and signposting. There are also autism hubs which are more independent and less stringent about eligibility criteria. These usually rely on multiple sources of funding including input from local councils, schemes such as lottery funding and donations. Providers felt that a requirement for service users to have an autism diagnosis was important to ensure the service was providing benefit only for the intended population and to limit demand. Researchers and providers emphasised the importance of evaluating services which were no longer operating to find out what had not worked previously. In Plymouth this included an autism hub and a befriending service. In the case of the befriending service this had shown some success, but there had been issues around matching people successfully and the burden of paperwork on those with higher support needs. Researchers also emphasised the value of evaluating and collaborating with organisations delivering similar models with other underserved groups experiencing similar issues with access to healthcare, such as refugees.

Additionally, local councils, in collaboration with the voluntary sector, provide more generic wellbeing hub services offering volunteering, time banking, financial advice, job support and general wellbeing support to local communities in ways which are tailored to local needs. For example, Plymouth City Council aims to increase the number of hubs available and introduce a social prescribing pathway within some of them. They felt the needs of autistic adults locally could be met through training such as autism awareness being delivered to staff at these hubs. Models of social prescribing such as the Frome model train community members as community connectors and to interview community members about local needs. The idea of autism community connectors who could bring together the expertise of the autistic community through lived experience was raised with PPIE groups but did not become a major point of discussion, suggesting this was not a priority, although the group did suggest other ways in which autistic experts through experience could shape services, discussed later. Additionally, researchers had experience of how outdoor spaces were often considered safer places by autistic adults due to reduced sensory overwhelm, and nature-based social prescribing could build on this.

Virtual opportunities such as apps were discussed with all groups in consideration to the challenges of Covid-19 as well as the geographical challenges presented earlier. Researchers felt there was a justification for virtual solutions in remote areas with a lack of resources. Providers of services were already using apps and other digital solutions and suggested ways that these could be integrated within a service. Researchers again highlighted the need for a solution to be novel and not replicate existing solutions such as Brain in Hand. One idea suggested to the PPIE group was the idea of a virtual or remote link worker, but again this did not become a priority of the group so was not discussed in depth. The PPIE group raised potential issues of digital exclusion for people on low incomes and with less confidence around technology. People suggested that apps and technology might have more appeal to younger groups, although some older adults in the group felt that they would welcome virtual opportunities to connect with peers and services. In terms of eligibility, providers of services felt digital solutions could allow for more flexibility.

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## FEASIBILITY, RESOURCES AND CAPACITY

Conversations with providers revealed that there was sometimes a feel of ‘too many travel agents but not enough holidays’ with social prescribing as demand outstripped provision of resources. Resources were also unequal across different locations.

## VISION FOR A SOCIAL PRESCRIBING BASED SOLUTION

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### SOUTH WEST COMMUNITY AUTISM NETWORK & HUB

Discussions with the PPIE group, researchers and services indicated that the preferred solution would be a community-led service with at least one physical hub and an online community resource designed to increase connections by allowing people in the autistic community to network, exchange information, manage wellbeing and independence skills, and navigate services. This could be trialled initially in the South West region. They emphasised the need for a holistic service offering access to therapies, information and advice on advocacy and available support (prioritising signposting to autistic-led organisations) and providing social opportunities such as cafes and day trips. PPIE contributors felt that a service should operate a drop-in or self-referral model and allow access for people of all ages, abilities and stages of diagnosis (including pre-diagnosis or self-diagnosed). The hub could also include a link worker as part of the service to facilitate community navigation to find opportunities such as volunteering and wellbeing support. This would facilitate development of skills and management of wellbeing goals.

PPIE contributors also discussed how virtual solutions could be built in to create a wider community network able to reach people in more remote locations, allow peer exchange of information and act as a backup in times of service closure such as in the case of further waves of Covid-19. Examples of virtual components included video calling and message boards, but it was recognised that this would not be accessible for people with higher support needs who would benefit from face to face support, and that some members of the community may be affected by digital exclusion. They felt a fully online service would not be suitable and would require a physical component such as a hub. The group also recognised the need for moderation of online spaces to ensure responsible usage. The format of online support would also need to be inclusive to people on low-data plans, such as options avoiding heavy usage of images and videos, and have an accessible interface, preferably with customisation options. One local authority stated that they were looking into methods of peer support and that an app-based solution would be a good fit for their aims and would help to meet government standards. They also emphasised that transferability of a solution to other groups would strengthen a virtual solution. Expert researchers also added that online solutions could complement and facilitate provision of holistic support packages.

PPIE contributors felt that hubs across multiple locations would maximise the reach and inclusivity of the service. Access needs and sensory environment would need to be considered carefully in selecting the locations for these services, and the group felt a physical hub should have a welcoming and non-judgemental ethos. As with existing hub models, this service would require significant funding and resources to develop. Additionally, providers of services stressed how creating virtual solutions can also be costly. The PPIE group discussed the need for a solution within the scope of the research budget and considered how aspects of the hub idea could be used to take a stepped approach to develop towards the ideal service, with community input and evaluation throughout. For example, autism pop-up shops could operate on specific days within existing community hubs to provide advice, information and services based on local need and resources, as well as offering opportunities to meet others. Some members of the group felt that relying on research funding may not be an inclusive approach to developing the service as it could cause delays and divert resources too heavily towards the research processes (e.g. funding researchers' salaries).

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### COLLABORATIVE APPROACH AND COPRODUCTION

The PPIE group discussed the importance of linking with an existing service such as a community wellbeing hub or social prescribing pathway, as this would minimise the amount of funding and resources needed to set up a new service, and make use of existing service users, premises and

staff. Researchers also gave the view that being linked with an existing service would ensure better accountability, safeguarding and a source of long-term funding. The PPIE group felt that staff would need to have a level of training beyond basic autism awareness, preferably involving co-design by autistic adults. A service provider suggested an up to date training package such as the Oliver McGowan training. A commissioner also added that adapting services could improve accessibility for other groups such as people with dementia.

A recurring priority for the PPIE contributors that was emphasised in all three PPIE meetings was the need for the research and service to be led or at least informed as much as possible by autistic people to ensure maximum inclusivity, relevance to lived experience and utilise strong community connections to build peer support groups and awareness of the service. PPIE contributors and researchers suggested that community members could be trained as volunteers to help facilitate activities and offered training to apply for further funding, to give the community more ownership over the service. The group also suggested that community volunteers who were skilled in technology could assist others with using digital components of the service. The group felt service users should also have the opportunity to vote on key decisions and give feedback, and that the choice of support provided should be based on community priorities and not those of service providers. Researchers also supported a coproduced approach, with one research group adding that involving family members of service users as a key part of service delivery may also be useful, although this may not be possible (or desirable) for all service users such as older adults or those living alone.

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## EVALUATION AND IMPACT

In discussions around outcomes, researchers emphasised the importance of measuring value for money such as social return on investment using tools such as the Warwick Edinburgh Mental Wellbeing Scale (WEMWBS). PPIE contributors discussed the importance of recognising individual and subjective wellbeing goals to avoid imposing external standards that may not measure quality of life in the way people value. A local authority suggested research could focus on comparing the effectiveness of online and face-to-face methods of support.

Autistic adults and parent/carers felt that continuing to maintain PPIE through all stages of a project would help maximise impact due to community connections. They also emphasised building partnerships with other services including GP practices, libraries and sports clubs to ensure reach.

## HOW FINDINGS FIT IN WITH RESEARCH LITERATURE

Coproduction is gaining more traction in research and service delivery and PPIE is now a requirement for most NIHR-funded health and social care research. Coproduction describes involving the public, patients and experts with lived experience in the development and delivery of services and research. Coproduction aims to shift the balance of power in services and research and acknowledge the role of service users and the public in the use of health services [22].

Autism research and services have traditionally been developed from a medical, outsider perspective, however this may have led professionals to focus too heavily on autism as a set of deficits [23], which is disempowering for autistic people, leading to distrust in traditional approaches [24]. Research that has analysed first-person accounts from autistic adults has been able to show how autistic traits can be strengths in some contexts [25] and reflect personal meanings underlying observed and often stigmatised autism characteristics [26, 27]. Such research has also been able to characterise important community-based concepts such as autistic masking, inertia and burnout that have not been described previously by medical research [28, 29]. This shows the value of first-person perspectives in strengthening what researchers and services know



about autism and how best to work with autistic people to improve quality of life and reduce stigma.

Research and services that have been coproduced with autistic people may be more acceptable to the community. An evaluation of an autistic-led post-diagnostic support group found that appreciation for this model was a major theme, and that it countered the vulnerability autistic people felt within services led by non-autistic leaders [30]. The group was also perceived to be more practical and positive about autism. The mechanism of peer support helped to cultivate a sense of belonging and self-understanding for people. Furthermore, coproduction can benefit professionals: in a mentoring scheme, people training to become mentors for autistic people valued the involvement of autistic speakers in the training [31].

However, there are debates over whether a project led by a research or medical institution could ever be fully coproduced, as it may not be possible to fully overcome existing power structures [e.g. 32] and other barriers imposed by institutions such as funding limitations [33]. On the other hand, it is sometimes important for professionals to retain a level of responsibility over a service to ensure it meets the correct standards and does not cause harm [22].

The person-centred approach of social prescribing may be valuable to the improvement of health and wellbeing outcomes for autistic adults by allowing people to conceptualise wellbeing and their goals in their own way rather than in ways that impose existing norms about good quality of life. Previous research has shown that quality of life for autistic and other disabled populations can look different to how non-disabled researchers and services may conceptualise it [34-37].

There has been little research attention to social prescribing as a solution to wellbeing for autistic adults. In our previous research [15] we found that aspects of the social prescribing pathway that may be particularly suited to autistic adults included the tailored and collaborative approach which allows the ability to focus on individual priorities. However, we also found that there would need to be modifications to the social prescribing pathway in order to best identify suitability. Social prescribing is currently accessed predominantly through primary care; however autistic adults experience barriers in accessing health services [38], suggesting a need for additional pathways, such as self-referral. There is also some evidence that despite having good knowledge of the benefits, autistic people sometimes face exclusion in activities such as exercise and sports groups [39, 40], which could be a barrier to uptake and wellbeing management. This suggests there is a need to ensure activities at the end point of the social prescribing pathway are accessible and inclusive enough to make a difference.

Although there are other services operating autism hubs models, there has been very little evaluation of these approaches. A study which evaluated a community-led autism service through interviews with service users, volunteers and providers found the service positively addressed the severe gaps in services for autistic adults who may otherwise receive little to no support [41]. It also improved employability by developing people's skills and signposting them to volunteering opportunities, including within the hub. The service was valued as a place to access information on a range of topics related to wellbeing, welfare and independent living skills and opportunities to interact with people with similar interests. Crucially, the findings also suggested the service may have reduced suicidality for some service users, addressing one of the leading causes of mortality for autistic adults without learning disabilities.

## RECOMMENDATIONS

The overall vision of a community hub and online network for autistic adults in the South West is ambitious and likely to require extensive resources, time, collaboration and funding to achieve. However, it may be able to respond to the gaps in services and provide access to peer support and assistance with navigating care pathways, which could provide essential support for autistic adults'

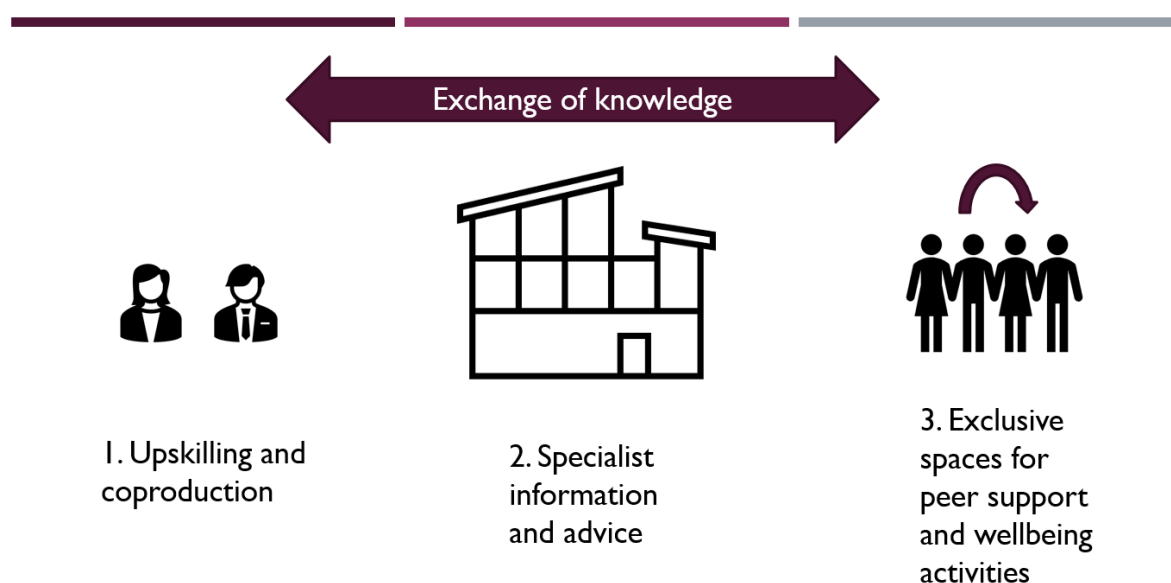
wellbeing. Previous research suggests the hub model would be a worthwhile goal to work towards, however additional research evidence may be needed to support the approach. While this evidence is being gathered, a stepped approach to implementing the service may help provide some of the supports that the stakeholders valued.

Some suggestions for interim services that may help to temporarily bridge gaps in provision are set out below. Furthermore, existing services may wish to draw from any of the findings of this report to make more immediate, interim changes to their services.

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#### UPSKILLING HUBS AND IMPROVING WELLBEING WITH ‘POP-UP SHOPS’

Existing community wellbeing hubs could adapt their practice to provide services which meet the needs of autistic people in their local communities. Autism awareness training, co-created and/or delivered with autistic adults, could be provided to enable staff at hubs to work inclusively to accommodate and value members of their community who are on the autistic spectrum. Hubs could provide autism-specific information and ‘pop-up’ consultation services on set days to assist people to navigate services. For example, information could be provided on autism diagnostic pathways as well as generic services such as the social care system. Hub staff could also work with local members of the autistic community to identify local autism peer-support groups, inclusive social and wellbeing activities, and employment schemes, employers and therapy services which are positive about neurodiversity. Hubs could allocate days to provide taster activities for autistic adults such as creative groups, exercise classes and peer-support meetings to increase opportunities for social connection and wellbeing management. Offering inclusive employment or volunteering opportunities to autistic adults to support these activities could also assist employability for local people.




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#### VIRTUAL AUTISM ONE STOP SHOP

A virtual one stop shop would be a coproduced virtual drop-in service, similar to the community hub but based entirely online, offering information and social opportunities to autistic adults, for example socialising via Zoom, virtual befriending or pre-recorded coproduced videos/podcasts on managing wellbeing and independence skills. This solution would require maximising accessibility and supporting digitally excluded individuals.

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## BEFRIENDING SERVICE

A virtual or in-person service which matches individuals based on their interests and location to increase social connections.

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## CITIZEN-SCIENCE COMMUNITY NAVIGATION/WELLBEING BANK

An online resource people could contribute to, using autism community expertise around availability and navigation of services to create a community map or wellbeing resource for the autistic community.

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## ADVICE EXCHANGE SERVICE

A moderated email-based network where individuals can submit questions and receive personalised answers with input from all users of the network.

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## EXISTING DIGITAL SOLUTIONS

Existing apps and other digital solutions could be built into social prescribing solutions where development of a new technology-based solution may be resource-intensive. Some examples shared and discussed through the scoping work are:

Welco-Me (<https://www.wel-co.me/>): Welco-Me is an example of an app which is focused on making community places accessible. Users can forward their support needs to services and other community locations such as shops, so provision can be in place when they arrive.

ADoddle (<https://adoddle.org/>): ADoddle is a community mapping service covering a wide range of areas in the UK. Features of the local community are identified and can be filtered by the type of service provided. Users can access information about how to contact a service and the role of a service. Information is monitored and traffic-light coded according to the date of last update.

Genie (<https://genie-net.org/>; [42, 43]): Genie is used in conjunction with primary care providers, and enables people to map their social networks, identify wellbeing goals and locate community programmes to help people achieve these. Genie has been implemented in Hampshire, the Isle of Wight and Manchester, as well as in Ontario, Canada.

Brain In Hand (<https://braininhand.co.uk/>): A personalised virtual solution to help people achieve their goals and self-manage wellbeing, which is often provided to individuals through adult social care and education services.

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## EXISTING AUTISM HUB SERVICES

Existing autism hubs services demonstrate examples of the types of support offered and how this is achieved. Centre for ADHD and Autism Support (<https://adhdandautism.org/>) and Autism Hub Islington (<http://autismhubislington.org/>) are examples of autism hubs in London.

## DEVELOPMENT OF RESEARCH QUESTIONS

Although research work alone may not support the full development of the desired autism network and hub service, the following research activities could help work towards the overall goal:

1. Conducting a scoping review of autism services and community hubs to identify gaps including area mapping, assessment of autistic community involvement, realist evaluation and estimation of social value (e.g. impact on quality of life)

2. Trialling coproduced upskilling of social prescribing and/or hubs service(s) through community-informed training and provision of additional support for autistic adults (e.g. piloting pop-up shop as above). Evaluation could measure social return on investment, quantitative measurement of outcomes for service users, service use and staff, and qualitative analysis of success, facilitators and barriers to upskilling the service.
3. Investigation into digital exclusion of autistic people in rural communities, the challenges this presents for wellbeing, and how to resolve this
4. Initiating novel social prescribing solutions with autistic adults presenting to primary care, mental health services or post-diagnostic autism services, such as embedding link workers within autism service pathways and adapting digital social prescribing tools such as the Genie app.

## REFERENCES

1. Kimberlee, R., *What is social prescribing?* Advances in Social Sciences Research Journal, 2015. **2**(1).
2. Younan, H.-C., et al., *Maximising the impact of social prescribing on population health in the era of COVID-19.* Journal of the Royal Society of Medicine, 2020.
3. Dayson, C., *Policy commentary - Social prescribing 'plus': a model of asset-based collaborative innovation?* People, Place and Policy Online, 2017. **11**(2): p. 90-104.
4. Polley, M., et al., *Making Sense of Social Prescribing.* 2017, University of Westminster: London, UK.
5. Ogden, J., *Where next for social prescribing in England?* Prescriber, 2018. **29**(5): p. 31-34.
6. Husk, K., et al., *What approaches to social prescribing work, for whom, and in what circumstances? A realist review.* Health & Social Care in the Community, 2019. **28**(2): p. 309-324.
7. Pescheny, J.V., Y. Pappas, and G. Randhawa, *Facilitators and barriers of implementing and delivering social prescribing services: a systematic review.* BMC Health Services Research, 2018. **18**(1): p. 86.
8. Cole, A., *Social prescribing: Case studies and insight from practitioners in the South West of England.* 2021, South West Academic Health Science Network: Exeter, UK.
9. Chatterjee, H.J., et al., *Non-clinical community interventions: a systematised review of social prescribing schemes.* Arts & Health, 2018. **10**(2): p. 97-123.
10. Hirvikoski, T., et al., *Premature mortality in autism spectrum disorder.* The British Journal of Psychiatry, 2016. **208**(3): p. 232-238.
11. Brugha, T.S., et al., *Epidemiology of Autism Spectrum Disorders in Adults in the Community in England.* Archives of General Psychiatry, 2011. **68**(5): p. 459-465.
12. Howlin, P., *Adults with Autism: Changes in Understanding Since DSM-111.* Journal of Autism and Developmental Disorders, 2021.
13. Smith, E., et al., *Autistica Briefing - Social Care.* 2020, Autistica: London, UK.
14. Sharpe, R.A., et al., *A public health approach to reducing health inequalities among adults with autism.* British Journal of General Practice, 2019. **69**(688): p. 534-535.
15. Featherstone, C., et al., *Health and wellbeing outcomes and social prescribing pathways in community-based support for autistic adults: A systematic mapping review of reviews.* Health & Social Care in the Community. **n/a**(n/a).
16. Huntley, M.K., et al., *Action Briefing: Strengths-Based Approaches.* 2019, Curtin University, KIND and Autistica.
17. Benevides, T.W., et al., *Listening to the autistic voice: Mental health priorities to guide research and practice in autism from a stakeholder-driven project.* Autism, 2020. **24**(4): p. 822-833.
18. Pellicano, E., A. Dinsmore, and T. Charman, *What should autism research focus upon? Community views and priorities from the United Kingdom.* Autism, 2014. **18**(7): p. 756-770.
19. Department of, H. and C. Social, *Care Act factsheets.* GOV.UK, 2016.
20. Social Care, L.G. and D.o.H. Care Partnership Directorate, *Think Autism: Fulfilling and Rewarding Lives, the strategy for adults with autism in England: an update.* 2014, HM Government: London, UK.

21. Charlton, R.A., et al., *Social prescribing for autistic people: A framework for service provision*. AMRC Open Research, 2020. **2**: p. 19.
22. Batalden, M., et al., *Coproduction of healthcare service*. BMJ Quality & Safety, 2016. **25**(7): p. 509-517.
23. Gernsbacher, M.A., M. Dawson, and L. Mottron, *Autism: Common, heritable, but not harmful*. The Behavioral and brain sciences, 2006. **29**(4): p. 413-414.
24. Milton, D.E.M., *Autistic expertise: A critical reflection on the production of knowledge in autism studies*. Autism, 2014. **18**(7): p. 794-802.
25. Russell, G., et al., *Mapping the Autistic Advantage from the Accounts of Adults Diagnosed with Autism: A Qualitative Study*. Autism in Adulthood, 2019. **1**(2): p. 124-133.
26. Kapp, S.K., et al., *'People should be allowed to do what they like': Autistic adults' views and experiences of stimming*. Autism, 2019. **23**(7): p. 1782-1792.
27. Welch, C., et al., *From "since" to "if": using blogs to explore an insider-informed framing of autism*. Disability & Society, 2020. **0**(0): p. 1-24.
28. Welch, C., et al., *Living in autistic bodies: bloggers discuss movement control and arousal regulation*. Disability and Rehabilitation, 2020. **0**(0): p. 1-9.
29. Raymaker, D.M., et al., *"Having All of Your Internal Resources Exhausted Beyond Measure and Being Left with No Clean-Up Crew": Defining Autistic Burnout*. Autism in Adulthood, 2020.
30. Crane, L., et al., *Supporting Newly Identified or Diagnosed Autistic Adults: An Initial Evaluation of an Autistic-Led Programme*. Journal of Autism and Developmental Disorders, 2020.
31. Milton, D., et al., *The development and evaluation of a mentor training programme for those working with autistic adults*. Good Autism Practice, 2017. **18**(1): p. 25-33.
32. Leyshon, C., M. Leyshon, and J. Jeffries, *The complex spaces of co-production, volunteering, ageing and care*. Area, 2019. **51**(3): p. 433-442.
33. Pickard, H., et al., *Participatory autism research: Early career and established researchers' views and experiences*. Autism, 2021: p. 13623613211019594.
34. McConachie, H., et al., *Enhancing the Validity of a Quality of Life Measure for Autistic People*. Journal of Autism and Developmental Disorders, 2018. **48**(5): p. 1596-1611.
35. Schalock, R.L., *Three Decades of Quality of Life*. Focus on Autism and Other Developmental Disabilities, 2000. **15**(2): p. 116-127.
36. Robertson, S.M., *Neurodiversity, Quality of Life, and Autistic Adults: Shifting Research and Professional Focuses onto Real-Life Challenges*. Disability Studies Quarterly, 2009. **30**(1).
37. Kim, S.Y., *The experiences of adults with autism spectrum disorder: Self-determination and quality of life*. Research in Autism Spectrum Disorders, 2019. **60**: p. 1-15.
38. Mason, D., et al., *A Systematic Review of What Barriers and Facilitators Prevent and Enable Physical Healthcare Services Access for Autistic Adults*. Journal of Autism and Developmental Disorders, 2019. **49**(8): p. 3387-3400.
39. Colombo-Dougovito, A.M., A.J. Blagrove, and S. Healy, *A grounded theory of adoption and maintenance of physical activity among autistic adults*. Autism, 2020: p. 1362361320932444.
40. Waldron, D.A., C. Coyle, and J. Kramer, *Aging on the Autism Spectrum: Self-care Practices and Reported Impact on Well-Being*. Journal of Autism and Developmental Disorders, 2021.

41. Southby, K. and O. Robinson, *Information, Advocacy and Signposting as a Low-Level Support for Adults with High-Functioning Autism Spectrum Disorder: An Example from the UK*. *Journal of Autism and Developmental Disorders*, 2018. **48**(2): p. 511-519.
42. Kennedy, A., et al., *Implementing a social network intervention designed to enhance and diversify support for people with long-term conditions. A qualitative study*. *Implementation Science*, 2016. **11**(1): p. 27.
43. Valaitis, R., et al., *A Web-Based Social Network Tool (GENIE) for Supporting Self-management Among High Users of the Health Care System: Feasibility and Usability Study*. *JMIR Formative Research*, 2021. **5**(7): p. e25285.

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