Abstract

There is a high incidence and prevalence of mental health problems amongst young people, with several barriers to help-seeking noted in this group. High rates of mental health problems have also been reported in children and adults on the autism spectrum. Taken together, young autistic people may be a particularly vulnerable group when it comes to mental health. Yet there has been remarkably little work on the mental health needs and experiences of young autistic adults (16-25 years). Adopting a community-based participatory research approach – in which academic researchers and young autistic adults collaborated in an equitable research partnership – we explored young autistic people's experiences of mental health problems and their perspectives on the support they sought, if any, for these problems. 130 young autistic adults took part in the research: 109 completed an online survey and 21 took part in detailed interviews. The results highlight how young autistic people find it difficult to evaluate their mental health, experience high levels of stigma, and often face severe obstacles when trying to access mental health support. The findings also demonstrate how listening to – and learning from – young autistic people is crucial in ensuring that their mental health needs are met.

Keywords: autism, mental health, youth, support, anxiety, depression, community-based participatory research

"Something needs to change": Mental health experiences of young autistic adults in

England

Mental health problems affect approximately 1 in 4 adults in the United Kingdom

(UK) (McManus, Bebbingon, Jenkins, & Brugha, 2016). This represents both a major public

health issue (Royal College of Psychiatrists, 2010) and a priority area for the UK government

(Social Care Local Government and Care Partnership Directorate, 2014). A key focus is on

identifying and addressing mental health problems as early as possible, as this may lead to

better long-term outcomes (Patel, Flisher, Hetrick, & McGorry, 2007). We know that most

mental health conditions develop between childhood and adulthood (Birchwood & Singh,

2013; P. Jones, 2013; Patel, Flisher, Hetrick, & McGorry, 2007), and have a particularly high

incidence and prevalence between the ages of 12-25 years (Australian Bureau of Statistics,

2007). As such, there have been efforts to identify how best to meet the mental health needs

of young people at this critical time in development. Yet, research has shown that the mental

health needs of young people tend to be unmet (Verhulst, van der Ende, Ferdinand, & Kasius,

1997), even in high-income countries (Patel et al., 2007).

One key barrier to meeting the mental health needs of young people is that they are

often reluctant to seek professional support (Essau, 2005; Rickwood, Deane, & Wilson, 2007;

Zachrisson, Rodje, & Mykletun, 2006). This is due to a range of factors, notably difficulties

identifying the symptoms of mental health problems in the first place, concerns about

stigmatising attitudes towards mental illness, and a preference for self-reliance (Gulliver,

Griffiths, & Christensen, 2010). Yet, when young people overcome these barriers and seek

support for their mental health problems, many experience problems navigating the

healthcare system. In the UK, Child and Adolescent Mental Health Services (CAMHS)

typically accept referrals until the ages of 16-18 years, while adult care is provided

separately, via Adult Mental Health Services (AMHS). The transition between CAMHS and

AMHS can be difficult due to problems getting a referral to AMHS from CAMHS, poorly planned transitions between CAMHS and AMHS, and the shift from the child-centred developmental approach offered by CAMHS to the adult-centred care offered by AMHS (Paul et al., 2013). Unfortunately, these issues can result in many young people with mental health problems dropping through the care gap (Singh et al., 2010), with the "current system [being] weakest where it needs to be strongest" (McGorry, 2013, p. 30). This has led to calls for urgent reforms, including an integrated care pathway that extends from 12 to 25 years of age (McGorry, Bates, & Birchwood, 2013).

Although autism is not a mental health condition, mental health problems are common in autistic people[1]. Approximately 70-80% of autistic children and adults experience mental health problems (Lever & Geurts, 2016; Simonoff et al., 2008), most commonly depression and anxiety (Strang et al., 2012). Yet, it is difficult to determine the true rates of depression and anxiety in autistic people. First, many features of autism (e.g., social withdrawal, sleep problems) overlap with symptoms of depression and anxiety, so it may be difficult for autistic adults to identify that they are experiencing these conditions (Kerns et al., 2015; Stewart, Barnard, Pearson, Hasan, & O'Brien, 2006). Second, characteristics associated with autism may affect the way mental health problems present themselves in autistic adults (Stewart et al., 2006). For example, autism is associated with alexithymia (a difficulty in describing and identifying feelings and emotions), which could impact upon the way depression presents itself in autistic people (Berthoz, Lalanne, Crane, & Hill, 2013; Hill, Berthoz, & Frith, 2004). Yet while the rates of mental health problems in autistic people are difficult to determine, the consequences are not. Autistic adults who are experiencing

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[1] There is debate about how autism is – and should be – described. In this paper, we use 'identify-first' language (i.e. 'autistic person') rather than person-first language (i.e., 'person with autism'), in accordance with the views of autistic activists (e.g., Sinclair, 1999) and many autistic people and their families in the UK (Kenny et al., 2016; see also Gernsbacher, 2017).

episodes of depression, for example, report high rates of suicidal thoughts, and suicide plans or attempts (Cassidy et al., 2014; Hirvikoski et al., 2016), prompting an urgent need for greater research in this area.

Given that the rates of mental health problems are disproportionately high in young people generally (McGorry et al., 2013), and that young adults display poor help-seeking behaviours (Gulliver et al., 2010), there is particular need to focus on young autistic adults, who may be especially vulnerable when it comes to mental health. Indeed, the transition from childhood to adulthood is a notoriously challenging time for young people on the autism spectrum in general (Friedman, Erickson Warfield, & Parish, 2013; Lounds Taylor, 2009), with high rates of bullying and victimisation (Cappadocia, Weiss, & Pepler, 2012; Fisher & Taylor, 2016), as well as low rates of post-secondary education (Shattuck et al., 2012), employment (Shattuck et al., 2012) and social participation (Lounds Taylor, Adams, & Bishop, 2017; Orsmond, Shattuck, Cooper, Sterzing, & Anderson, 2013). Furthermore, the quality of life of young autistic people has been shown to be lower than that of non-autistic people across a range of areas (physical well-being, psychological well-being, social support, and peers) (Biggs & Carter, 2016). Particularly worrying is that even autistic adults with "good" outcomes (e.g., higher rates of employment, marriage/partnership, and independent living) show "strikingly high" rates of co-occurring mental health conditions (Gotham et al., 2015, p. 794)

When young autistic adults seek support for mental health problems, significant challenges may occur; especially as this tends to happen at the same time as other major life transitions (Kuhlthau, Warfield, Hurson, Delahaye, & Crossman, 2015). For example, pediatric healthcare providers (Kuhlthau et al., 2015), parents (Cheak-Zamora & Teti, 2015) and young autistic people (Cheak-Zamora & Teti, 2015) have all raised concerns about the transition from child to adult healthcare services for those on the autism spectrum. While not

specific to mental health services, these findings highlight how healthcare transitions can be a particular challenge for young autistic people, not least for those with co-occurring mental health problems.

The current project uniquely examined young autistic adults' experiences of mental health and mental health support using a community-based participatory research (CBPR) approach. CBPR involves a partnership between, for example, community members and academic researchers, in which different types of expertise are valued equally, and ownership of the research is shared (Israel et al., 2005; Nicolaidis et al., 2011). A key benefit of CBPR is that it ensures that the topic of study reflects the priorities of the community group (Israel et al., 2005). This is particularly relevant to autism, since there is often a mismatch between the research that gets funded and the research priorities of the autistic (and broader autism) communities (Pellicano, Dinsmore, & Charman, 2014a). In the current research, the 'community' comprised a group of young autistic people from the UK charity Ambitious about Autism, referred to as the myVoice team. myVoice is a project for young autistic people between the ages of 16 and 25 years, helping them to have a say in the decisions that affect their own lives, in their own communities. The myVoice team unanimously selected mental health in young autistic people as a priority topic, reflecting other research priority setting exercises within the autistic and broader autism communities (Autistica, 2016). They then commissioned and developed a research project in collaboration with a team of academic researchers at the Centre for Research in Autism and Education (CRAE).

The research itself was conducted by a team of three young autistic people from the broader myVoice team (FA, GH and JW) and two academic researchers (LC and LP), who collaborated – as full and equal partners – during all stages (design, implementation, analysis, interpretation and dissemination) of the research. The role of the community partners was to draw on their own personal and/or professional expertise, whilst the academic partners

ensured that the research was conducted to a high methodological standard (Nicolaidis et al., 2011). The team jointly decided on the methods to be used in the research (an online survey and in-depth interviews), as well as the specific research questions: (1) What are young autistic people's views and experiences of mental health problems and services? and (2) How can we best support young autistic people who are experiencing mental health problems?

Method

Participants

Criteria for inclusion in the study were that participants needed to: (1) be 16-25 years of age; (2) have received a formal diagnosis of an autism spectrum condition; and (3) be currently living in England. The research was advertised via existing databases (at Ambitious about Autism and at CRAE), social media, and personal contacts of the research team, between February and March 2017.

In total, 130 young autistic people took part: 109 completed the online survey, and a separate group of 21 young people were recruited to take part in a semi-structured interview (see Table 1 for participant details)[2]. Given the methodologies used, it is unsurprising that many young people in our sample were diagnosed with Asperger syndrome, educated in mainstream schools, had gained educational qualifications, and were currently employed and/or in education. Although there were a mix of gender identities and regions of England represented in our sample, the lack of ethnic diversity is notable (with most of the sample from a White ethnic background).

[insert Table 1 about here]

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[2] The survey and interview aspects of the research were run concurrently, which meant that the young people who took part in the interviews were not recruited from the broader survey sample.

Most of the sample – 74 (of 109) survey respondents (67.9%) and 15 (of 19) interviewees (78.9%) – had received other diagnoses, in addition to autism (see Table 2).

[insert Table 2 about here]

Materials and Procedure

The survey and interviews were granted ethical approval by UCL Institute of Education's Research Ethics Committee (REC 879).

Online survey. The online survey comprised five parts.

Part 1 – 'About you'. Respondents' completed questions about their background characteristics, including: age; gender identity; ethnicity; geographic location; education (type of school attended, highest educational qualification); current employment/education status; and living arrangements.

Part 2 – 'About your autism and any other diagnoses'. Respondents were asked to provide information on: their autism diagnosis (the specific diagnostic label given, and the age at which they were diagnosed); and if they had received any other medical and/or psychiatric diagnoses.

Part 3 – 'What's your normal?' Respondents were presented with 19 statements: 12 were from Goldberg and Williams' (1988) General Health Questionnaire, and seven were adapted from a mental health toolkit developed by Ambitious about Autism. These statements covered a range of areas including emotions (e.g., feeling happy, feeling unhappy and depressed), cognition (e.g., being able to concentrate on what you are doing, being able to overcome difficulties), behaviour (e.g., engaging in drinking, smoking or taking drugs) and basic needs (e.g., eating, sleeping). Respondents were asked to rate how their 'normal' (i.e., their typical behaviour) compared to that of other non-autistic people of a similar age (either 'more than other people', 'about the same as other people', or 'less than other people'). This

approach was taken as one of the aims of the autistic project partners was to assess how young autistic people's "normal" compared to that of the young non-autistic population. In the absence of a comparison group of non-autistic young people, it was felt that this "comparison framing" provided an important indicator of this perspective. Respondents were reassured that this may be difficult to judge, but were to try their best to respond.

After rating these 19 statements, respondents were asked whether they had previously or currently experienced mental health problems, stressing that we were interested in respondents' own opinions of this (i.e., irrespective of whether this has resulted in a professional diagnosis of a mental health problem). The final question asked respondents who had experienced mental health problems to consider whether their mental health symptoms were perceived to be different from their autism (i.e., their 'normal'). If respondents selected that there was a difference, they were then presented with the 19 statements (from the start of Part 3) again, and were asked to indicate if or how their 'normal' changed when they were experiencing mental health problems (either 'more than my normal', 'about the same as my normal', or 'less than my normal').

Part 4 – 'Your experiences with mental health services'. Respondents who had experienced mental health problems were asked whether they had ever sought help or assistance for mental health problems[3]. If they answered 'no' to this question, they were asked to explain their reasons why (in an open-text box). Those who had sought help or assistance for mental health problems were asked whether they had received this help or assistance from (a) clinical or healthcare professionals, (b) school/college/university, (c) family, (d) friends, (e) a charitable or non-profit organisation, or (f) anybody else. If

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[3] The focus of this paper is the young people's *experiences* of mental health services. It is possible therefore that our participants' responses to this question may reflect an underestimation of actual rates of mental health service use (e.g., if these services were requested by parents and received many years ago). These data therefore need to be interpreted with caution.

respondents had sought help or assistance from any of these options, follow-up questions were asked to determine (a) how useful this was, and (b) how comfortable they felt disclosing their mental health problems. These were both rated on five-point scales from 'not at all' (score of '1') to 'extremely' (score of '5').

Part 4 ended by asking all respondents (both those who had, and those who had not, sought help for mental health problems) to rate their confidence [all on five-point scales, from 'not at all' (score of '1') to 'extremely' (score of '5')] in: (a) knowing who to contact if they were experiencing mental health problems; (b) getting appropriate support for mental health problems, if they did seek help; and (c) knowing whether they are experiencing mental health problems. Higher scores reflect greater confidence.

Part 5 – Quality of Life. Respondents completed the World Health Organisation's Brief Quality of Life (WHOQOL-BREF) questionnaire (World Health Organization (WHO), 1996). This questionnaire comprises one item from each of the 24 facets of the World Health Organisation's WHOQOL-100 questionnaire, as well as two items from the Overall Quality of Life and General Health facets. The items assessed quality of life across four domains: Physical health (e.g. activities of daily living; sleep and rest; energy and fatigue); Psychological (e.g. positive and negative feelings; self-esteem; thinking, learning, memory and concentration); Social relationships (e.g. personal relationships, social support); and Environment (e.g. financial resources; home environment; health and social care). The WHOQOL-BREF has good to excellent psychometric properties (reliability and validity) (Skevington, Lotfy, & O'Connell, 2004) and has previously been used with young autistic adults (Kamp-Becker, Schröder, Remschmidt, & Bachmann, 2010). However, the community partners expressed concern regarding the item 'How satisfied are you with your sex life?', given the age range of the sample and the personal nature of the question, so this was changed to 'How satisfied are you with your romantic relationships?'. Internal consistency in

the current sample was high for those who completed both the survey (α = .88) and interview (α = .90).

   Interviews. Detailed semi-structured interviews were conducted by one of the academic researchers (LC), at the request of the myVoice collaborators, either face-to-face (n=16; 76.2%), on the phone (n=1; 4.8%), on Skype (n=1; 4.8%) or via an instant messenger service (n=3; 14.3%). The interviews covered four key areas: (1) experiences of receiving an autism diagnosis and any support received in relation to autism; (2) experiences of mental health problems and any support received in relation to these diagnoses; (3) perceptions of the differences, if any, between difficulties experienced due to their autism and difficulties experienced due to mental health problems; and (4) life more generally. The length of the interviews ranged from 10 to 145 minutes, with the written interviews tending to take longer than the verbal interviews.

   At the end of the interview, interviewees were asked to complete a background questionnaire (providing demographic information), and the Second Edition of the Social Responsiveness Scale (SRS-2) (Constantino & Gruber, 2012); a well validated, 60-item self-report measure, identifying the presence and severity of difficulties associated with autism[4]. For each item on the SRS-2, the young people were asked to rate their own behaviour over the past 6 months on a 4-point scale ranging from 1 ('not true') to 4 ('almost always true'), with higher scores on this measure indicating greater severity of symptoms. More specifically, a total T-score of 76 or above is strongly associated with a clinical diagnosis of autism spectrum condition (ASC). T-scores of 66-75 indicate ASC of moderate severity; T-scores of 60 to 65 indicate mild to moderate difficulties in social interaction; and T scores of

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[4] The SRS-2 was only completed by our interview participants; providing an indication of where they lie on the autism spectrum. Although, ideally, the SRS-2 would have been completed by survey respondents too, its inclusion resulted in the survey being very long and we were keen not to discourage participation and/or increase the likelihood of missing data.

59 and below are not typically associated with clinically significant ASC. The mean score of the current sample was 70.68 (SD = 8.88), which fell in the 'moderate severity' range. The SRS-2 has excellent reliability (Cronbach's alpha = 0.95) and strong predictive validity. Internal consistency for the current sample was high (α= 0.89).

All verbal interviews were digitally recorded with participants' prior consent and transcribed verbatim (only one participant did not provide consent to have their interview recorded, therefore detailed notes were taken throughout the interview). Data were analysed using thematic analysis following Braun and Clarke (2006). Specifically, data were interpreted within an essentialist framework (to report the experiences, meanings and reality of the participants), using an inductive ('bottom-up') approach (i.e., without integrating the themes within any pre-existing coding schemes, or preconceptions of the researchers). The process of analyses involved the research team – both the academic and autistic partners – independently familiarising themselves with the data, and reviewing the transcripts to develop an initial set of themes and sub-themes. The team then liaised several times to review these themes and subthemes, discussing them using a semantic approach, in which themes were identified at a 'surface' level, without theorizing beyond the actual content of the data. This process enabled the team to reach agreement regarding the codes, review the results, resolve any discrepancies and decide on the final themes and subthemes.

Results

Online survey

What's 'my normal'? Survey respondents (n=109) reflected on a series of statements and rated how their 'normal' (i.e., their typical behaviour) compared to that of other non-autistic people of a similar age. As shown in Table 3, the respondents' 'normal' tended to be different to that of other people, and rather negative. For example, the respondents

highlighted how they generally felt: unhappy and depressed; worthless; under strain; unable to overcome their difficulties; unable to face up to problems; and lacking in confidence.

[insert Table 3 about here]

Of the 109 respondents, 88 (80.7%) said that they had experienced mental health problems, including 67 (61.5%) who said they were currently, and had previously, experienced mental health problems; 7 (6.4%) who said they were currently, but had not previously, experienced mental health problems; and 14 (12.8%) who said they had previously, but were not currently, experiencing mental health problems. Of the remaining respondents, 16 (14.7%) said they had not experienced mental health problems, and 5 (4.6%) were unsure.

These respondents were asked whether their mental health symptoms were different to their 'normal'. Of the 88 respondents who were eligible to answer this question, 86 replied: 49 (57%) felt their mental health symptoms were different to their 'normal'; 6 (7%) did not; and 31 (36%) were unsure. Reflecting on the same 19 statements they saw earlier, respondents noted several changes to their 'normal' when they were experiencing mental health problems (see Table 4). Further, many of these changes were in areas that they normally differed from other people. For example, many young autistic people reported feeling under strain typically, but reported that this was further exacerbated when they were experiencing mental health problems (see Tables 3 and 4 for comparison).

Experiences with mental health services. 73 (90.1%) respondents reported having sought assistance for mental health problems. As shown in Table 5, all of these respondents had sought help from clinical/healthcare professionals, with almost 70% also seeking help from education professionals. Yet, few respondents (23.2% and 13.7%, respectively) found this support 'very' or 'extremely' useful, and even fewer (13.7% and 9.8%, respectively) felt comfortable disclosing their mental health problems to these professionals. Family and

friends were commonly used sources of support (in 63% and 31.5% of the respondents, respectively). Further, many respondents found their support to be 'very' or 'extremely' useful (47.8% and 39.1%, respectively) and many also felt 'very' or 'extremely' comfortable discussing their mental health problems with these individuals (41.3% and 39.1%, respectively). Support provided by charitable or non-profit organisations was also perceived favourably. Despite small numbers seeking help from such organisations (n=27), 40.7% of respondents reported their support to be 'very' or 'extremely' useful, and 48.1% felt 'very' or 'extremely' comfortable discussing their mental health problems with them.

[insert Table 5 about here]

Confidence. 101 respondents answered questions about their confidence regarding aspects of mental health. Few participants were confident in knowing who to contact if they were experiencing mental health problems: 30 (29.7%) were 'not at all confident', 32 (31.7%) were 'a little confident', 23 (22.8%) were 'moderately confident'; 12 (11.9%) were 'very confident' and 4 (4%) were 'extremely confident'; and even fewer were confident that, if they sought help, they would get appropriate support for their mental health problems: 40 (39.6%) were 'not at all confident', 28 (27.7%) were 'a little confident', 23 (22.8%) were 'moderately confident', 7 (6.9%) were 'very confident' and 3 (3%) were 'extremely confident'. Finally, when asked whether they were confident in knowing that you were experiencing mental health problems, results were mixed: 18 (17.8%) were 'not at all confident', 25 (24.7%) were 'a little confident', 26 (25.7%) were 'moderately confident', 19 (18.8%) were 'very confident', and 13 (12.9%) were 'extremely confident'.

Quality of life. 101 respondents completed the WHOQOL-BREF, to assess quality of life across four domains. As can be seen in Table 6, low levels of quality of life were reported amongst the young autistic people in the sample [population norms provided for reference, including (large) effect sizes].

[insert Table 6 about here]

Interviews. Twenty-one young autistic people spoke to us about (1) how they felt about their life in general and, more specifically, being autistic, (2) their experiences of mental health problems, and (3) the support they received for autism and/or mental health problems. We identified four key themes: (1) (Not) understanding my normal; (2) Stigma; (3) Barriers to support; and (4) Relationships (example quotes given in Table 7).

[insert Table 7 about here]

Theme 1: (Not) understanding my normal

Uncertainty regarding the distinction between autism and mental health. Many young autistic people were unsure whether the difficulties they were experiencing were due to their autism or due to mental health problems. Some young people could tell that they were experiencing mental health problems due to changes in their everyday autistic traits. Yet for others, this 'worsening' of autistic traits did not necessarily signal the start of a mental health problem, but could – at some point – lead to one. The young people also stressed how, even if they could identify the subtle differences between their autism and their mental health problems, it may not be obvious to others. Overall, interviewees felt that any support offered needed to bridge both autism and mental health, as they were so interlinked.

Difficulties navigating a neurotypical world. Many young autistic people felt that their mental health problems resulted from the pressure to act 'normal' in a neurotypical world. The young people we spoke to – all of whom were verbally and intellectually able – reported that they were often seen as too 'normal' to be autistic and, equally, too 'different' to be 'normal'. They felt that this led to delays in receiving a formal diagnosis of autism, and years of hiding their true selves. Young autistic women appeared to have a particularly difficult time, with many reporting that delays in receiving an autism diagnosis were associated with mental health problems. Over the long-term, this was felt to have negative

consequences: "the reason that so many people with autism develop [mental health] conditions is because of the way that we are treated. From early childhood, autistic kids are excluded, frowned upon and made to feel unnatural. We are constantly pressured to be more "normal", whatever that means. I think that if somebody who wasn't autistic grew up being excluded, bullied, and pressured to be something that they are not, they would very likely develop the same conditions".

Taken together, the links between autism and mental health were perceived to be incredibly complex: "You've got to deal with being autistic and having a mental health issue as opposed to just being neurotypical and having a mental health issue, which is difficult enough. You've got to work twice as hard because you've got to interpret things and understand things, as everybody does, but you've got to interpret and understand things from the perspective of somebody who doesn't have autism and quite often people won't communicate to us as autistic people, we've got to adapt and conform to their ways of communication, their ways of doing things".

Theme 2: Stigma

Stigma was commonly reported; in different ways, by different people. Some young autistic people felt society was (gradually) more accepting of mental health problems, perhaps even more so than autism. Yet, they also felt that society had a long way to go: "I still feel like there's quite a big stigma about mental health and with all like invisible illnesses, people don't seem to take it as seriously as they would like something, like an ear infection – and it's just as important".

Concerns were raised about disclosing specific mental health problems, such as psychoses or personality disorders, and the young people felt that greater awareness of more 'severe' mental health problems was needed. Interviewees also noted that reactions from friends or family (i.e., those who mattered most) could sometimes be negative, and they felt it

was important for professionals to address issues such as stigma with friends and family members, to ensure that young autistic people with mental health problems get the personal support they need.

Theme 3: Barriers to support

The young autistic people we spoke to struggled to access support for several reasons. First, they felt there was a general **lack of available services**, both in relation to autism and mental health. Many young people reported that their mental health problems were not deemed "quite severe enough for support", even when they had formally diagnosed mental health problems, and specific concerns were raised about support only being offered at crisis point, when it might be too late.

When support or services were available, the young people felt that there were considerable **delays** before these could be accessed (in relation both to autism as well as mental health problems). Yet after these lengthy waits, they often reported that support just did not materialise: "I was on the waiting list for months for counselling before I came to university but it never happened".

The young people highlighted several other areas in which improvements were needed. First, they felt **services were not tailored to their individual needs**, particularly to their autism. Some examples of good practice were noted, whereby the young people felt professionals appreciated that "we're all different, we're all unique and we all have our own different needs and it's okay to meet those needs". Likewise, many young people were aware of what would, and would not, 'work' for them, and were pleased when this was taken into consideration. However, when services were not tailored to their needs, it often resulted in withdrawal from clinical services.

If the young people overcame the problems associated with seeking mental health support and felt things were 'working' (i.e., they had reached the top of the waiting list, and

found the support that they were satisfied with), problems often still arose. One young person recalled how she sought help from a charitable/non-profit organisation as well as via Child and Adolescent Mental Health Services (CAMHS), but found out (at a time when things were progressing very well) that this additional support was not permitted. Other young people recalled the constant pressure they felt as a result of services trying to discharge patients from services as quickly as possible, before they felt they were ready. Others reported how funding for these services could be (and often was) withdrawn at short notice. Once this happened, there were **no other options available**.

Young people were also unhappy with the way that both diagnostic and mental health services were **'disjointed'**, and this was noted in several different ways. Those who had moved away from home to attend university commented on how services in different locations did not work together effectively: "I essentially got bounced around between systems". Others also commented on the lack of a pathway when transitioning both between and within services.

CAMHS were, however, perceived positively by the young autistic people we spoke to: "even though there's a 0 to 16 service and a 16 to 19 service, they allowed me to stay with the same person from when I was 15 right through to when I was 19… they kind of just did everything they could to work with me rather than just against me. I was lucky that I had CAMHS for as long as I did".

Yet, the **poor transition from child to adult services** was seen as an area of particular concern, with many young people reporting a sudden decrease in the amount of help and support available: "you hit 18 and all your services just go 'poof' and just disappear". Child services were found to offer more help and support on an ongoing basis, so the lack of adult services was concerning for many young people. The young people also felt that the criteria for accessing support was different for child and adult services, with adult

services requiring the individual to be in crisis. Finally, concerns were also raised about the huge transition from child-centred services to less supportive adult services, and how they would cope.

When support was offered via adult services, the young people felt this to be less structured than what they experienced in child services. The exception to this pattern was for those still in education (e.g., at University), who still had access to quite structured support. Nevertheless, these young people also expressed concerns about what would happen to them afterwards: "the help I got fluctuated as I've got older and now at uni it's great 'cause I have a teaching assistant, I have a mentor, and I have all of these other things just from DSA[5], which is great, but next year, I'll probably be graduating from uni … what's going to happen next after that help has kind of almost disappeared?"

The young people felt that AMHS gave more control and power to the service users to manage their own mental health. Yet some felt that they were not yet at the stage where they could manage this independently. This was felt to be a particular issue for young people on the autism spectrum: "people have this sort of weird perception of becoming an adult but they don't have a perception of what it's like to be a disabled adult, as it were and that's a very different side to it".

When discussing support, many young people wanted "something more long term". Others, aware of the limited nature of such services, were particularly pleased to have been given tools and techniques to manage their needs. Unfortunately, for other individuals, the support had simply not been of use: "I've consistently been let down by all of the people that were supposed to be able to diagnose me and be able to know what would support me and all

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[5] Disabled Students Allowance – additional funds provided for higher education students with disabilities in the United Kingdom.

of that stuff. It was just consistent my whole entire life. I don't think I've ever had one particularly useful bit of advice ever".

Overall, interviewees were generally unhappy about the standard of the services they accessed: "I wasn't very happy with any way that my mental health was handled my whole entire life really". In spite of this, they were made to feel that should express gratitude that they were receiving any support at all: "I just felt like a burden 'cause I didn't get as much as I wanted to but I was made to feel that that was more than I deserved".

Theme 4: Relationships

Family and friends were perceived as a strong source of support. This was felt to be essential as a lack of professional support resulted in many young people relying on an informal network of friends and family. Yet, many were reluctant to use such support for fear of worrying those closest to them or burdening them: "I usually go to my mum or my boyfriend, because they're both really open about mental health issues and don't make me feel judged. It is a bit of a problem though, because they have their own problems too, so if they have problems at the same time then I don't know who to turn to".

Many young people we spoke to wanted to **bridge the gap between formal support (from healthcare and educational services) and personal support (from friends and family).** Peer support was suggested as a compromise between the two. Yet, they added that this support needed to be tailored to an individual's needs, rather than simply providing access to a generic group of autistic people. There was also a desire for the support to be formal, facilitated by specially trained autistic people.

The young people emphasised the importance of having **strong, trusting relationships** with friends and family members, and strived for this with professionals too. However, concerns were often raised about seeking support from professionals who did not have high levels of expertise and knowledge relating to autism. Some young people

highlighted, though, that this very much "depends on the person you get"; and, encouragingly, examples of good practice were noted. Ultimately, there were a number of qualities that young people felt professionals needed to display, which centred on the principles of trust and respect. Further, whilst many young people highlighted the importance of having strong personal support, they felt strongly that this should not take the place of professional support: "What I'd like is somebody I can trust, someone to talk to and someone who understands autism; a professional person".

Discussion

Emerging adulthood is a difficult time for anyone, but especially so for a young person on the autism spectrum. Our research identified how young autistic adults generally felt unhappy and depressed, worthless, under strain, unable to overcome their difficulties, unable to face up to problems, and lacking in confidence. They also rated their quality of life to be poor. These difficulties were felt to be exacerbated by co-occurring mental health problems, which were present in the majority of our sample (approximately 80%), akin to previous reports (Leyfer et al., 2006; Simonoff et al., 2008). In the words of one young person, "something needs to change".

This change begins with helping the young people identify the specific challenges they face, thereby improving their mental health literacy (Jorm et al., 1997). Difficulties identifying the signs and symptoms of mental health problems are not unique to young autistic people; young non-autistic people also struggle to know whether their experiences are "normal" and whether they need to seek professional help (Biddle, Donovan, Sharp, & Gunnell, 2007; Rickwood & Braithwaite, 1994; Rickwood, Deane, Wilson, & Ciarrochi, 2005). Nevertheless, it is likely that there are specific problems faced by young autistic people in this regard. The participants in our research reported finding it difficult to identify the changes in their thoughts, feelings and behaviour that might be a sign of a mental health

problem and this appeared to be because many of the areas in which they noted difficulties when they experienced mental health problems were areas in which they were having problems anyway (e.g., 83% of young autistic people reported that they normally felt under strain, but a high proportion of these felt even more under strain when experiencing mental health problems). Such challenges also apply to physical health, with illness in autistic adults also tending to present as a change from baseline (Nicolaidis, Kripke, & Raymaker, 2014). This could be especially challenging for young autistic people, who may find it hard to identify and describe emotions (Hill et al., 2004) or express their needs (Nicolaidis et al., 2014). Whilst there is little evidence about how best to improve mental health literacy amongst non-autistic young people or adults (Kelly, Jorm, & Wright, 2007), it is thought that success depends on approaches that are specifically tailored to the audience to which they are directed, opposed to more generic initiatives (Noar, 2006). Involving young autistic people in the development of interventions designed to improve mental health literacy is, therefore, essential.

After having identified the signs and symptoms of mental health problems, it is vital that young autistic people seek and receive appropriate support. Yet the young autistic people in our sample felt that there were high levels of stigma associated with both autism and mental health problems that rendered them less likely to seek personal or professional help for the difficulties they were experiencing. Mental health problems have long been considered to be one of the most powerful stigmas (Bathje & Pryor, 2011), but there is also a growing body of literature linking stigma to autism. Nicolaidis et al. (2015), for example, reported how stigma about autism can affect healthcare interactions, with autistic people expressing concerns about disclosing their autism diagnosis to professionals. This suggests that young autistic people who are experiencing mental health problems may be doubly disadvantaged in this respect. Indeed, our autistic participants were often reluctant to discuss

their needs with other people (such as professionals or friends and family), particularly if they were experiencing 'severe' mental health issues (e.g., psychosis, personality disorder) that have particularly strong stigma attached to them (Crisp, Gelder, Rix, Meltzer, & Rowlands, 2000). In this regard, change needs to come not from the young autistic people themselves, but from the non-autistic population, who may hold misconceptions about autism. Training packages have been developed to improve knowledge and decrease stigma associated with autism amongst non-autistic people, and these have had some success (Gillespie-Lynch et al., 2015). Changes in attitudes can be slow to occur, however, especially since negative judgements of autistic people are "remarkably robust" (Sasson et al., 2017, p. 1).

Even when the young autistic people overcame the barriers they faced in seeking help for their mental health problems, they nevertheless reported encountering further barriers to accessing appropriate help and support. Many of these barriers (e.g., a lack of available services, poor transitions from child to adult mental health services, lengthy waiting times) are not unique to young autistic people and have been highlighted also by young non-autistic people (Birchwood & Singh, 2013). Yet the young autistic adults who took part in this research stressed a lack of support in relation to both autism *and* mental health, explaining how they did not benefit from services designed around the neurotypical norm. Using a CBPR approach, Nicolaidis et al. (2015) highlighted several autism-specific factors affecting healthcare interactions more generally (i.e., not specific to mental health). These included challenges relating to verbal communication skills, sensory sensitivities, processing speed, non-verbal communication, and organization, as well as a need for consistency. Nicolaidis et al. (2014) provide clear and explicit guidance for professionals – developed in collaboration with autistic people – to improve access to healthcare for people on the autism spectrum, and many of these recommendations can also be applied to mental health services. This is

essential to bridge the "significant" disparities in healthcare outcomes between autistic and non-autistic adults (Nicolaidis et al., 2013).

Nicolaidis et al.'s (2014) research also highlighted the need for increased training for healthcare professionals; a finding echoed in the current research. Specifically, the young autistic people who shared their mental health experiences explained how they wanted to feel confident that the people from whom they sought help were knowledgeable about autism *and* mental health difficulties, understood the unique challenges associated with being a young autistic person with mental health problems, and showed genuine concern for their wellbeing. This fostered strong and trusting relationships, which appeared to be essential in ensuring positive experiences of mental health support. Nicolaidis et al. (2015) highlighted how training for healthcare professionals needs to extend beyond mere knowledge of the characteristics of autism, and focus on promoting respectful and effective healthcare (via changes in the attitudes, skills and behaviours of professionals). This is corroborated by a recent survey of General Practitioners (physicians) in the United Kingdom, who were shown to be knowledgeable about the general characteristics of autism, but were not confident about providing effective care for their autistic patients (Unigwe et al., 2017).

A key strength of this study was the use of a CBPR approach. This sharing of expertise between academic and community partners conferred several benefits to the research: it ensured that the research topic and target samples were priorities for the autistic community; it allowed us to design and adapt instruments to ensure they were accessible and acceptable to young autistic people; it facilitated recruitment of participants for a project on a sensitive topic within a limited time frame; and it resulted in the data being interpreted and presented both with academic rigour and through an autistic lens (see also Israel et al., 2005; Nicolaidis et al., 2011). Anecdotally, the young autistic members of the research team felt that this experience gave them unique insights into process of designing, conducting and

analysing research, and the academic members of the team thought that the work was more

meaningful and impactful as a result of the collaboration. It will be important for future

participatory autism research to more formally evaluate the impact of involving autistic

people in the research process.

This research is not, however, without its limitations. First, the survey and interviews

were advertised as part of a research project on mental health in young autistic people. As

such, those opting to take part in the research may have been particularly likely to have

experienced mental health problems. Notwithstanding, the rates of mental health problems in

this sample were similar to those noted in previous studies (e.g., Lever & Geurts, 2016;

Simonoff et al., 2008), warranting confidence in the results. Second, there was no non-

autistic comparison group against which to compare the reports of the young autistic people

who took part in this research. We know that young people are already negative about their

lives, but it is unclear *how* negative (i.e., different from already-negative typical young

people) the young autistic people we sampled feel about their lives. Third, while the sample

comprised a range of gender identities, ages (from 16 to 25 years), and geographic locations

across England, there was a lack of ethnic diversity, as found in other surveys involving the

autistic and broader autism communities (e.g., Crane, Chester, Goddard, Henry, & Hill, 2016;

L. Jones, Goddard, Hill, Henry, & Crane, 2014). Greater stigma may be attached to mental

health problems in minority ethnic communities (Gary, 2005), meaning that young people

from non-White backgrounds may be even less likely to seek help for their mental health

problems, or may not be able to access help and support tailored to their cultural needs. This

is worthy of further study, as is the need to focus on mental health across the lifespan, given

that older adults are a neglected group in autism research more generally (e.g., Michael,

2016). Fourth, we used a bespoke tool to measure the mental health problems of young

autistic people, which we were unable to validate formally. Nevertheless, it appears to have

shown strong validity in that (a) the tool itself was developed with our autistic co-researchers (face validity) and (b) the results of the survey responses were corroborated both by the WHOQOL-BREF results within the same sample and the interview results from a separate sample (concurrent validity). Finally, the young autistic people who took part in the current research were verbally and cognitively able (with high rates of employment and education). As such, their views and experiences may not translate to those on the autism spectrum who have additional intellectual disabilities or are unable to advocate for themselves verbally. Nevertheless, it is striking that even in this sample of young autistic people who might be considered to have "good outcomes", mental health problems prevailed (see also Gotham et al., 2015).

Conclusion

This research was identified as a priority topic by young autistic adults and was designed, implemented, analysed and interpreted in partnership with young autistic adults – a rare occurrence in current autism research (Pellicano et al., 2014b). Our findings clearly demonstrate that young autistic people might be particularly disadvantaged as a result of the mental health challenges that confront them – through difficulties evaluating their own mental health *and* the many obstacles they face when trying to access mental health support (especially the lack of autism-specific and person-centred support from key professionals). Listening to – and learning from – young autistic people who have experienced mental health problems, particularly in relation to service design and delivery, should be a priority for researchers and professionals alike.

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Table 1. Participant demographics (online survey and interviews).

Background variables	Survey (n=109)	Interview (n=21)[a]
Age (in years)		
Mean (SD)	20.57 (2.86)	20.90 (2.98)
Range	16-25	16-26
Diagnosis on the autism spectrum		
Asperger syndrome	62 (56.9%)	6 (28.6%)
Autism	22 (18.3%)	2 (9.5%)
Autism spectrum disorder/condition	24 (22%)	9 (42.9%)
Pervasive developmental disorder	0 (0%)	2 (9.5%)
Age at diagnosis		
Mean (SD)	13.34 (6.44)	14.68 (4.22)
Range	1-25	4-22
Gender identity		
Female (including transgender female)	56 (51.4%)	10 (47.6%)
Male (including transgender male)	33 (30.3%)	9 (42.9%)
Non-binary	17 (15.6%)	2 (9.5%)
Prefer not to disclose	3 (2.7%)	0 (0%)
Ethnicity		
White background	95 (87.1%)	20 (95.2%)
Black background	1 (.9%)	0 (0%)
Asian background	6 (5.5%)	0 (0%)
Mixed background	4 (3.7%)	1 (4.8%)
Any other ethnic group / prefer not to say	3 (2.7%)	0 (0%)
Geographic location		
East Midlands	6 (5.5%)	0 (0%)
East of England	4 (3.7%)	1 (4.8%)
London	30 (27.5%)	7 (33.33%)
North East	6 (5.5%)	2 (9.5%)
North West	12 (11%)	5 (23.8%)

South East	27 (24.8%)	0 (0%)
South West	7 (6.4%)	2 (9.5%)
West Midlands	9 (8.2%)	1 (4.8%)
Yorkshire and the Humber	8 (7.3%)	3 (14.3%)
Education		
Mainstream school	93 (85.3%)	18 (94.74%)
Specialist school	7 (6.4%)	0 (0%)
Specialist units/bases in mainstream school	5 (4.6%)	0 (0%)
Independent/private school	2 (1.8%)	0 (0%)
Home school	2 (1.8%)	0 (0%)
Other	0 (0%)	1 (5.26%)
Highest qualification		
GCSEs	25 (22.9%)	4 (19%)
A/AS Levels	45 (41.3%)	5 (23.8%)
First degree (e.g. BA, BSc)	18 (16.5%)	5 (23.8%)
Higher degree (e.g. MA, MSc, PhD)	5 (4.6%)	2 (9.5%)
National Vocational Qualification (NVQ)	6 (5.5%)	1 (4.8%)
Other or no qualifications	6 (5.5%)	2 (9.5%)
Currently studying?		
No	43 (39.4%)	5 (23.8%)
Yes, full-time	56 (51.4%)	11 (52.4%)
Yes, part-time	10 (9.2%)	5 (23.8%)
Currently employed		
No, not looking for work	46 (42.2%)	7 (33.33%)
No, looking for work	13 (11.9%)	2 (9.5%)
Yes, full-time paid work	15 (13.8%)	2 (9.5%)
Yes, part-time paid work	14 (12.8%)	4 (19%)
Yes, working voluntarily	9 (8.3%)	2 (9.5%)
Other	12 (11%)	2 (9.5%)
Current living arrangements		
With parents and/or siblings	69 (63.3%)	12 (57.1%)

With friends	16 (14.7%)	3 (14.3%)
With partner and/or children	12 (11%)	1 (4.8%)
On my own	0 (0%)	2 (9.5%)
Other	12 (11%)	2 (9.5%)

[a] Note: two adults who took part in the interviews only provided their age, gender identity ethnicity and educational status. All other data presented in the column are for 19 of the young people who took part in an interview.

Table 2. Confirmed lifetime diagnoses of the participants who took part in the online survey and interviews.

	Confirmed diagnosis from a healthcare professional	
	Survey (n=109)	*Interview (n=19)*
Anxiety disorder	43 (39.4%)	12 (57.1%)
Attention Deficit Hyperactivity Disorder (ADHD)	15 (13.8%)	3 (14.3%)
Bipolar disorder	2 (1.8%)	1 (4.8%)
Depression	35 (32.1%)	8 (38.1%)
Developmental Coordination Disorder (DCD)/dyspraxia	20 (18.3%)	6 (28.6%)
Dyslexia	21 (19.3%)	3 (14.3%)
Epilepsy	2 (1.8%)	1 (4.8%)
Fragile X	0 (0%)	1 (4.8%)
Obsessive Compulsive Disorder (OCD)	10 (9.2%)	2 (9.5%)
Post-Traumatic Stress Disorder (PTSD)	3 (2.7%)	1 (4.8%)
Schizophrenia	0 (0%)	1 (4.8%)
Tourette syndrome	1 (.9%)	1 (4.8%)

Table 3. What's my 'normal'? Survey respondents' (n=109) ratings of their 'normal' thoughts, feelings and behaviours.

	More than other people	About the same as other people	Less than other people
Able to concentrate on what you are doing	28 (25.7%)	30 (27.5%)	51 (46.8%)
Tend to sleep	31 (28.4%)	28 (25.7%)	50 (45.9%)
Feel you play a useful part in things	11 (10.1%)	32 (29.3%)	66 (60.6%)
Feel capable of making decisions	7 (6.4%)	34 (31.2%)	68 (62.4%)
Feel under strain	83 (76.1%)	21 (19.3%)	5 (4.6%)
Feel able to overcome difficulties	18 (16.5%)	29 (26.6%)	62 (56.9%)
Enjoy daily activities	19 (17.4%)	45 (41.3%)	45 (41.3%)
Feel able to face up to problems	16 (14.7%)	30 (27.5%)	63 (57.8%)
Feel unhappy and depressed	74 (67.9%)	26 (23.8%)	9 (8.3%)
Feel confident in yourself	12 (11%)	29 (26.6%)	68 (62.4%)
Feel worthless	63 (57.8%)	31 (28.4%)	15 (13.8%)
Feel happy	10 (9.2%)	53 (48.6%)	46 (42.2%)
Enjoy interests and hobbies	54 (49.5%)	39 (35.8%)	16 (14.7%)
Tend to eat	32 (29.3%)	49 (45%)	28 (25.7%)
Spend time with people socially	3 (2.7%)	14 (12.8%)	92 (84.4%)
Spend time on appearance	5 (4.6%)	29 (26.6%)	75 (68.8%)
Have high levels of energy	20 (18.3%)	28 (25.7%)	61 (56%)
Engage in drinking/smoking/taking drugs	8 (7.3%)	24 (22.0%)	77 (70.6%)
Engage in repetitive behaviours	85 (78%)	16 (14.7%)	8 (7.3%)

Table 4. How survey respondents' (n=81) 'normal' changes when they are experiencing mental health problems.

	More than my normal	About the same as my normal	Less than my normal
Able to concentrate on what you are doing	4 (4.9%)	9 (11.1%)	68 (83.9%)
Tend to sleep	22 (27.2%)	13 (16%)	46 (56.8%)
Feel you play a useful part in things	1 (1.2%)	9 (11.1%)	71 (87.6%)
Feel capable of making decisions	1 (1.2%)	13 (16%)	67 (82.7%)
Feel under strain	65 (80.2%)	7 (8.6%)	9 (11.1%)
Feel able to overcome difficulties	5 (6.2%)	8 (9.9%)	68 (83.9%)
Enjoy daily activities	4 (4.9%)	12 (14.8%)	65 (80.2%)
Feel able to face up to problems	1 (1.2%)	13 (16%)	67 (82.7%)
Feel unhappy and depressed	66 (81.5%)	9 (11.1%)	6 (7.4%)
Feel confident in yourself	5 (6.2%)	15 (18.5%)	61 (75.3%)
Feel worthless	56 (69.1%)	16 (19.7%)	9 (11.1%)
Feel happy	2 (2.5%)	15 (18.5%)	64 (79%)
Enjoy interests and hobbies	6 (7.4%)	18 (22.2%)	57 (70.4%)
Tend to eat	18 (22.2%)	21 (25.9%)	42 (51.8%)
Spend time with people socially	3 (3.7%)	12 (14.8%)	66 (81.5%)
Spend time on appearance	3 (3.7%)	21 (25.9%)	57 (70.4%)
Have high levels of energy	6 (7.4%)	7 (8.6%)	68 (83.9%)
Engage in drinking/smoking/taking drugs	24 (29.6%)	34 (42%)	23 (28.4%)
Engage in repetitive behaviours	41 (50.6%)	27 (33.3%)	13 (16%)

Table 5. Support sought by survey respondents (n=73) experiencing mental health problems.

		Not at all	A little	Moderately	Very	Extremely
Clinical/healthcare professional (n=73, 100%)	How useful?	17 (23.3%)	20 (27.4%)	19 (26.0%)	12 (16.4%)	5 (6.8%)
	How comfortable disclosing?	19 (26.0%)	24 (32.9%)	20 (27.4%)	7 (9.6%)	3 (4.1%)
School/ college/ university (n=51; 69.9%)	How useful?	16 (31.4%)	16 (31.4%)	12 (23.5%)	4 (7.8%)	3 (5.9%)
	How comfortable disclosing?	18 (35.3%)	12 (23.5%)	16 (31.4%)	2 (3.9%)	3 (5.9%)
Family (n=46; 63.0%)	How useful?	3 (6.5%)	6 (13%)	15 (32.6%)	12 (26.1%)	10 (21.7%)
	How comfortable disclosing?	10 (21.7%)	8 (17.4%)	9 (19.6%)	14 (30.4%)	5 (10.9%)
Friends/partner (n=23; 31.5%)	How useful?	0 (0%)	8 (34.8%)	6 (26.1%)	6 (26.1%)	3 (13.0%)
	How comfortable disclosing?	1 (4.3%)	6 (26.1%)	7 (30.4%)	6 (26.1%)	3 (13.0%)
Charitable/non-profit organisation (n=27; 37.0%)	How useful?	3 (11.1%)	6 (22.2%)	7 (25.9%)	8 (29.6%)	3 (11.1%)
	How comfortable disclosing?	2 (7.4%)	5 (18.5%)	7 (25.9%)	4 (14.8%)	9 (33.3%)
Other (n=4; 5.5%)	How useful?	0 (0%)	1 (25%)	1 (25%)	1 (25%)	0 (0%)
	How comfortable disclosing?	0 (0%)	1 (25%)	0 (0%)	3 (75%)	0 (0%)

Table 6. Quality of life (WHOQOL-BREF) (REF) scores of the survey respondents (n=101).

	Mean (SD)	Range	Population norm[a]	Effect size (Cohen's d)
Physical health	57.25 (19.09)	3.57 – 89.29	73.5 (18.1)	0.87
Psychological	43.77 (23.05)	0 – 87.50	70.6 (14.0)	1.41
Social relationships	46.53 (28.49)	0 – 100	71.5 (18.2)	1.04
Environment	55.29 (21.00)	6.25 – 96.88	75.1 (13.0)	1.13

[a] Taken from Hawthorne, Herrman and Murphy (2006), n = 866 (male = 379, female = 487), participants all 20 years of age or older.

Table 7. Themes and sub-themes identified from young people's interviews.

Themes	Subthemes	Illustrative quotes
(Not) understanding my normal	Uncertainty regarding the distinction between autism and mental health.	"I usually detect [depression] because my Asperger's traits get worse, like I have more meltdowns that last longer and feel sadder afterwards" "If I'm actually having a really bad day then [autism and mental health problems] kind of blur into one... If I'm having a really good few weeks or months, then I'll think actually, no, there is a clear difference between the two because the autism doesn't have to make me ill, but the depression does". "I'm more likely to have mental health issues if I'm feeling overwhelmed because of the autism. "I can feel a difference but I don't know if it would as easy for someone else to tell". "Not only do [my autistic traits] get worse when I have mental health problems but sometimes the issue's in reverse, that I've had too many things to cope with and don't know how and end up with worse mental health, so the only way to solve that is to address my Asperger traits, addressing the mental health problems in that situation wouldn't change anything".
	Difficulties navigating a neurotypical world	"I almost feel like there's a guide that I've missed out on how to like exist as a person" "I didn't know what was kind of 'wrong' with me, if you like. I always felt different, massively different from other people and it just frustrated me so much" "I think if I had been diagnosed with Asperger's much younger, like many boys are, then I could have avoided some of my mental health issues. I think lots of girls are diagnosed too late or are just completely missed"
Stigma		"It's become more normal, not such like a freakish thing … I'm definitely more open about [mental health problems] than about the autism" "I can tell [mum] doesn't like the thought of her daughter having mental illnesses" "Recently there's been a lot more discussion about anxiety and depression and it's much more generally accepted, but the idea of hallucinations, specifically hearing voices, that really freaks people out, that makes people very uncomfortable to be around you, there's misconceptions" "It might have been good if they discussed with my mum how she could support me as I feel she doesn't understand mental illness and certainly sees a stigma around it" "I've got my psychosis to thank for the fact that I got my autism diagnosis because they were far more worried about the fact that I was hearing voices, there's more stigma behind that, even though none of them ever came across as violent. And that sort of really spurred them on to diagnose everything and sort

		of sort out whether there is depression on top of that or OCD or anything like that, which there wasn't to a diagnosable extent"
Barriers to support	Lack of available services	"I asked for a GP [General Practitioner] referral to a service for people with autism, but they didn't have any to suggest" "If I'm self-harming or if I feel like suicidal or things like that, then there isn't anyone for me to go to other than A&E [Accident and Emergency]…I know that there's no support there should I need it and that scares me"
	Delays	"I was 18, but the psychiatrist told me I had [autism] when I was 17, just I had to wait for the assessment which took quite a while" "Another five, four or five year waiting list in my area and my mum basically said that she wouldn't take me home until they assessed me because it would just end up with me having another breakdown again and again and again without an answer"
	Services were not tailored to their individual needs	"She was clearly used to working with five or six year olds and I was like 16 and 17 when I was seeing her … that isn't working for me" "I don't work like normal people work and so all these techniques that that apparently work for other people have never worked for me. And nobody seems to have wanted to spend the time of day with me to actually figure out how to get something that does work for me" "I wasn't allowed to talk about anything at all that I was struggling with, I had to keep within the parameters of issues they'd chosen… think I'd have benefitted more if there had been a therapy tailored to my traits and what I felt like I needed, everything was being decided for me and when I expressed that I wasn't comfortable I was made to feel like I wasn't complying"
	No other options available	"They tried doing CBT [Cognitive Behavioural Therapy] with me and going and talking to them helped but the actual CBT did nothing and then after that they kind of just said, we don't really know how to help you"
	Disjointed services	"I got my diagnosis just after I'd left Child and Adolescent Mental Health Services (CAMHS), 'cause I turned 18 … and if there is a support service that the people that diagnosed me would have been able to offer me they couldn't because they were from CAMHS, not Adult Mental Health Services (AMHS). So they were kind of like, we can't really do anything … And they kind of, they sent me a list of support groups and that was about it"

	Poor transition from child to adult services	"Before turning 18, I got regular support but now I'm 18 they say that I'm too well to get referred to anyone. I'm worried this will have negative effects in the future. There was always someone there before. What will happen when it gets cut?" "When I was discharged from CAMHS when I was 19, that was it basically, there wasn't any kind of support from the mental health side of things mainly because to get into adult services, you have to be like acutely mentally unwell there and then, it wasn't like a thing, we'll refer you and then give you support so you don't get unwell, it's kind of like, we'll refer you when you are unwell" "Especially after having just come out of CAMHS into AMHS, there just didn't seem to be any sort of pre-existing support system that they had…it was just, we have some support groups" "Mentally I wasn't an adult. I'd only just come out of hospital, I hadn't experienced like a good couple years of my life, I hadn't been at school. I was still like really immature anyway and I didn't act like an adult and it was kind of like they were there treating me, expecting me to behave like an adult, not taking into perspective what actually had happened in my past kind of thing" "[The support] started to form the basis of when I've been implementing my own self-managing techniques and then that built on further at university when it was sort of much more about the organisational, you know, how are you going to be able to implement your coping strategies with your lectures on top and that sort of thing. So it helped along that sort of process of independence".
Relationships	Bridging the gap between formal and personal support	"It would have been nice to have someone who understood exactly what I was going through" "I like having that connection with other people who are, who are autistic. I hold that very dear, and I really feel it's vital to foster that relationship in general in autistic people" "There wasn't anything out there for girls, like every single person she spoke to was like, we have this group but it's just four or five boys in it and there's no – like why would I want to go to a group with five teenage boys?" "I got given a mentor [at university] and they were like, 'yeah, yeah, he's done the same degree as you, he's on the spectrum, it'll be great', but it was just like another person on the spectrum (laughs), it wasn't a mentor, it was just like they didn't have any mentoring skills. It was just, it was just like talking to myself"
	Strong, trusting relationships	"[My GP] took me seriously, he got me the help that I needed, he sent me to the right people and he like referred me to CAMHS and wrote the referral in a way that would mean I would get the help that I needed. And he was lovely and he always like, even now, he's still interested in how I am doing and how things are for me, so that's good"

		"My CAMHS worker was really good and she kind of didn't patronise me and she didn't annoy me or say things that made me feel worse, she just basically listened and let me just vent to her and tried to get me to explain how I was feeling" "I had someone I can trust to speak to, like a confidant, who I could actually tell how I feel and not have to worry whether someone's listening or being judged for it" "She kind of let me lead the sessions and kind of asked me what I needed but she knew that I knew myself best and she, she respected that and kind of worked with me"