"*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

Janina Brede[1], Eilidh Cage[2], Joseph Trott[3], Lisa Palmer[4], Anika Smith[4], Lucy Serpell[1,5], Will Mandy[1], Ailsa Russell[6]

[1]Research Department of Clinical, Educational and Health Psychology, University College London, 1-19 Torrington Place, London, WC1E 6BT, UK

[2]Department of Psychology, University of Stirling, Faculty of Natural Sciences, University of Stirling, Stirling, FK9 4LA, Scotland, UK

[3]Department of Psychology, Goldsmiths, University of London, Whitehead Building, New Cross, London SE14 6NW, UK

[4]No affiliation, London, UK

[5] Eating Disorder Service, North East London Foundation NHS Trust, Essex, UK

[6]Department of Psychology, University of Bath, Claverton Down, Bath, BA2 7AY, UK

Correspondence concerning this article should be addressed to Janina Brede, Research Department of Clinical, Educational and Health Psychology, University College London, 1-19 Torrington Place, London WC1E 6BT, UK, Janina.brede@ucl.ac.uk, +44 7589626517.

Abstract

Co-occurring mental health difficulties among autistic adults are common and this association has implications for mental health services. Gaining a comprehensive understanding of autistic adults' experiences of accessing and receiving mental health support is a critical step to fully inform service provision. We conducted a systematic review and meta-synthesis of qualitative studies exploring autistic adults' mental health service experiences, triangulating the perspectives of autistic adults, clinicians and parents. Electronic database searches in MEDLINE, PsycINFO and Embase were conducted up to October 2021. This identified 10,068 studies, of which 38 met study inclusion criteria. Using a thematic synthesis approach, we generated three superordinate analytical themes "Lonely, difficult service experience", "Complexity needs flexibility" and "Collaboration and empowerment", each with several subthemes. Our findings show that currently, mental health services do not adequately support autistic adults, and can even cause additional harm. There is a need for a more flexible, comprehensive and holistic approach, considering how being autistic affects the individual's mental health presentation and tailoring support to their needs. Building trusting relationships, listening to autistic adults, and empowering them to take agency, appear to be fundamental steps towards more successful mental health care provision.

Key words: Autism Spectrum Condition, Mental Health, Adulthood, Service experience

Abbreviations: United Kingdom (UK), United States (US), Autism spectrum condition (ASC), Intellectual disability (ID)

"*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

Autistic adults[*] are at high risk of having co-occurring mental health difficulties, and existing service provision is not currently meeting their resultant support needs (Joshi et al., 2013). Several studies have explored autistic adults' experiences in mental health services, reporting on the perspectives of autistic adults themselves, family members and professionals working in mental health care settings, and there is a need to synthesise these perspectives to inform efforts to improve service provision for this population. The current paper presents a systematic review and meta-synthesis of studies utilising qualitative methodologies to investigate autistic adults' experiences of accessing and receiving support for mental health difficulties.

Autism spectrum condition (ASC; hereafter 'autism') is a neurodevelopmental condition, characterised by persistent differences in social communication and interaction, as well as repetitive patterns of behaviour, focused interests and activities and sensory sensitivities (American Psychiatric Association (APA), 2013). Presentations of autistic characteristics and associated strengths and difficulties vary widely across autistic individuals, and depend partly on the environment and support the individual receives (Mandy & Lai, 2016). Around 1% of the UK and US population meet diagnostic criteria for autism (Baird et al., 2006; Brugha et al., 2018). At least 15-29% of autistic individuals present with co-occurring intellectual disability (ID; Kinnear et al., 2020), although estimates vary to as high as 50-70% (Matson & Shoemaker, 2009). Autistic characteristics are present from early childhood, although not always recognised and diagnosed at that point, and persist across the life span (Matson & Horovitz, 2010).

Recently, there has been increased interest in understanding the presentation, experiences and support needs of autistic adults (Murphy et al., 2016; Wise, 2020). This reflects a growing

---

[*] We are using identity-first language when talking about people on the autism spectrum, as this term tends to be preferred by autistic people, but acknowledge that different people have different ways of identifying and referring to themselves/people on the autism spectrum (Bury, Jellett, Spoor, & Hedley, 2020; Kenny et al., 2016).

recognition in clinical practice and research that autism occurs across the lifespan, not just in childhood. Those diagnosed in childhood become adults, and increasingly many autistic individuals are diagnosed in adulthood, due to changes in diagnostic criteria (Bent, Barbaro, & Dissanayake, 2017), growing awareness of variation in autistic presentations (Dillenburger, Jordan, McKerr, Devine, & Keenan, 2013), and increased screening (Gernsbacher et al., 2005).

Autistic adults experience elevated rates of co-occurring mental health conditions compared to the general population (Croen et al., 2015; Lai et al., 2019; Joshi et al., 2013). Studies consistently report high prevalence rates of mental health conditions for autistic adults ranging between 54-80% (Croen et al., 2015; Lever & Geurts, 2016), with up to 57% meeting criteria for multiple co-occurring conditions (Gotham et al., 2015; Lever & Geurts, 2016). The presence of co-occurring mental health problems affects quality of life and wellbeing of affected individuals (Mason, Mackintosh, et al., 2019) and their families (Herrema et al., 2017), and can contribute to premature mortality (Hirvikoski et al., 2018). Despite this, service provision for autistic adults with co-occurring mental health difficulties is insufficient: Autistic adults report higher levels of unmet mental health needs compared to non-autistic adults (Nicoladis, 2018) and children on the spectrum (Turcotte, 2017), and autistic adults with mental health difficulties report being less satisfied with services than those seeking support for physical health difficulties (Vogan et al., 2017).

Both policy and the autism community view mental health care for autistic individuals, and specifically adults, as a priority. For example, the World Health Organization (WHO, 2013) has recognized unmet needs of autistic adults as a public health concern and highlighted the importance of a life-course perspective for autistic people. In England, the Autism Act (2009) was put into place to ensure that the needs of autistic adults and their family members are met, and updates to the Act emphasised the need for greater autism awareness in adult mental health services (Department of Health, 2015). In addition, the National Health Services (NHS) long-term plan published in 2019 makes improving the health and wellbeing of autistic individuals a priority for healthcare developments in the next ten years (NHS, 2019). In line with this, an online survey of UK

stakeholders identified 'How can public services best meet the needs of autistic people?' as one of the top autism research priorities across stakeholders (N=1624), including autistic adults, family members, practitioners and researchers (Pellicano, Dinsmore, & Charman, 2014). Another survey with 255 autistic adults and 143 representatives of adults with high support needs in the US found 'improving public services', 'health care access', and 'public acceptance' to be key priority research areas (Gotham et al., 2015). A UK community priority exercise recognised identifying suitable interventions and adapting existing treatments and services to better meet the needs and improve the mental health of autistic individuals among autistic people's top ten research priorities (Cusack & Sterry, 2016).

To inform efforts to improve the accessibility and effectiveness of mental health services for autistic adults, a critical first step is to generate a better understanding of their experiences in existing mental health services. Qualitative research in particular has the potential to document the complexity and variety of experiences (Lachal, Revah-Levy, Orri, & Moro, 2017) and to suggest explanations for why specific factors might promote or hinder successful service provision (Hannes, Booth, Harris, & Noyes, 2013). There have been various studies investigating different aspects of autistic adults' experience in general and mental health services. However, on their own, qualitative studies are rarely used to inform services provision (Lachal et al., 2017). Recently, systematic reviews have attempted to bring together different studies on autistic individuals' healthcare experience, including both qualitative and quantitative studies. Existing reviews focused on physical health care for autistic adults (Calleja, Islam, Kingsley, & McDonald, 2020; Mason, Ingham, et al., 2019) and on barriers and facilitators to accessing psychological treatment, but reporting these combined for both autistic children and adults (Adams & Young, 2020). Adams and Young's (2020) review identified 12 quantitative and qualitative studies, with the most commonly reported barriers being therapists lacking autism knowledge and lack of tailored approaches. In addition, they identified service-related barriers (e.g. long waiting lists, inaccessibility) as well as what they categorise as client-based barriers (e.g. not knowing how to access services, poor emotional literacy of issues). Few studies

they identified had reported on facilitators to accessing services; of those that did, continuity of therapist and of service provision was most consistently reported.

The current study adds to existing insights by synthesizing qualitative studies to explore the broader experience of accessing and engaging with support for mental health difficulties, focusing on autistic adults specifically. This review is also distinct in that it combines the perspectives of autistic adults themselves with those of parents/carers and healthcare professionals, who may support autistic adults in accessing and engaging with services. Different stakeholder groups will experience issues related to service provision for autistic individuals in different ways (Shattuck et al., 2020). Triangulating perspectives can enrich our understanding of available support, as well as giving insight whether others involved in autistic adults' care understand their experience (Carter, Bryant-Lukosius, DiCenso, Blythe, & Neville, 2014). Additionally, we employed a meta-synthesis approach to combine study findings. Meta-syntheses offer an in-depth, systematic approach to combine perspectives from qualitative studies and bring together a broad range of participants' perspectives (Lachal et al., 2017). By identifying patterns and developing an overarching interpretation of studies included in the synthesis, we can generate new insights beyond the findings of individual studies (Barnett-Page & Thomas, 2009). Accordingly, meta-syntheses are particularly well suited to identifying research gaps and providing evidence for the development, implementation, and evaluation of healthcare interventions and policies (Lachal et al., 2017; Tong, Palmer, Craig, & Strippoli, 2016). Therefore, the aim of the current study was to systematically review and meta-synthesize qualitative studies on autistic adult's experiences of accessing and engaging with support for mental health difficulties, from the perspectives of autistic adults, their parents/carers and healthcare professionals.

Methods

We conducted a systematic review of existing literature and used thematic meta-synthesis (Thomas & Harden, 2008) to consider and combine the findings of identified studies, using qualitative methodology to elucidate autistic adults' experiences of accessing and receiving mental

health support. The study was the product of a larger review exercise initiated by the 'Autistica

Mental Health study group', an interest group bringing together autistic people, parents, researchers

and professionals to co-develop strategic initiatives to facilitate high-quality research on mental

health in autism (Autistica, 2018). A subset of this group joined the team for this research project,

actively contributing to the systematic review and meta-synthesis process. The systematic review

protocol was pre-specified and pre-registered (PROSPERO ID: 163706), and findings are reported in

line with PRISMA guidelines (Moher, Liberati, Tetzlaff, & Altman, 2009).

Eligibility criteria

This review focused on empirical peer-reviewed qualitative and mixed-method studies

(including unpublished doctoral dissertations). Participants had to include autistic adults (with or

without co-occurring intellectual disability (ID), aged 16 years or older), and/or their parents/carers,

and/or healthcare professionals working with autistic adults in a field related to mental health care

provision, including gatekeepers, such as family doctors. Studies had to explore autistic adults'

experiences of accessing and receiving support for mental health difficulties. Research on physical

healthcare provision, experiences of accessing other support services or experiences in adulthood

more generally were only included if they made direct reference to mental health care. They had to

either ask specific questions about mental health services experiences, or report on this because

participants had brought this up in response to general questioning. Only publications in English

were included due to lack of resources for translation.

Information sources

We conducted electronic database searches in three bibliographic databases (MEDLINE,

PsycINFO and Embase) within the Ovid interface in December 2019, which was repeated in October

2021 to identify any additional publications[†]. Reference lists of included studies, relevant position

---

[†]The original protocol specified additional searches on NICE evidence search, British Library EthOS and Google scholar. However, since the other elements of the search strategy produced more extensive results than anticipated, this was deemed no longer necessary.

pieces and existing systematic reviews on related topics were manually scanned for additional studies. Experts in the field were contacted to obtain any missed studies.

Search

The search strategy was developed with the help of a subject librarian. Similar search terms and operators were used for all database searches. The searches combined text words and MeSh terms, or equivalent subject headings, related to the concepts of 'autism', 'mental health', 'service provision' and 'experience'. No restrictions for date of publication were applied. The full search strategy is available in Appendix A.

Study selection

Screening was conducted in two stages. First, the title and abstract of all identified studies were screened against the pre-established inclusion and exclusion criteria. Second, the full texts of potentially relevant studies or those where more information was required were assessed for eligibility. At this stage a rationale for excluding any paper was recorded.

Two reviewers (*JB,EC*) conducted inter-rater checks to ensure inclusion and exclusion criteria were applied consistently across all papers. One reviewer screened all papers at both stages of the screening process. The second reviewer blindly screened 11% of randomly selected papers at stage one, with 99% agreement, and 25% at stage two, with 85% agreement. Any disagreements were resolved by discussion. Two other members of the research team (*WM,AR*) were consulted to confirm these decisions. After discussing any points of uncertainty, they agreed with the other two reviewer's ratings and rationale for exclusion. The second reviewer then checked the first reviewer's decisions for the remaining papers at stage two to confirm the final set of included studies.

Data collection process

We developed a list of study characteristics of interest in collaboration with the Autistica Mental Health Study Group and refined it through discussion with the research team. One reviewer (*JT*) extracted key characteristics from included studies and a second reviewer (*JB*) checked the extracted data.

Risk of bias in individual studies (Quality assessment)

Quality assessment was performed using the Mixed Methods Appraisal Tool (MMAT-Version 18, Hong et al., 2018). The MMAT has good validity and reliability (Hong et al., 2018). It was chosen because it is designed to appraise the methodological quality of studies with diverse designs, including studies using qualitative and mixed methodologies, and thus allowed us to appraise all studies utilising the same tool. We used the 2018 version of the MMAT (Hong et al., 2018), which consisted of two screening questions, followed by five items specific to the study design. Mixed method studies were rated on a total of 15 items; five items for each for the qualitative and quantitative element of the study, as well as five additional items to determine the integration of these elements. Total methodological quality scores were calculated based on the percentage of criteria met. Only qualitative elements of the mixed-method study were included in the synthesis, but the methodology scores are reported for the whole study as it was published.

Two reviewers (*JB, EC*) conducted the appraisal process to confirm eligibility and determine overall quality scores for each study. They independently rated 10% of the studies (82% agreement) and discussed any discrepancies until agreement was reached. One reviewer then rated all papers and the other reviewer reviewed these ratings. Any disagreements were discussed until resolved. No studies failed to meet the two screening criteria, and thus all studies were included irrespective of their methodological quality scores. While the researchers were mindful of quality scores, they also considered other study characteristics, including the specificity of overall study aim to autistic adults' mental health service experience, when conducting the meta-synthesis.

Synthesis of results

A meta-synthesis of qualitative data was conducted following guidelines for thematic synthesis (Lachal et al., 2017; Thomas & Harden, 2008). NVivo software (QSR International Pty Ltd., 2020) was used to aid the analysis, using electronic copies of the articles as primary documents. First, all papers were read and re-read to stimulate consideration of potential codes and themes. Second, we conducted line-by-line coding of the results section of each paper, applying codes to all

sections relevant to autistic adults' mental health service experiences. Codes were created inductively to capture the meaning and content of each sentence, sometimes applying multiple codes to one section. Third, codes across articles were grouped and categorised to construct descriptive themes. At this stage codes and initial themes were extracted to Excel (Microsoft Corporation, 2018), to aid exploration of relationships between codes and themes. Finally, through further interpretation of the descriptive themes in relation to the research aim and discussion within the research team, analytical themes were created. While the descriptive themes had remained 'close' to the original studies (Lachal et al., 2017), this stage 'moved beyond' these, generating new interpretive constructs (Thomas & Harden, 2008). The researchers moved back and forward between these steps until the final set of analytical themes was felt to sufficiently describe and/or explain the initial descriptive themes. The resulting meta-synthesis is a third-order account of autistic adults' experience of mental health services, as it is the researchers' interpretation of other authors' interpretation of participants' reports.

We employed a collaborative approach, with all members of the research team contributing to the analytic process. The research team consisted of a diverse group of researchers, clinicians and autistic adults, some of whom had personal experience with mental health care and/or had supported autistic individuals with accessing services. This approach was considered to be important, as each researcher were likely to view themes in light of their own experience and knowledge, which would influence their judgment about the relevance of a theme and how to describe it (Toye et al., 2014; Braun & Clarke, 2019). Bringing together different perspectives not only enriched the final interpretation, but also allowed us to challenge individual assumptions.

Results

Study selection

The flow of information through each stage of the systematic review is presented in Figure 1. The combined database searches identified 12,843 records, reduced to 10,064 after duplicate removal. Four additional papers were identified by screening reference lists of included papers and

asking experts in the field. The title and abstract of 10,068 records was screened. Full text screen

was conducted for 216 references. This procedure identified 34 relevant studies - details of

exclusions are noted in Figure 1.

Figure 1 here

Study characteristics

Key characteristics of each study are presented in Table 1.

There were 30 qualitative studies and eight mixed-method studies. All included studies

(N=38) were published from 2012 onwards, with the majority (N=31) published after 2015. Twenty-

six studies were conducted in the UK, seven in the US, three in Canada, one in Belgium, and one in

Singapore. Twenty-four studies included first person accounts from autistic adults, ten from family

members and 13 from professionals; eight included multiple participant groups. In total, 826 autistic

adults, 142 family members and 927 professionals were included as participants. Ten studies

reported using a participatory approach, with members of the autism community actively involved in

shaping and/or conducting the research.

Twenty-three studies directly focused on autistic adults' experience in mental health

services. Twelve of these focused on a specific mental health difficulty (five on eating disorders, two

on anxiety, two on depression, one on social anxiety, one on ADHD, one on suicidality and self-

harm). Six focused on a specific treatment approach or setting (two on guided self-help/CBT, one on

medication use, on inpatient care, one on high secure psychiatric hospital and one on general

practice). The remaining studies explored experiences in non-specialist healthcare, in other support

settings, and of the life of autistic adults more generally, but all included mention of mental health

care. Thirteen studies focused on specific groups of autistic adults (eight on young adults, three on

autistic women, one on students in higher education and one on older adults).

Twenty-four studies reported on whether autistic adults themselves, parents' children or

professionals' clients presented with co-occurring ID. Fourteen focused exclusively on the

experience of autistic adults without ID, whereas nine, predominantly those using parental report, looked at the experience of autistic adults of whom some (N=6) or most (N=3) had co-occurring ID.

Thirty studies included autistic individuals and/or their parents, all of which reported autistic adults' gender. Three studies had an all-female sample, and one study included all females apart from two participants identifying as non-binary. Most remaining studies included more males than females, but the proportion of male participants ranged from 38.5-89%. Two studies reported including participants identifying as non-binary or transgender.

Nineteen of the 30 studies reported the age at which autistic adults had received their autism diagnosis. Six of these, often with a focus on young adults, reported mostly on the experience of adults who had been diagnosed in childhood. Six studies included participants for whom age of diagnosis ranged widely, covering both child- and adulthood, and six included participants who had predominately or exclusively received their autism diagnosis in adulthood.

Fourteen studies of the 30 studies reported the ethnicity of autistic adults. For two studies all participants identified as White. For seven studies more than 90%, for 11 studies more than 80% and for one study 73% of participants were described to be White. One study had a more diverse sample with 50% (n=4) of participants reporting to be of Asian or Latino heritage, and one study was conducted exclusively with participants with Asian heritage. Five out of 13 studies that included professionals reported on their ethnicity. The majority of professionals were White (min 69.9%; see Table 1 for other ethnicities included).

Of the eight mixed-method studies four included autistic adults and four focused on healthcare professionals. The quantitative data collected by mixed-methods studies with autistic adults covered the types of mental health diagnoses they had received and agreement with these diagnoses (Au-Young et al., 2019), past or current treatments experienced and current unmet support needs (Camm-Crosbie et al., 2019), ratings of their current mental health status and confidence in their mental health ratings (Crane, Adams et al., 2019). Merrick and colleagues (2020) collected survey responses about contextual factors and engagement with services across multiple

time points to identify predictors for transferral from child and adolescent to adult mental health services. Mixed-method studies with healthcare professionals included surveys and questionnaires about their autism knowledge, levels of training, experience, and their confidence and attitudes towards working with autistic individuals (Crane, Davidson et al., 2019; Cooper et al., 2018; Murphy & McMorrow, 2015; Unigwe et al., 2017).

Risk of bias within studies (Quality assessment)

Total methodological quality scores based on the MMAT (Hong et al., 2018) are reported in Table 1. Detailed ratings on each item can be found in Appendix B. Overall, the quality of included studies was high. For the qualitative studies, 27/30 studies met 100% of quality criteria and one study met 80%, because the study did not state the analytic approach used. For the mixed-method studies, five met over 80%, two met 66.6% and one met 40% of the quality criteria. The main issues were the samples' limited representativeness of the target population (e.g. high proportion of females, majority of participants being highly educated) and lack of explicit integration of findings from the qualitative and quantitative elements of the studies.

Table 1 here

Thematic meta-synthesis

We generated three superordinate analytical themes "Lonely, difficult service experience", "Complexity needs flexibility" and "Collaboration and empowerment", each with several subthemes. An overview of all analytical themes and subthemes is provided in Figure 2.

Autistic adults' experience of accessing and receiving support for mental health difficulties

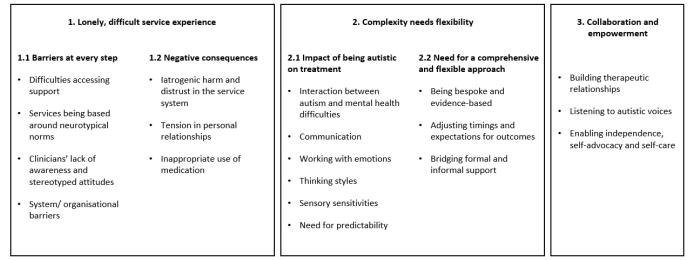| 1. Lonely, difficult service experience		2. Complexity needs flexibility		3. Collaboration and empowerment
1.1 Barriers at every step	**1.2 Negative consequences**	**2.1 Impact of being autistic on treatment**	**2.2 Need for a comprehensive and flexible approach**	
• Difficulties accessing support	• Iatrogenic harm and distrust in the service system	• Interaction between autism and mental health difficulties	• Being bespoke and evidence-based	• Building therapeutic relationships
• Services being based around neurotypical norms	• Tension in personal relationships	• Communication	• Adjusting timings and expectations for outcomes	• Listening to autistic voices
• Clinicians' lack of awareness and stereotyped attitudes	• Inappropriate use of medication	• Working with emotions	• Bridging formal and informal support	• Enabling independence, self-advocacy and self-care
• System/ organisational barriers		• Thinking styles		
		• Sensory sensitivities		
		• Need for predictability		

Figure 2: Overview of analytical themes and subthemes from the thematic meta-synthesis.

In the following description of each theme, first-order accounts (participants' direct quotes) are presented in quotation marks and italics, whereas second-order accounts (the original authors' interpretations) are referred to in quotation marks with no italics. For both, study IDs (see Table 1) are used to link them to the original paper. Additional first-order quotes illustrating each of the themes are provided in Appendix C.

1. Lonely, difficult service experience

This theme encapsulated a sense of lonely, frustrating and difficult service experiences that the majority of autistic participants had encountered. Existing services tend to be unsuccessful in providing support for mental health difficulties and were perceived to be unsuitable, inaccessible and at times unwilling to meet autistic adults' needs. This experience had negative effects on autistic adults' wellbeing, motivation for future help-seeking and family relationships. For some, this experience was also thought to have resulted in inappropriate reliance on medication. Several subthemes were identified within this theme:

1.1 Barriers at every step

Potential barriers were reported at almost every step towards service engagement, resulting in many autistic adults not receiving the support they needed or encountering various obstacles along the way:

Difficulties accessing support. Both autistic individuals themselves and those involved in their care, such as family or doctors, struggled with recognising symptoms of mental health difficulties, often assuming presenting difficulties were part of being autistic. Some parents worried about their adult child recognising their own need for mental health support, and expressed frustration about not being able to initiate care on their child's behalf since they had entered adult services. Some autistic adults expressed a sense of being '*used to doing things [their own] way*'[9], feeling like '*someone's trying to interfere*'[9], when others expressed concern or offered help, even though '*it's probably for the best*'[9].

Autistic adults also reported that asking for support could be daunting, with 'the steps to accessing services being too overwhelming'[27]. Some found it difficult to judge '*what the boundaries are concerning emotional things*'[18], resulting in hesitancy to talk to others about their difficulties. For others, their hesitancy stemmed from previous experiences of not being believed. Many also seemed put off from approaching services because of uncertainty about what the therapy process might entail and a perceived lack of transparency. Additionally, autistic adults and their parents reported being rejected by services because of co-occurring autism diagnosis, which 'made them '*too complicated*', and ineligible for services'[7] without alternative services being available. Practitioners also stated that many mental health services were '*reluctant to work with autistic individuals*'[13].

The existing service system was perceived to be complex and confusing. Participants had experienced disjointed services systems, particularly between different services, such as mental health and autism diagnostic or learning disability services. This incoherence resulted in help-seeking individuals being 'batted back and forth between agencies'[3], with a risk of 'slip[ping] through the net'[7] of available services. Further, there were physical barriers to services - for example, travel to and from services and the service setting itself prevented some autistic adults from accessing or engaging with treatment, due to social or sensory overload on public transport, in waiting areas, on inpatient wards, or in group settings.

Services being based around neurotypical[‡] norms. Participants felt that available services were often inappropriate and '*not fit for purpose*'[7], with autistic individuals *'being a square peg in a round hole*'[36]. In some cases, their perceived difficulty to engage led to early discharge or they were actively discouraged from approaching available services, as services were deemed unsuitable to meet their needs. Clinicians commented on rigid service structures, which they felt prohibited flexibility to meet heterogeneous needs. They also criticized reliance on self-report measures, developed based on non-autistic presentations, to assess mental health difficulties and track outcomes, which were often required for service commissioning purposes. This was deemed especially problematic, when access to services was being denied based on low scores on such measures. Clinicians argued that atypical presentation of mental health difficulties, use of compensatory strategies, and difficulties with introspection may confound self-report, making them less valid for autistic individuals.

Autistic adults and their parents commented on services being inconsiderate of autistic individuals' developmental stage. For example, some young adults felt they had not reached the level of independence expected of them when they transferred to adult services. Similarly, parents of adult children with co-occurring intellectual disability struggled to find settings that were developmentally appropriate. While some questioned whether it was appropriate for their adult children to be treated in paediatric settings, others recounted *'horror stories*'[19] of their offspring being admitted to general adult psychiatric provisions, pressing the need for specialist provision.

Clinicians' lack of awareness and stereotyped attitudes. Participants across groups reported varied, yet overall low, levels of confidence and competence among professionals involved in mental health care for autistic adults. Many autistic adults, who experienced mental health difficulties throughout their lives, had not been diagnosed until adulthood, and participants wondered if earlier recognition could have helped them to find appropriate support sooner. Further, participants felt

---

[‡] 'Neurotypical' refers to individuals, whose cognition, perception or behaviours are not affected by living with a neurodevelopmental condition.

that many professionals lacked an in-depth 'understanding of the unique challenges'[12] associated

with being autistic and living with mental health difficulties. Several papers discussed 'stereotypical

and homogenizing attitudes towards autism'[33] among professionals, which was particularly

problematic for autistic individuals who tend to present differently from the traditional autistic

norm, such as autistic women. Autistic adults also described encountering harmful assumptions, for

example, about being 'high-functioning'[7] and therefore able to cope, when in fact they were

struggling, or being labelled as potentially violent, without any indication that this was the case.

Others reported incidences of clinicians challenging or refusing to acknowledge autism diagnoses. In

cases where autism was recognized, autistic adults felt they were not listened to or that being

autistic was used as a reason to not take them seriously.

Although some autistic adults described clinicians as *'well-meaning'*[7], many perceived the

clinicians they had encountered as insensitive and unaccommodating, 'unable or unwilling to shift'[36]

stereotyped views or to adapt their approach to meet the needs of autistic individuals. Several

autistic adults described experiences of being blamed for lack of treatment success. Even among

professionals, who expressed an awareness of the variability and complexity of presentation in

autistic adults, many admitted having 'low confidence'[24], feeling they did not have the skills to

provide adequate support or reported little practical experience of applying their theoretical

knowledge to individuals' specific circumstances. It was suggested that 'fear of failure'[11] might lead

to them rejecting autistic adults in need.

System/organisational barriers. Several papers discussed service barriers on a systemic and

organisational level that were preventing autistic adults accessing support for mental health

difficulties. The cost of accessing treatment presented a significant barrier for some. In the US,

frustration was expressed about seemingly arbitrary insurance coverage for mental health issues in

autistic adults. Even in the UK, where mental health care is free at point of access, funding was often

withdrawn on short notice, funded services were not appropriate, or autistic individuals

encountered long waiting times for services. Those who had recently transitioned from child and

adolescent to adult services reported a 'sudden decrease in the amount of help and support available'[12]. These circumstances often left autistic individuals no choice but to pay for private treatment, which not everyone could afford. Clinicians also expressed frustration about limited funding, which they felt was preventing them from offering more tailored services. They described a disconnection between clinical reality and service funding, which they perceived to be fuelled by misconceptions about the value of providing mental health treatments to autistic individuals.

Further, clinicians commented on a lack of evidence, training and support to guide working with autistic adults. Clinicians explained that adaptations to treatment delivery and content were often made 'ad-hoc'[2], requiring them to *'learn on their feet'*[2]. Providing adequate support was described to be challenging as there are 'no hard or fast rules'[35] about the best approach and little evidence to inform adaptations. Additionally, they criticised the lack of support within their services and connection with other specialist provisions, resulting in *'feeling isolated'*[24] and leaving them 'to their own resourcefulness'[2]. Participants across groups also highlighted the lack of training and continued support for mental health professionals and gatekeepers who are likely to engage with autistic adults in their work.

1.2 Negative consequences

Having to navigate this complex service system and being held back by various barriers to care had negative effects on autistic adults:

Iatrogenic harm and distrust in the service system. Attempting to gain access to and/or engaging with treatment was described to be exhausting, frustrating and anxiety-provoking. Several papers highlighted the 'harmful'[11] effect of seeking support for mental difficulties, whereby professionals, who are supposed to help, at times had an 'adverse effect'[11]. The lack of appropriate services resulted in unsupported individuals remaining in distress and gave them and their family members the impression that autistic adults' mental health was less valued than that of non-autistic individuals. Experiences of not being believed and being blamed resulted in autistic adults not feeling *'worthy of support'*[7] and doubting themselves. This experience caused individuals in need of

support to feel desperate, hopeless and isolated. For some, accumulative experiences eventually led

'to *'loss of trust'* towards professionals and services'[7] and affected confidence in and motivation

towards future help-seeking.

Tension in personal relationships. Lack of services meant that responsibility for care often

fell on families and friends, putting those who did not have a strong support network at

disadvantage. It also created pressures for families who were able to provide support, and took

away from their capacity to take on other roles in their autistic family member's life. Several autistic

adults mentioned feeling conflicted about being dependent on family and friends, aware of the

impact caring responsibilities had on other's well-being, and frequently chose to suffer in silence to

minimise the burden on others. Family member's involvement in autistic adults' care also caused

tension due to power imbalances and disparity in family's and autistic adults' expectations and

desired outcomes. Further, some commented that relying on the support of family and friends might

reduce autistic adults' potential for developing independence.

Inappropriate use of medication. Lack of options often resulted in long-term medication

use, which was perceived by some participants to be inappropriate and ineffective. Several

participants, particularly parents, praised immediate effects and emphasised that 'medication has

made a great deal of difference'[16]. Yet, for most autistic adults 'the balancing act of the right

medications and the right dosage is something that is a lifelong challenge'[19]. Participants across

groups raised concerns about medication being used due to lack of alternatives, not because it was

effective, and without much consideration of the complexity of the individual's presentation, thus

making little difference to their mental health.

2   Complexity needs flexibility

Across papers, participants emphasised the impact being autistic had on mental health

presentation, as well as on the skills, abilities and needs they brought to treatment. Participants felt

that the resulting variability of presentation and complexity of needs should be accounted for in

treatment.

2.1 Impact of being autistic on treatment

Interaction between autism and mental health difficulties. Participants felt that autistic characteristics and autism-related difficulties played a significant role in the development, maintenance and presentation of mental health difficulties, and it was important to acknowledge this interaction and to modify treatment accordingly.

Autistic adults' experiences of mental health difficulties were described to be fundamentally shaped by being autistic, with some even perceiving 'their mental health difficulties to [be] resultant of ASC'[5]. For example, depression and anxiety were described as *'a reaction to stress associated with having autism'*[7] and a 'repercussion of masking or compensating for social communication difficulties'[36]. Further, some autistic characteristics were described to mimic symptoms of mental health conditions, for example, sensory sensitivities presenting as eating issues, resulting in potential misdiagnosis or diagnostic overshadowing. Further, it was noted that mental health difficulties could affect the presentation of autistic characteristics, which in turn could intensify the manifestation of their mental health difficulty or impact on their ability to cope. For example, sensory sensitivities might be amplified when an autistic individual experiences high levels of anxiety.

Participants across groups noted that healthcare professionals often gave priority to treating mental health conditions, leaving underlying autistic and other psychosocial needs unmet. Some autistic adults emphasised that clinicians should 'focus on treating the co-occurring conditions, not on changing core autistic traits'[25]. However, several autistic adults reported having received their autism diagnosis when seeking support for mental health difficulties and felt that this had positively affected their mental health and the treatment they had received, allowing them to 'make sense of the diagnosis as part of the therapeutic work'[11]. One clinician pointed out that not all potentially autistic individuals benefit from receiving a diagnosis, and that this, as well as the timing of diagnosis, should be considered on an individual basis and in the context of the therapy they are receiving.

Communication. Almost all papers commented on communication difficulties and needs affecting autistic adults' treatment experiences. Both sides of the service user/clinician dyad saw the reason for this in themselves as well as in their communication partner. Autistic adults explained how they sometimes struggled to express themselves, especially when talking about emotional states or when in crisis. In addition, some reported being overwhelmed by too much verbal input and may '*zone out*'[1], not processing what is being said. However, autistic adults felt communication difficulties also persisted due to *'practitioner's inability to try to understand their lived experience and about different ways of communicating'*[11]. Clinicians noted that less experienced colleagues might misunderstand some autistic people's communication style as being disinterested, but that communication difficulties could prove challenging for any clinician as it can be '*really hard to get communication going*'[21] and *'to find a way to communicate more abstract concepts in a way that was understandable to [autistic clients]'*[10].

Participants suggested several strategies to facilitate communication. Clinicians felt that adapting a 'clear and concrete'[24] communication style was beneficial in that it led them to being 'more honest and genuine with their clients'[24]. Autistic adults generally preferred direct questioning but warned about the risk of making assumptions and '*putting words in [the client's] mouth*'[18]. Instead, they felt it was important to '*give them time to fully express themselves*'[18]. Clinicians emphasised periodically checking in with clients to ensure they understood the concepts discussed, even though this may sometimes feel 'patronising'[36]. This seems to be a balancing act, with some autistic adults noting that some communication they had received felt 'too simplistic and childlike'[11].

Working with emotions. Difficulties with identifying, understanding, expressing, communicating and/or regulating emotions were widely discussed as a potential interference with therapy. Further, since autistic individuals might express distress differently, clinicians suggested it was important to 'look beyond initial presentations'[35] when assessing autistic adults for mental health difficulties, and to enquire about different *'cognitive and physiological symptoms'*[35], rather than just asking how people were feeling. Relatedly, clinicians emphasised the need to pay increased

attention to suicidal ideation, as 'flat affect might hide contemplations'[24]. Several clinicians and autistic adults reported finding it helpful to engage in preparatory emotional literacy work prior to the start of therapy. Others suggested that it was helpful to turn the focus away from emotions and take a more pragmatic approach.

Thinking styles. A few papers, mainly those representing the views of clinicians, noted how differences in thinking style 'can interfere with traditional therapy'[25] and could 'potentially hinder engagement in, and the success of, psychological treatments'[35], if these are not adapted accordingly. Such thinking styles may include 'rigid thought patterns associated with autism'[20], 'concrete thinking'[35], difficulties with 'executive function'[24], *'a very fixed world view'* and *'not always generalising experience'*[10]. A few autistic adults also noted how being 'rigid in their thinking'[14] could make it more difficult for them to take on new strategies to cope with stress or to 'transfer learnt information to real-life situations'[6].

Sensory sensitivities. Often treatment environments, especially in-patient settings, were described as 'not autism-friendly'[1], resulting in sensory overload and discomfort that 'distracted or distressed autistic individuals during therapy sessions'[26]. It was noted that sensory sensitivities may be heightened and that self-regulation may be more difficult in novel situations or when individuals are overwhelmed or distressed. Triggering stimuli included excessively bright lighting, overpowering smells of other people's perfume or strong cleaning products, loud air conditioning systems, noise from other people, and the taste, smell and texture of the hospital food. Although many of these sensory aversions could be accommodated, autistic adults reported that this possibility was often not considered. For some, their requests for sensory sensitivities to be accommodated were interpreted as part of their pathology, such as requests for specific food textures to be avoided being viewed as symptoms of an eating disorder, rather than stemming from their autism.

Need for predictability. Change and uncertainty were repeatedly discussed as a source of concern for autistic individuals, for example, in relation to the prospect of starting a new treatment, transition between services, changes in staff, or being discharged. Participants across groups noted

the importance of structure, predictability and transparency of treatments and during individual

sessions to make 'the encounter less anxiety-provoking'[11]. Examples of how to implement this

included keeping a 'routine with appointment times and location'[21], 'setting clear expectations'[30]

before starting a new treatment, and 'following a similar structure for each session'[25]. Autistic adults

in inpatient settings described how building new routines and engaging in regular activities helped

them to manage anxieties related to being in an unfamiliar environment. Clinicians suggested that

the notion of change should be discussed 'in a tentative and considered manner'[35] and that changes

may need to be introduced gradually.

2.1 Need for a comprehensive and flexible approach

Participants voiced the need for flexibility in treatment provision to better suit autistic

adults. They argued that this requires services to move away from their rules and regulations, and to

'be as flexible as [they] can be'[11] to give everyone the opportunity to engage with the treatments

they are offering:

Being bespoke and evidence-based. Participants emphasised that adaptations should be

tailored towards the individual as well as evidence-based. However, there was much variation in

what adaptations they considered to be effective, with the heterogeneity of autism acknowledged.

Therefore, rather than following standard adaptations and recommendations for 'a generic group of

autistic people'[12], participants emphasised that adaptations should be considered and implemented

based on 'individual client's unique profile of strengths, weaknesses, and interests'[25]. It was noted

that if time was taken to assess an individual's needs, clinicians could still draw on pre-existing

adaptations to appropriately support the individual, with one clinician suggesting it would be helpful

to have *'some kind of tool-kit of interventions that can be customised to a particular patient'*[35].

Participants highlighted the need for research to find out what worked for whom and why, to inform

the development of evidence-based treatments and adaptations for this group.

Adjusting timings and expectations for outcomes. Participants advocated for the need to

consider more preventative approaches to mental health care, to adjust the timing of treatment,

and to re-evaluate desired outcomes. Existing service systems were critiqued for their reactive

approach, only responding when individuals were in crisis. This approach was viewed to be

problematic, as participants felt the severity of autistic individual's difficulties was often

underestimated. Participants thought it was necessary to consider the presence of co-occurring

mental health difficulties more routinely and to ensure that support was more readily available,

particularly for sub-groups exposed to high levels of stress, such as autistic students in Higher

Education.

Autistic adults felt that standard treatment provision was often not long or frequent enough

to '*make yourself well*'[7]. They reported to be '*struggling to make progress within the typical time*

frames for treatment'[20] and felt they were '*being asked to do things that they did not feel ready*

for'[34]*.* Participants suggested that therapy sessions for autistic adults need to be longer and at 'a

slower pace'[2] or 'shorter [and] more frequent'[10].

Criticising 'the limited nature of services'[12], participants suggested that it might be necessary

to 'continue support after psychological therapy to ensure on-going [mental health] management'[2].

Autistic adults described taking care of their mental health as 'a constant battle'[18]. Further, clinicians

reported frequent regression and suggested it might be more difficult for some autistic adults to

maintain progress under changing circumstances.

Several participants discussed how expectations for recovery and outcomes should be re-

evaluated for some autistic individuals. For example, autistic women who have had treatment for

eating disorders and considered themselves recovered, described still having certain behaviours

around food, such as a need for control, which they viewed as 'stemming from their autism rather

than from Anorexia Nervosa'[20]. Clinicians suggested that it might not be helpful to eliminate all

behaviours associated with the mental health difficulty, even if they superficially look like they might

be maintaining the problems, as they might also represent autism-related coping strategies. For

example, for someone recovered from an eating disorder it might still be important to follow rigid

routines at mealtime as a means of introducing structure to their day. Participants felt that it was

more important to consider 'the extent to which symptoms impact on functioning or cause

distress'[35] and to '*work towards a good quality of life*'[21].

Bridging formal and informal support. Participants emphasised a need for greater

collaboration between social, educational, and health services and between formal and informal

support sources to provide more comprehensive and holistic support. Autistic adults valued staying

'connected to the community [...] to apply the skills they learned'[14]. Several papers discussed the

benefit of informal support, but also acknowledged challenges (see 'tension in personal

relationships' above). Friends and family members were a valuable resource to ensure continued

support after psychological therapy or to help with implementation between sessions. Clinicians

highlighted that this should be considered when planning treatment and might require additional

resources to manage dynamics within a therapy context and for supporters to develop necessary

skills.

Autistic adults valued autistic peer support, appreciating the 'common connection'[18] with

others who identified as autistic and commenting that 'shared experience of the world'[18] made it

easier for them to express themselves and feel understood. Yet, autistic adults emphasised that peer

support needed to be specific to the individual's needs, 'rather than simply providing access to a

generic group of autistic people' and expressed a desire for such support to be 'formal [and]

facilitated by specially trained autistic people'[12].

3. Collaboration and Empowerment

Autistic adults with positive experiences of receiving support for their mental health

difficulties reported the relationship with their clinician to be pivotal, and empowerment was a

central element of the treatment process as well as an overarching goal for treatment outcomes:

Building therapeutic relationships. Participants across groups viewed therapeutic

relationships to be 'the most important aspect of therapy'[11] and 'essential to ensure positive

experiences of mental health support'[12]. Participants felt it was fundamentally important to foster

'strong and trusting relationships'[12] 'before expecting [autistic adults] to do any difficult

psychological work'[1]. Clinicians noted that it might take some autistic adults a little longer to develop trust but emphasised that this could be *'true of everybody'*[11] and that autistic adults were capable of building and utilising therapeutic relationships. As such, they saw a need to prioritise working on this and highlighted their responsibility to assist with finding another therapist if unable to establish a connection themselves. Autistic adults agreed that they could sometimes struggle to build an *'immediate connection'*[7] and that it can take them *'ages to develop good rapport'*[7]. For this reason, they highly valued 'continuity of care'[7] that allowed them to build trust. Autistic adults who were satisfied with the relationship with their clinician experienced these relationships to be 'reciprocal and responsive to [their] needs'[30] and were appreciative of the support they had received. Clinicians described 'being humbled'[24] and feeling a 'sense of fulfilment'[24] from successfully establishing such relationships.

Listening to autistic voices. Participants felt it was important to engage autistic individuals in treatment decisions, treating them as experts of their own experience. Clinicians reported that they encouraged autistic adults to be 'active participants'[35] in the therapy process and asked them about 'their views on the pace and content of the clinical work'[35]. Clinicians noted that autistic individuals 'may have had limited opportunities to develop assertiveness skills to express their views'[35] and that 'an implicit element of the therapeutic relationship and process should involve encouraging patients to feel confident to say what they think'[35]. Thereby, they thought it was important for clinicians to clearly communicate their willingness to 'understand [the autistic adults'] experience to the best of [their] ability'[24]. To empower their autistic client to partake in treatment, clinicians needed to 'step into [their] client's worldview'[11] and 'speak the same language'[21]. Relatedly, clinicians felt it was important to demonstrate understanding if autistic adults were sceptical due to previous experiences of *'being failed by various systems [and] society not recognising their needs'*[34], showing 'empathy and 'patience'[24]. Those autistic adults who felt their insights were 'taken into consideration'[12] described 'better treatment experiences and outcomes'[20]. Clinicians spoke about this being a learning experience, and that listening to autistic adults gave them new insight into the

diversity of human experiences and improved their skills as a therapist, making them '*more empathic and less judgmental*'[24].

Despite the importance of listening to them, autistic individuals and their families were adamant that professionals should not rely on them to teach them about autism and it was the clinician's responsibility to acquire sufficient knowledge prior to offering treatment. However, several papers discussed the potential benefits of involving autistic adults in creating and delivering training for staff in mental health settings.

Enabling independence, self-advocacy and self-care. It was considered of high import to help autistic adults to develop independence and autonomy in managing their mental health outside of therapy. Even though most participants seem to have been disappointed by the care they received, those who were satisfied felt it had provided them with the opportunity to increase their 'self-awareness' and *'compassion for [themselves] as a human being'*[7]. They reported that among the most valuable things they had taken from treatment were *'self-management techniques'*[12] and 'strategies to raise [their] mood'[34], with some reporting they 'routinely employed the techniques [they] had been taught'[32]. They also realised that they did not have to 'do it all by [them]selves'[7] and felt more able to ask for help if needed in the future. Autistic adults described how appropriate tailored support and treatment 'empowered them, gave them autonomy, facilitated their inclusion in social networks and wider society and gave them hope for a future'[7].

Discussion

The current study systematically reviewed and synthesised qualitative research on autistic adults' experience of accessing and receiving mental health support, triangulating perspectives of autistic adults, professionals and family members, to generate an evidence-based understanding of autistic adults' experiences in mental health care. We identified 38 studies related to autistic adults' experiences of accessing support for mental health difficulties. The thematic synthesis highlighted that autistic adults' experience in current service systems is predominantly negative, with autistic adults facing several barriers when accessing and engaging with support for mental health

difficulties. There is a clear need for a more flexible, comprehensive and holistic approach, which takes account of how being autistic affects the individual's mental health presentation and engagement with treatment. Building trusting relationships, including autistic adults as active participants in the treatment process, and empowering them to take agency are important steps for more effective and inclusive mental health care provision.

Overall, the views of participants from the different stakeholder groups were consistent with each other. This is encouraging as it grants the possibility of working together towards a common goal of improving service provision for this group. Professionals and family members also reported frustrating and lonely experiences, which were impacting on their ability and motivation to support autistic adults. Working towards better mental health care provision for autistic adults should not only result in more positive outcomes for this group, but also make the roles for parents and clinicians more enjoyable and rewarding.

However, participants' accounts also suggested that conflicting perceptions and stereotyped views of and lack of specialist training/expertise in working with autistic individuals held by clinicians may interfere with successful service provision for autistic adults. Clinicians participating in included studies commented on lacking confidence when working with autistic adults. This is in line with larger scale surveys of different professional groups autistic adults might encounter in the mental health care system, suggesting that, while they tend to have good basic knowledge of autism, many lack formal training and/or do not feel adequately supported to work with autistic individuals (Murphy 2015, Unigwe, Buckley et al. 2017, Crane, Davidson et al. 2019, Hu and Chandrasekhar 2020). As highlighted by the Double Empathy Problem (Milton, 2012), we must consider how the clinician's own difficulties in understanding autistic minds may impact on mental health care. Indeed, Mitchell et al. (2021) discuss how misunderstandings and misperceptions from non-autistic people can serve to isolate autistic people and worsen their mental health. Critically, our meta-synthesis highlighted collaboration and empowerment as key themes - and we argue that these are not achievable unless autistic people are truly listened to and understood.

Another important and concerning finding in our meta-synthesis was that services seem to be not only ineffective in supporting autistic people with co-occurring mental health problems, but can also pose a risk of worsening the individual's condition through iatrogenic harm. While some of this harm seems to be due to lack of knowledge and stereotyped beliefs about autistic adults' ability to benefit from treatment, even motivated and experienced clinicians encountered challenges and constraints, feeling unable to offer more appropriate support in what was perceived to be a rigid and tightly commissioned service system. Thus, the current systems appear to be potentially causing more harm than good. With 'avoiding harm' being a key principle of psychological practice (APA, 2017; British Psychological Society, 2017), a clinician's initial response could be to withdraw and be even more hesitant with offering support to autistic people. Instead, there is a need to actively work towards changing the status quo. Further, given how frequently autistic adults report negative service experiences and iatrogenic harm, it could be sensible to routinely ask new autistic services users about previous experiences of care and consider this in formulation and subsequent care provision.

Apart from social responsibility, there are also potential economic reasons to work hard to improve the mental health support offered to autistic individuals. Currently, autistic adults have to repeatedly engage with services that are poorly equipped to meet their needs, which has been demonstrated to be expensive for individuals, their families and society as a whole (Buescher, Cidav, Knapp, & Mandell, 2014). In addition, the impact of persistent mental health difficulties on autistic adults' daily living and independence (Chiang & Gau, 2016; Hendricks, 2010) means they are more likely to require further support and are less likely to be able to work. Indeed, autistic adults' medical costs exceed those of children, and during adulthood access to supportive living and productivity loss are among the factors contributing the highest cost for autistic individuals (Buescher et al., 2014). Working towards removing barriers to access and investing into the development of more effective, proactive, tailored services may be among the most efficient ways to reduce this cost, while simultaneously improving individual's productivity and ability to work (Iemmi, Knapp, & Ragan,

2017). Improved support across the healthcare system may also reduce the impact on individual clinicians. Thus, both for autistic adult's wellbeing (Mason, Mackintosh, et al., 2019) and for societal/economic benefits (Buescher et al., 2014) it is desirable to continue to work towards offering appropriate and effective help to autistic adults seeking support for mental health difficulties. The current review demonstrated the benefits of successful service provision and, importantly, offered insights into how to achieve this.

The meta-synthesis provided clear suggestions for changes and adaptations to current service provision and accessibility. First, autistic adults encounter barriers to accessing the support needed, and these barriers could be addressed by raising awareness of diversity in mental health presentations among gatekeepers and assisting autistic adults with navigating the service system. Second, within services, simple adaptations, such as tailoring communication, addressing sensory stressors, and including autistic adults in decision making processes, can be implemented without many additional resources. More complex adaptations, such as adapting the timings and number of therapy sessions, tailoring treatment approaches, and developing new interventions specifically for autistic people, will require higher levels of expertise, facilitated by clinician training and continuous support for staff, as well as changes on a service/commissioning level, including additional funding and greater flexibility within services.

Although these suggestions were identified via an exploration of autistic adults' experiences, they seem helpful to inform improvements of mental healthcare more generally. Principles of Universal Design, which outline how deliberately designing products and services to serve all can reduce the need for later adaptation, have been applied to education, conceptualising the inclusive classroom as able to flexibly accommodate all learners (e.g. Burgstahler & Russo-Gleivher, 2015; Milton, Martin & Melham, 2016). Extending these principles to the design of mental health services, emphasising bespoke individualised and person-centred care from the very outset, could improve the experience and effectiveness of service provision for all service users, not just autistic people.

The steps to improve mental health provision for autistic adults that were highlighted by the current study align with others' suggestions. For example, Green (2019) discussed the need for a strategic, developmentally-informed approach to services for autistic individuals, including management of co-occurring mental health difficulties, to optimise long-term outcomes for autistic individuals. This suggestion is consistent with our meta-synthesis, arguing for a more comprehensive long-term approach and for empowering autistic individuals through facilitating self-care. Further, Green (2019) argued that in the absence of autism-specific evidence for mental health intervention, already evidenced interventions for specific conditions should be used with appropriate adaptation, but also highlighted the need to develop an evidence base specific to autistic individuals. This argument aligns with conclusions drawn from the meta-synthesis, that research to inform the development of new treatments and adaptations, and to evaluate their implementation, will be vital for improving mental health care provision for autistic adults.

While there is emerging evidence for the effectiveness of some approaches and adaptations for treating mental health difficulties in autistic adults (A. Russell et al., 2019; Russell et al., 2013; Sizoo & Kuiper, 2017), there is a need to continue this work with high-quality studies and focus on translation into practice (Lounds Taylor et al., 2012; Spain, Sin, Chalder, Murphy, & Happe, 2015; White et al., 2018). Thereby, it will be important to collaborate with autistic adults to ensure acceptability of potential interventions (Benevides et al., 2020). Further, with the high use of psychotropic medication in autistic adults (Nylander, Axmon, Bjorne, Ahlstrom, & Gillberg, 2018), there is a specific need for more research exploring the effectiveness and experiences of medication use in this population (Esbensen, Greenberg, Seltzer, & Aman, 2009; Lake, Milovanov, Sawyer, & Lunsky, 2015). It is possible that an over-reliance on medication stems from a false belief amongst clinicians that autistic individuals are unable to engage in or benefit from talking therapies. Our synthesis also highlighted the need for autism-specific outcome measures (Gotham, Unruh, & Lord, 2015) and the potential value of 'toolboxes' to support autistic adults accessing mental health support as well as professionals providing care to this population, similar to those developed to aid

communication in physical health settings (Nicolaidis et al., 2016) and the 'Know your Normal'

toolkit for young autistic adults (Crane, Adams, Harper, Welch, & Pellicano, 2017).

Strengths and limitations

Overall, this study identified a larger number of papers than previous reviews on similar

topics (Calleja, et al., 2020; Mason, et al., 2019; Adams & Young, 2020), presumably due to the

broader scope of looking at autistic adults' experience of accessing services for mental health

difficulties in general, rather than focusing on barriers and facilitators to access specifically. In

addition, this topic seems to be a growing area of research, with several included papers being

published since the searches of previous reviews were conducted. Thus, the current review provides

a more up-to-date overview of the existing literature. The included studies were rated high in

quality, strengthening the validity of this review. However, the MMAT (Hong et al., 2018) is one of

several possible frameworks for appraising study quality and offers a less detailed evaluation of

qualitative studies than some other appraisal tools developed exclusively for qualitative studies,

which might have resulted in a more generous rating.

Although a relatively large number of qualitative papers were identified, the detail in which

they covered autistic adults' experience of support for mental health difficulties varied (see Table 1),

and consequently they contributed to the meta-synthesis to different degrees. In terms of the

breadth of experiences included, there is still scope for more focused explorations of specific aspects

of autistic adults' experience in mental health settings, such as specific therapeutic approaches or

treatment for specific co-occurring conditions, as have started to emerge for eating disorders

(Adamson, et al., 2020; Kinnaird, Norton, Stewart & Tchanturia, 2019; Kinnaird, Norton, &

Tchanturia, 2017; Kinnaird, E., Oakley, et al., 2021; Babb et al., 2021). Such in-depth qualitative

explorations could be used together with larger scale quantitative studies to inform and evaluate

adaptations to treatment specific to those circumstances. In addition, most studies highlight barriers

and challenges individuals experienced when accessing services and draw conclusions about what

could have been done differently to make these experiences more positive, but there is less focus on

what aspects of mental health care are experienced as helpful. It could be valuable to ask autistic adults who have had good experiences about what worked for them and why, highlighting examples of good practice.

The current review included mixed-method studies, but did not report on their quantitative findings, and excluded studies employing solely quantitative methodology, as this was considered to be beyond the scope of the current review. However, there are likely to be quantitative studies that have generated relevant insights about autistic adults' experiences of mental health services, for example by using questionnaires or surveys about their satisfaction with specific aspects of the support they received or studies on predictors of greater service need (e.g. Merrick et al., 2020; Schott et al., 2021). A systematic review of such studies could be considered by future research.

The meta-synthesis combined the views of participants from a wide range of studies, yet it is still likely to present a limited set of voices. Almost all studies were conducted in Western countries, with the majority conducted in the UK. Due to differences in the healthcare system, experiences are likely to vary across countries. Additionally, certain groups of autistic adults, such as those with co-occurring ID or those from certain ethnic groups, were underrepresented. The experience of autistic adults with ID might be different to those without, for example because they tend to access support via learning disability teams, rather than general adult mental health (Bhaumik, Tyrer, McGrother, & Ganghadaran, 2008). There also seem to be unique challenges, such as the developmental appropriateness of services, highlighted in our findings. Similarly, Black, Asian and Minority Ethnic (BAME) groups are disproportionately affected by health care inequalities (Bignall, Jeraj, Helsby, & Butt, 2019) and likely to face additional and different challenges (Memon et al., 2016), which must be considered by service providers and clinicians. The underrepresentation of these groups has been noted by others and systemic change in autism research is needed to better represent those with co-occurring ID and autistic people from diverse ethnic groups (G. Russell et al., 2019; Jones & Mandell, 2020).

Conclusions

The current systematic review and meta-synthesis provided a comprehensive overview of qualitative research on autistic adults' experience of accessing and engaging with support for mental health difficulties. Based on the included studies, current mental health service provision does not adequately support autistic adults with co-occurring mental health difficulties. There is a need for a more flexible, comprehensive and holistic approach, considering how being autistic affects the individual's mental health presentation and engagement. Building trusting relationships, listening to autistic adults, and empowering them to take agency, are fundamental steps towards more successful mental health care provision. Improvements to mental health care informed by autistic adults' unique experiences will likely also benefit other services users as well as improving conditions for professionals providing treatment. There is a need to further explore autistic adults' experience of specific treatment approaches, as well as the experiences of currently underrepresented groups of autistic adults, including those with co-occurring ID and from BAME backgrounds. Qualitative insights should be combined with larger scale quantitative studies to inform the development of new treatments and adaptations, and to evaluate their implementation in mental health service settings.

References

Adams, D., & Young, K. (2020). A Systematic Review of the Perceived Barriers and Facilitators to Accessing Psychological Treatment for Mental Health Problems in Individuals on the Autism Spectrum. *Review Journal of Autism and Developmental Disorders*. doi:10.1007/s40489-020-00226-7

Adamson, J., Kinnaird, E., Glennon, D., Oakley, M., & Tchanturia, K. (2020). Carers' views on autism and eating disorders comorbidity: qualitative study. *BJPsych Open, 6*(3), e51. doi:10.1192/bjo.2020.36

Ainsworth, K., Robertson, A. E., Welsh, H., Day, M., Watt, J., Barry, F., . . . Melville, C. (2020). Anxiety in adults with autism: Perspectives from practitioners. *Research in Autism Spectrum Disorders, 69 (no pagination)*(101457). doi:http://dx.doi.org/10.1016/j.rasd.2019.101457

Anderson, C., & Butt, C. (2018). Young Adults on the Autism Spectrum: The Struggle for Appropriate Services. *Journal of Autism and Developmental Disorders, 48*(11), 3912-3925. doi:http://dx.doi.org/10.1007/s10803-018-3673-z

Anderson, C., Lupfer, A., & Shattuck, P. T. (2018). Barriers to receipt of services for young adults with autism. *Pediatrics, 141*(Supplement 4), S300-S305. doi:http://dx.doi.org/10.1542/peds.2016-4300G

APA. (2013). *Diagnostic and statistical manual of mental disorders (5th ed.)*. Washington, DC: Author.

APA. (2017). Ethical Principles of Psychologists and Code of Conduct.   Retrieved from https://www.apa.org/ethics/code

Au-Yeung, S. K., Bradley, L., Robertson, A. E., Shaw, R., Baron-Cohen, S., & Cassidy, S. (2019). Experience of mental health diagnosis and perceived misdiagnosis in autistic, possibly autistic and non-autistic adults. *Autism, 23*(6), 1508-1518. doi:http://dx.doi.org/10.1177/1362361318818167

Autistica. (2018). Autism Study Groups. Retrieved from https://www.autistica.org.uk/get-involved/take-part-in-research/autism-study-groups

Babb, C., Brede, J., Jones, C. R. G., Elliott, M., Zanker, C., Tchanturia, K., Serpell, L., Mandy, W., & Fox, J. R. E. (2021). 'It's not that they don't want to access the support . . . it's the impact of the autism': The experience of eating disorder services from the perspective of autistic women, parents and healthcare professionals. *Autism, 25*(5), 1409–1421. https://doi.org/10.1177/1362361321991257

Baird, G., Simonoff, E., Pickles, A., Chandler, S., Loucas, T., Meldrum, D., & Charman, T. (2006). Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: the Special Needs and Autism Project (SNAP). *Lancet, 368*(9531), 210-215. doi:10.1016/S0140-6736(06)69041-7

Barnett-Page, E., & Thomas, J. (2009). Methods for the synthesis of qualitative research: a critical review. *BMC Medical Research Methodology, 9*(1), 59. doi:10.1186/1471-2288-9-59

Benevides, T. W., Shore, S. M., Andresen, M.-L., Caplan, R., Cook, B., Gassner, D. L., . . . Wittig, K. (2020). Interventions to address health outcomes among autistic adults: A systematic review. *Autism, 24*(6), 1345-1359. doi:10.1177/1362361320913664

Bhaumik, S., Tyrer, F. C., McGrother, C., & Ganghadaran, S. K. (2008). Psychiatric service use and psychiatric disorders in adults with intellectual disability. *Journal of Intellectual Disability Research, 52*(11), 986-995. doi:http://dx.doi.org/10.1111/j.1365-2788.2008.01124.x

Bignall, T., Jeraj, S., Helsby, E., & Butt, J. (2019). *Racial disparities in mental health: literature and evidence review*. Retrieved from London: https://raceequalityfoundation.org.uk/wp-content/uploads/2020/03/mental-health-report-v5-2.pdf

Braun, V., & Clarke, V. (2019). Novel insights into patients' life-worlds: the value of qualitative research. *The Lancet Psychiatry, 6*(9), 720-721. doi:https://doi.org/10.1016/S2215-0366(19)30296-2

British Psychological Society. (2017). *Code of Ethics and Conduct*. Retrieved from Leister, UK: https://www.bps.org.uk/sites/bps.org.uk/files/Policy%20-%20Files/BPS%20Code%20of%20Ethics%20and%20Conduct%20%28Updated%20July%202018%29.pdf

Brugha, T. S., Spiers, N., Bankart, J., Cooper, S.-A., McManus, S., Scott, F. J., . . . Tyrer, F. (2018). Epidemiology of autism in adults across age groups and ability levels. *British Journal of Psychiatry, 209*(6), 498-503. doi:10.1192/bjp.bp.115.174649

Buescher, A. V. S., Cidav, 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. doi:10.1001/jamapediatrics.2014.210

Burgstahler, S., & Russo-Gleicher, R. J. (2015). Applying universal design to address the needs of postsecondary students on the autism spectrum. *Journal of Postsecondary Education and Disability, 28*(2), 199-212.

Bury, S. M., Jellett, R., Spoor, J. R., & Hedley, D. (2020). "It Defines Who I Am" or "It's Something I Have": What Language Do [Autistic] Australian Adults [on the Autism Spectrum] Prefer? *Journal of Autism and Developmental Disorders*. doi:10.1007/s10803-020-04425-3

Calleja, S., Islam, F. M. A., Kingsley, J., & McDonald, R. (2020). Healthcare access for autistic adults: A systematic review. *Medicine, 99*(29).

Camm-Crosbie, L., Bradley, L., Shaw, R., Baron-Cohen, S., & Cassidy, S. (2019). 'People like me don't get support': Autistic adults' experiences of support and treatment for mental health difficulties, self-injury and suicidality. *Autism, 23*(6), 1431-1441. doi:http://dx.doi.org/10.1177/1362361318816053

Carter, N., Bryant-Lukosius, D., DiCenso, A., Blythe, J., & Neville, A. J. (2014). The use of triangulation in qualitative research. *Oncol Nurs Forum, 41*(5), 545-547. doi:10.1188/14.onf.545-547

Cheak-Zamora, N. C., & Teti, M. (2015). "You think it's hard now ... It gets much harder for our children": Youth with autism and their caregiver's perspectives of health care transition services. *Autism, 19*(8), 992-1001. doi:http://dx.doi.org/10.1177/1362361314558279

Chiang, H. L., & Gau, S. S. (2016). Comorbid psychiatric conditions as mediators to predict later social adjustment in youths with autism spectrum disorder. *Journal of Child Psychology & Psychiatry & Allied Disciplines, 57*(1), 103-111. doi:10.1111/jcpp.12450

Coleman-Fountain, E., Buckley, Carole, Beresford, Bryony. (2020). Improving mental health in autistic young adults: a qualitative study exploring help-seeking barriers in UK primary care. *The British journal of general practice : the journal of the Royal College of General Practitioners, 70*(694), e356-e363. doi:https://dx.doi.org/10.3399/bjgp20X709421

Cooper, K., Loades, M. E., & Russell, A. J. (2018). Adapting Psychological Therapies for Autism - Therapist Experience, Skills and Confidence. *Research in Autism Spectrum Disorders, 45*, 43-50. doi:https://dx.doi.org/10.1016/j.rasd.2017.11.002

Coxon, S. (2016). The lived experiences of practitioner's facilitation of and adults with high-functioning autism spectrum disorder (HFASD) undergoing psychological therapies. *Dissertation Abstracts International Section C: Worldwide, 74*(12-C), No Pagination Specified.

Crane, L., Adams, F., Harper, G., Welch, J., & Pellicano, E. (2019). 'Something needs to change': Mental health experiences of young autistic adults in England. *Autism, 23*(2), 477-493. doi:http://dx.doi.org/10.1177/1362361318757048

Crane, L. A. F., Harper; G., Welch, J.; Pellicano, E. (2017). Know your normal: Mental health in young autistic adults. Retrieved from London, UK: 22/01/2021

Crane, L., Davidson, I., Prosser, R., & Pellicano, E. (2019). Understanding psychiatrists' knowledge, attitudes and experiences in identifying and supporting their patients on the autism

spectrum: online survey. *BJPsych Open, 5*(3), e33.
doi:https://dx.doi.org/10.1192/bjo.2019.12

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. doi:http://dx.doi.org/10.1177/1362361315577517

Department of Health. (2015). Statutory Guidance for Local Authorities and NHS Organisations to Support Implementation of the Adult Autism Strategy.   Retrieved from https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/422338/autism-guidance.pdf

Dillenburger, K., Jordan, J. A., McKerr, L., Devine, P., & Keenan, M. (2013). Awareness and knowledge of autism and autism interventions: A general population survey. *Research in Autism Spectrum Disorders, 7*(12), 1558-1567. doi:https://doi.org/10.1016/j.rasd.2013.09.004

Ee, J., Lim, J.M., Stenfert Kroese, B. and Rose, J. (2021), What Are the Experiences of People with Neurodevelopmental Disorders Receiving Outpatient Mental Health Services in Singapore?. *Journal of Policy and Practice in Intellectual Disabilities.* https://doi.org/10.1111/jppi.12392

Elichaoff, F. (2015). What's it like being you? Growing old(er) with Autism Spectrum Conditions – a scoping study. *The European Journal of Social and Behavioural Sciences, 13*(2), 1851-1864. doi:doi:10.15405/ejsbs.166

Esbensen, A. J., Greenberg, J. S., Seltzer, M. M., & Aman, M. G. (2009). A longitudinal investigation of psychotropic and non-psychotropic medication use among adolescents and adults with autism spectrum disorders. *Journal of Autism & Developmental Disorders, 39*(9), 1339-1349. doi:10.1007/s10803-009-0750-3

Gotham, K., Marvin, A. R., Taylor, J. L., Warren, Z., Anderson, C. M., Law, P. A., . . . Lipkin, P. H. (2015). Characterizing the daily life, needs, and priorities of adults with autism spectrum disorder from interactive Autism Network data. *Autism, 19*(7), 794-804. doi:http://dx.doi.org/10.1177/1362361315583818

Gotham, K., Unruh, K., & Lord, C. (2015). Depression and its measurement in verbal adolescents and adults with autism spectrum disorder. *Autism, 19*(4), 491-504. doi:10.1177/1362361314536625

Green, J. (2019). Editorial Perspective: Delivering autism intervention through development. *Journal of Child Psychology & Psychiatry & Allied Disciplines, 60*(12), 1353-1356. doi:10.1111/jcpp.13110

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. doi:https://dx.doi.org/10.1177/1362361311405223

Hannes, K., Booth, A., Harris, J., & Noyes, J. (2013). Celebrating methodological challenges and changes: reflecting on the emergence and importance of the role of qualitative evidence in Cochrane reviews. *Systematic Reviews, 2*(1), 84. doi:10.1186/2046-4053-2-84

Hendricks, D. (2010). Employment and adults with autism spectrum disorders: Challenges and strategies for success. *Journal of Vocational Rehabilitation, 32*(2), 125-134.

Henry, A. R. (2014). Barriers to accessing support services in employment and health care for adults with autism spectrum disorders: A qualitative study. *Dissertation Abstracts International Section A: Humanities and Social Sciences, 75*(5-A(E)), No Pagination Specified.

Herrema, R., Garland, D., Osborne, M., Freeston, M., Honey, E., & Rodgers, J. (2017). Mental Wellbeing of Family Members of Autistic Adults. *Journal of Autism and Developmental Disorders, 47*(11), 3589-3599. doi:10.1007/s10803-017-3269-z

Hirvikoski, T., Mittendorfer-Rutz, E., Boman, M., Larsson, H., Lichtenstein, P., & Bölte, S. (2018). Premature mortality in autism spectrum disorder. *British Journal of Psychiatry, 208*(3), 232-238. doi:10.1192/bjp.bp.114.160192

Hong, Q. N., Fàbregues, S., Bartlett, G., Boardman, F., Cargo, M., Dagenais, P., . . . Pluye, P. (2018). The Mixed Methods Appraisal Tool (MMAT) version 2018 for information professionals and researchers. *Education for Information, 34*, 1-7. doi:10.3233/EFI-180221

Hu, Q., & Chandrasekhar, T. (2020). Meeting the Mental Health Needs of College Students with ASD: A Survey of University and College Counseling Center Directors. *Journal of Autism and Developmental Disorders*. doi:10.1007/s10803-020-04530-3

Iemmi, V., Knapp, M., & Ragan, I. (2017). *The autism dividend. Reaping the rewards of better investment*.

Jones, P. B. (2018). Adult mental health disorders and their age at onset. *British Journal of Psychiatry, 202*(s54), s5-s10. doi:10.1192/bjp.bp.112.119164

Jones, D. R., & Mandell, D. S. (2020). To address racial disparities in autism research, we must think globally, act locally. *Autism*, *24*(7), 1587–1589. https://doi.org/10.1177/1362361320948313

Jordan, A. L., Marczak, M., Knibbs, J. (2020). 'I Felt Like I was Floating in Space': Autistic Adults' Experiences of Low Mood and Depression. *Journal of Autism and Developmental Disorders*. doi:http://dx.doi.org/10.1007/s10803-020-04638-6

Joseph-Kent, K. E. (2018). Autism spectrum disorders and the healthcare experiences of aging adults. *Dissertation Abstracts International Section A: Humanities and Social Sciences, 78*(7-A(E)), No Pagination Specified.

Joshi, G., Wozniak, J., Petty, C., Martelon, M. K., Fried, R., Bolfek, A., . . . Biederman, J. (2013). Psychiatric comorbidity and functioning in a clinically referred population of adults with autism spectrum disorders: a comparative study. *Journal of Autism & Developmental Disorders, 43*(6), 1314-1325. doi:10.1007/s10803-012-1679-5

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, 20*(4), 442-462. doi:https://dx.doi.org/10.1177/1362361315588200

Kinnaird, E., Norton, C., & Tchanturia, K. (2017). Clinicians' views on working with anorexia nervosa and autism spectrum disorder comorbidity: A qualitative study. *BMC Psychiatry Vol 17 2017, ArtID 292, 17*.

Kinnaird, E., Norton, C., Stewart, C., & Tchanturia, K. (2019). Same behaviours, different reasons: What do patients with co-occurring anorexia and autism want from treatment? *International Review of Psychiatry*, No Pagination Specified. doi:http://dx.doi.org/10.1080/09540261.2018.1531831

Kinnaird, E., Oakley, M., Lawrence, V. et al. (2021). A peer interview qualitative study exploring support for carers of people with comorbid autism and eating disorders. *J Eat Disord* 9, 42. https://doi.org/10.1186/s40337-021-00397-6

Kinnear, D., Rydzewska, E., Dunn, K., Hughes-McCormack, L., Melville, C., Henderson, A., & Cooper, S.-A. (2020). The relative influence of intellectual disabilities and autism on sensory impairments and physical disability: A whole-country cohort of 5.3 million children and adults. *Journal of Applied Research in Intellectual Disabilities, 33*(5), 1059-1068. doi:https://doi.org/10.1111/jar.12728

Lachal, J., Revah-Levy, A., Orri, M., & Moro, M. R. (2017). Metasynthesis: An Original Method to Synthesize Qualitative Literature in Psychiatry. *Frontiers in Psychiatry, 8*, 269-269. doi:10.3389/fpsyt.2017.00269

Lake, J. K., Milovanov, A., Sawyer, A., & Lunsky, Y. (2015). Parent perspectives on psychotropic medication use and interactions with prescribing health care providers among adolescents and adults with an autism spectrum disorder. *Focus on Autism and Other Developmental Disabilities, 30*(3), 165-173. doi:http://dx.doi.org/10.1177/1088357614559215

Lake, J. K., Vogan, V., Sawyer, A., Weiss, J. A., & Lunsky, Y. (2015). Psychotropic medication use among adolescents and young adults with an autism spectrum disorder: Parent views about medication use and healthcare services. *Journal of Child and Adolescent Psychopharmacology, 25*(3), 260-268. doi:http://dx.doi.org/10.1089/cap.2014.0106

Lai, M.-C., Kassee, C., Besney, R., Bonato, S., Hull, L., Mandy, W., . . . Ameis, S. H. (2019). Prevalence of co-occurring mental health diagnoses in the autism population: a systematic review and meta-analysis. *The Lancet Psychiatry, 6*(10), 819-829. doi:https://doi.org/10.1016/S2215-0366(19)30289-5

Lever, A. G., & Geurts, H. M. (2016). Psychiatric Co-occurring Symptoms and Disorders in Young, Middle-Aged, and Older Adults with Autism Spectrum Disorder. *Journal of Autism & Developmental Disorders, 46*(6), 1916-1930. doi:10.1007/s10803-016-2722-8

Lounds Taylor, J., Dove, D., Veenstra-VanderWeele, J., Sathe, N. A., McPheeters, M. L., Jerome, R. N., & Warren, Z. (2012). AHRQ Comparative Effectiveness Reviews *Interventions for Adolescents and Young Adults With Autism Spectrum Disorders*. Rockville (MD): Agency for Healthcare Research and Quality (US).

Mack, J. (2020). Lived experiences of counselors providing counseling to adults with autism spectrum disorder: A qualitative phenomenological study. *Dissertation Abstracts International: Section B: The Sciences and Engineering, 81*(9-B), No-Specified.

Maddox, B. B., Crabbe, S., Beidas, R. S., Brookman-Frazee, L., Cannuscio, C. C., Miller, J. S., . . . Mandell, D. S. (2019). "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.* doi:http://dx.doi.org/10.1177/1362361319882227

Maloret, P., & Scott, T. (2018). Don't ask me what's the matter, ask me what matters: Acute mental health facility experiences of people living with autism spectrum conditions. *Journal of Psychiatric and Mental Health Nursing, 25*(1), 49-59. doi:http://dx.doi.org/10.1111/jpm.12438

Mandy, W., & Lai, M. C. (2016). Annual Research Review: The role of the environment in the developmental psychopathology of autism spectrum condition. *Journal of Child Psychology & Psychiatry & Allied Disciplines, 57*(3), 271-292. doi:10.1111/jcpp.12501

Mason, D., Ingham, B., Urbanowicz, A., Michael, C., Birtles, H., Woodbury-Smith, M., . . . 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 & Developmental Disorders, 49*(8), 3387-3400. doi:10.1007/s10803-019-04049-2

Mason, D., Mackintosh, J., McConachie, H., Rodgers, J., Finch, T., & Parr, J. R. (2019). Quality of life for older autistic people: The impact of mental health difficulties. *Research in Autism Spectrum Disorders, 63*, 13-22. doi:https://doi.org/10.1016/j.rasd.2019.02.007

Matson, J. L., & Horovitz, M. (2010). Stability of Autism Spectrum Disorders Symptoms over Time. *Journal of Developmental and Physical Disabilities, 22*(4), 331-342. doi:10.1007/s10882-010-9188-y

Matson, J. L., & Shoemaker, M. (2009). Intellectual disability and its relationship to autism spectrum disorders. *Research in Developmental Disabilities, 30*(6), 1107-1114. doi:https://doi.org/10.1016/j.ridd.2009.06.003

McMorris, C. A., Baraskewich, J., Ames, M. A., Shaikh, K. T., Ncube, B. L., & Bebko, J. M. (2018). Mental health issues in post-secondary students with autism spectrum disorder: Experiences in accessing services. *International Journal of Mental Health and Addiction*, No Pagination Specified. doi:http://dx.doi.org/10.1007/s11469-018-9988-3

Memon, A., Taylor, K., Mohebati, L. M., Sundin, J., Cooper, M., Scanlon, T., & de Visser, R. (2016). Perceived barriers to accessing mental health services among black and minority ethnic (BME) communities: a qualitative study in Southeast England. *BMJ Open, 6*(11), e012337. doi:10.1136/bmjopen-2016-012337

Merrick, H., King, Chris, McConachie, Helen, Parr, Jeremy R., Le Couteur, Ann, Transition Collaborative, Group. (2020). Experience of transfer from child to adult mental health services of young people with autism spectrum disorder. *BJPsych Open, 6*(4), e58. doi:https://dx.doi.org/10.1192/bjo.2020.41

Microsoft Corporation. (2018). Microsoft Excel. Retrieved from https://office.microsoft.com/excel

Milton, D. (2012). On the ontological status of autism: the 'double empathy problem', *Disability & Society, 27*:6, 883-887, DOI: 10.1080/09687599.2012.710008

Milton, D., Martin, N., & Melham, P. (2016). Beyond reasonable adjustment: autistic-friendly spaces and Universal Design. in D. Milton & N. Martin (Eds), *Autism and Intellectual Disabilities in Adults* (pp.81-81). Hove, UK: Pavilion Publishing and Media

Mitchell, P., Sheppard, E., & Cassidy, S. (2021). Autism and the double empathy problem: Implications for development and mental health. *British Journal of Developmental Psychology, n/a*. doi:10.1111/bjdp.12350

Moher, D., Liberati, A., Tetzlaff, J., & Altman, D. G. (2009). Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *PLoS Med, 6*(7), e1000097. doi:10.1371/journal.pmed.1000097

Murphy, D., McMorrow, K. (2015). View of autism spectrum conditions held by staff working within a high secure psychiatric hospital. *The Journal of Forensic Practice, 17*, 231-240. doi:10.1108/JFP-01-2015-0005

Murphy, C. M., Ellie Wilson, C., Robertson, D. M., Ecker, C., Daly, E. M., Hammond, N., . . . McAlonan, G. M. (2016). Autism spectrum disorder in adults: Diagnosis, management, and health services development. *Neuropsychiatric Disease and Treatment, 12*, 1669-1686. doi:http://dx.doi.org/10.2147/NDT.S65455

Newlove-Delgado, T., Ford, T. J., Stein, K., & Garside, R. (2018). 'You're 18 now, goodbye': the experiences of young people with attention deficit hyperactivity disorder of the transition from child to adult services. *Emotional and Behavioural Difficulties, 23*(3), 296-309. doi:http://dx.doi.org/10.1080/13632752.2018.1461476

NHS. (2019). The NHS long term plan. Retrieved from https://www.longtermplan.nhs.uk/

Nicolaidis, C., Raymaker, D., McDonald, K., Kapp, S., Weiner, M., Ashkenazy, E., . . . Baggs, A. (2016). The Development and Evaluation of an Online Healthcare Toolkit for Autistic Adults and their Primary Care Providers. *Journal of General Internal Medicine, 31*(10), 1180-1189. doi:http://dx.doi.org/10.1007/s11606-016-3763-6

Nylander, L., Axmon, A., Bjorne, P., Ahlstrom, G., & Gillberg, C. (2018). Older adults with autism spectrum disorders in Sweden: A register study of diagnoses, psychiatric care utilization and psychotropic medication of 601 individuals. *Journal of Autism and Developmental Disorders, 48*(9), 3076-3085. doi:http://dx.doi.org/10.1007/s10803-018-3567-0

Pellicano, E., Dinsmore, A., & Charman, T. (2014). What should autism research focus upon? Community views and priorities from the United Kingdom. *1*(7), 756-770.

Petty, S., Bergenheim, ML., Mahoney, G. et al. Adapting services for autism: Recommendations from a specialist multidisciplinary perspective using freelisting. *Curr Psychol* (2021). https://doi.org/10.1007/s12144-021-02061-3

QSR International Pty Ltd. (2020). NVivo (Version 12). Retrieved from https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software/home

Robertson, A. E., Stanfield, A. C., Watt, J., Barry, F., Day, M., Cormack, M., & Melville, C. (2018). The experience and impact of anxiety in autistic adults: A thematic analysis. *Research in Autism Spectrum Disorders, 46*, 8-18. doi:http://dx.doi.org/10.1016/j.rasd.2017.11.006

Russell, A., Gaunt, D., Cooper, K., Horwood, J., Barton, S., Ensum, I., . . . Wiles, N. (2019). Guided self-help for depression in autistic adults: the ADEPT feasibility RCT. *Health Technology Assessment (Winchester, England), 23*(68), 1-94. doi:10.3310/hta23680

Russell, A., Jassi, A., Fullana, M. A., Mack, H., Johnston, K., Heyman, I., . . . 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. doi:http://dx.doi.org/10.1002/da.22053

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. *Mol Autism, 10*, 9. doi:10.1186/s13229-019-0260-x

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

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. doi:10.1007/s11920-020-1136-7

Simonoff, E., Pickles, A., Charman, T., Chandler, S., Loucas, T., & Baird, G. (2008). Psychiatric disorders in children with autism spectrum disorders: prevalence, comorbidity, and associated factors in a population-derived sample. *J Am Acad Child Adolesc Psychiatry, 47*(8), 921-929. doi:10.1097/CHI.0b013e318179964f

Sizoo, B. B., & Kuiper, E. (2017). Cognitive behavioural therapy and mindfulness based stress reduction may be equally effective in reducing anxiety and depression in adults with autism spectrum disorders. *Research in Developmental Disabilities, 64*, 47-55. doi:http://dx.doi.org/10.1016/j.ridd.2017.03.004

Spain, D., Rumball, F., O'Neill, L., Sin, J., Prunty, J., & Happe, F. (2017). Conceptualizing and Treating Social Anxiety in Autism Spectrum Disorder: A Focus Group Study with Multidisciplinary Professionals. *Journal of Applied Research in Intellectual Disabilities, 30 Suppl 1***, 10-21. doi:https://dx.doi.org/10.1111/jar.12320**

Spain, D., Sin, J., Chalder, T., Murphy, D., & Happe, F. (2015). Cognitive behaviour therapy for adults with autism spectrum disorders and psychiatric co-morbidity: A review. *Research in Autism Spectrum Disorders, 9*, 151-162. doi:http://dx.doi.org/10.1016/j.rasd.2014.10.019

Thomas, J., & Harden, A. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Medical Research Methodology, 8*(1), 45. doi:10.1186/1471-2288-8-45

Tint, A., & Weiss, J. A. (2018). A qualitative study of the service experiences of women with autism spectrum disorder. *Autism, 22***(8), 928-937. doi:http://dx.doi.org/10.1177/1362361317702561**

Tong, A., Palmer, S., Craig, J. C., & Strippoli, G. F. (2016). A guide to reading and using systematic reviews of qualitative research. *Nephrol Dial Transplant, 31*(6), 897-903. doi:10.1093/ndt/gfu354

Toye, F., Seers, K., Allcock, N., Briggs, M., Carr, E., & Barker, K. (2014). Meta-ethnography 25 years on: challenges and insights for synthesising a large number of qualitative studies. *BMC Medical Research Methodology, 14*(1), 80. doi:10.1186/1471-2288-14-80

Unigwe, S., Buckley, C., Crane, L., Kenny, L., Remington, A., & Pellicano, E. (2017). GPs' confidence in caring for their patients on the autism spectrum: An online self-report study. *British Journal of General Practice, 67***(659), e445-e452. doi:http://dx.doi.org/10.3399/bjgp17X690449**

Van Hees, V., Moyson, T., & Roeyers, H. (2015). Higher Education Experiences of Students with Autism Spectrum Disorder: Challenges, Benefits and Support Needs. *Journal of Autism and Developmental Disorders, 45***(6), 1673-1688. doi:http://dx.doi.org/10.1007/s10803-014-2324-2**

White, S. W., Simmons, G. L., Gotham, K. O., Conner, C. M., Smith, I. C., Beck, K. B., & Mazefsky, C. A. (2018). Psychosocial Treatments Targeting Anxiety and Depression in Adolescents and Adults on the Autism Spectrum: Review of the Latest Research and Recommended Future Directions. *Current Psychiatry Reports, 20 (10) (no pagination)*(82). doi:http://dx.doi.org/10.1007/s11920-018-0949-0

WHO. (2013). *Autism Spectrum Disorders and Other Developmental Disorders: From Raising Awareness To Building Capacity*. Retrieved from Geneva:

Wise, E. A. (2020). Aging in Autism Spectrum Disorder. *The American Journal of Geriatric Psychiatry, 28*(3), 339-349. doi:10.1016/j.jagp.2019.12.001