

Research Report

Autistic adults' views of their communication skills and needs

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Abstract

Background: Autistic people require varying levels of support at different stages of their lives. Yet, the healthcare needs of autistic adults are largely unmet. Speech and language therapy (SLT) is one healthcare service that has an important role in supporting autistic people: both with initial diagnosis, and with the ongoing support needed to navigate different communicative challenges across the lifespan. Despite recommendations for such support, currently there is no clear SLT pathway for autistic adults, and a lack of established approaches to support autistic adults' speech, language and communication needs.

Aims: To seek autistic adults' views on (1) their communication skills and support needs; (2) the type of support SLT could offer; and (3) how such support could be provided.

Methods & Procedures: A total of 18 autistic adults were interviewed in their preferred mode of communication (e.g., face to face, phone call, text messaging, e-mail), expressing their views on their communication skills and needs. Interview data were analysed using thematic analysis.

Outcomes & Results: Autistic adults presented complex views on communication, identifying the benefits of communication, while also emphasizing the significant negative impact that communication difficulties can have on their everyday lives. Identifying a range of internal (e.g., personal feelings) and external (e.g., the communication partner) factors, they highlighted the need for support at both individual levels (for specific life situations) and broader societal levels (to increase awareness and acceptance of communication difficulties).

Conclusions & Implications: Considering the negative impact that communication difficulties can have for autistic adults, a need for support was emphasized. Despite recognition of this need within current legislation (in the UK) and positive steps toward providing support, more needs to be done. As experts in supporting individuals with communication difficulties, speech and language therapists could play a pivotal role in providing support at an individual level, as well as increasing awareness of communication differences more widely.

Keywords: autism, adults, communication, speech and language therapy.

What this paper adds

What is already known on this subject

- There is a growing population of autistic adults with unmet support needs. A core characteristic of autism is difficulty with neurotypical social communication and interaction, which persists into adulthood and impacts across various life domains.

What this paper adds to existing knowledge

- Autistic adults outlined the types of communication difficulties they experience, and how these can negatively impact on physical and mental health. Results highlight how these difficulties are not just rooted within the person themselves but can be influenced by external factors (e.g., the environment and the communication partner).

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What are the potential or actual clinical implications of this work?

- Some autistic adults may benefit from direct support from SLT services. However, increased awareness and respect for communication differences at a broader societal level is also needed. Speech and language therapists can play an important role in increasing this level of awareness, positively highlighting differences in communication and ways to support people with communication difficulties/differences.

Introduction

Autism is a neurodevelopmental condition characterized by difficulties with reciprocal social communication, and the presence of restricted and repetitive behaviours and interests (American Psychiatric Association (APA) 2013). While all autistic¹ people share these core characteristics, the diagnostic label incorporates a heterogeneous population with varying strengths, difficulties, needs and preferences. It is estimated that at least 1% of adults in England are on the autism spectrum (Brugha *et al.* 2011). With an ageing population, a growing number of adults are seeking an autism diagnosis later in life, and more autistic children reach adulthood each year (Shattuck *et al.* 2012).

Although autism is lifelong, and people spend the majority of their lives in adulthood, the support needs of autistic adults are largely unmet (Shattuck *et al.* 2012, Wright *et al.* 2019). While true for all autistic adults, this is particularly pertinent for those without intellectual disabilities. This group lack a clear healthcare pathway (National Institute for Health and Care Excellence (NICE) 2012) and are at risk of falling 'between the cracks' of existing, yet inaccessible, services (Barber 2017: 420, National Autistic Society (NAS) 2009). It is essential that we better understand how to support this group transition to, and thrive in, adulthood (Turcotte *et al.* 2016).

Communication difficulties associated with autism (APA 2013) persist into adulthood and can impact significantly on day-to-day functioning (Jennes-Coussens *et al.* 2006). Müller *et al.* (2008) interviewed 18 autistic adults about their experiences of social challenges and identified communicative difficulties in areas such as initiating conversation, understanding abstract language and reading body language. Despite a desire for social interaction, these autistic adults reported that their social difficulties led to feelings of isolation. These interviews were conducted exclusively face to face and may not represent the views and experiences of all autistic adults (especially those whose communication difficulties preclude engagement in face-to-face interviews with a researcher; Nicolaidis *et al.* 2015). Yet, the issues identified, and their perceived impact, warrant further consideration.

Within a healthcare context, barriers to accessing services include difficulties processing information and fears about communicating with professionals (Raymaker *et al.* 2017). This is concerning given the high rates of co-occurring psychiatric conditions in this population that require service access (Lai *et al.* 2019, Lever and Geurts 2016). Autistic adults also perceive their communication difficulties to impact negatively on employment (Hurlbutt and Chalmers 2004). Yet, maintaining supported employment within communities enhances quality of life (García-Villamizar *et al.* 2002). More generally, the need for research relevant to the day-to-day lives of autistic people has been highlighted by the autistic and autism communities (Gotham *et al.* 2015, Pellicano *et al.* 2014), and communication is one such area (Autistica 2016).

In the UK, legislation is continually evolving in response to the identified needs of autistic adults. The Autism Strategy (Department of Health, 2010), created following the Autism Act 2009, provided requirements regarding minimum levels of support for adults (e.g., awareness training for all staff providing services to autistic adults). This was superseded by Think Autism (2014), which built on themes within the Autism Strategy and highlighted 15 priority areas for development (e.g., acceptance within the local community and connection with other people). Despite the importance of communication emphasized throughout these documents, SLT is not specifically referenced.

One of the roles of speech and language therapists is to support autistic people throughout their lives (Royal College of Speech and Language Therapists (RCSLT) 2018). As well as providing input during the diagnostic process, SLT should maximize opportunities to develop communication skills, and minimize risks associated with mental health difficulties. Currently, SLT research/services tends to be targeted toward autistic children, with a range of established supports including parent-based approaches (e.g., Sussman and Hanen Centre 1999, Pickles *et al.* 2016), group-based approaches (e.g., Legoff and Sherman 2006, Barry *et al.* 2003), individual therapy (e.g., Flippin *et al.* 2010) and environmental adaptation and assistance (e.g., Mavropoulou *et al.* 2011). While the RCSLT (2018) acknowledge that adults may have specific

risks and requirements for support, precisely what that support should look like for autistic adults is less clear.

Also unclear is what support autistic adults *want* from SLT. Historically, there has been a lack of involvement from autistic people regarding their healthcare needs (Nicolaidis *et al.* 2011). This is changing, with special health authorities (e.g., NICE 2012) advocating for a person-centred approach: recognizing the need to work in partnership with autistic people, and considering individual needs and preferences with respect to service provision. This positive and important development reflects how autistic adults are experts by experience, often able to provide information about what works best for them (Gotham *et al.* 2015, Hurlbutt and Chalmers 2002). Yet, the heterogeneity of this population and their underlying commonality of communication differences pose challenges to ensuring meaningful involvement in service provision. Adjustments such as allowing participants to choose their mode of participation (e.g., face-to-face or text-based modalities), and wording questions in a concrete manner, can help facilitate access to the views of a diverse range of people (Nicolaidis *et al.* 2015, 2019). This is critically important as autistic adults with varying communicative skills, needs and preferences must be involved in the what, how, when and where of potential service provision (Barber 2017), particularly regarding services relating to communication.

In the current study, we elicited the views of autistic adults on their communication skills and needs. Using semi-structured interviews with a range of communication methods, we addressed the following research questions: (1) How do autistic adults view their own communication skills and what are their communication preferences? (2) What impact does their communicative competence and/or level of need have on their day-to-day lives? (3) What type of support could SLT offer autistic adults and how could this support be provided?

Method

Participants

A total of 18 autistic adults (12 male, six female) were recruited. Purposive sampling ensured the recruitment of a diverse group of participants, with varying life experiences and views on communication. Specifically, 27 services for autistic adults were contacted from select categories of services listed on the National Autistic Society website (e.g., day services, social groups, education, professional networks; $n = 11$). Subsequent participants were recruited via social media ($n = 3$) and snowball sampling ($n = 4$).

Participants were based in the UK, and ranged in age from 19 to 52 years (mean = 34.89, SD = 11.02). They were formally diagnosed with Asperger's syndrome (a previously separate category of autism, which now falls under the broad banner of autism spectrum disorder; APA 2013) ($n = 10$), autism ($n = 5$) or autism spectrum disorder ($n = 3$). A total of 12 participants were diagnosed in childhood, and the remaining six were diagnosed in adulthood. The Social Responsiveness Scale—Second Edition (SRS-2; Constantino and Gruber 2012) was used to provide a measure of the presence and severity of social difficulties. SRS-2 total scores indicated that the majority of participants scored in the mild-moderate range (mean = 70.61, SD = 9.98). Most participants had co-occurring diagnoses, especially anxiety ($n = 11$) and depression ($n = 6$). Five participants were in paid employment (three part-time, two full-time), and two were completing undergraduate degrees. See table 1 for further demographic information.

Materials and procedure

Ethical approval was granted from the UCL Institute of Education Research Ethics Committee (REC 1114). All participants gave written, informed consent before participating.

Background questionnaire

Background information was collected via a two-part questionnaire. Part 1 comprised 18 demographic questions relating to age, gender, ethnicity, communication, diagnoses, education, living arrangements and employment. Part 2 comprised the SRS-2 (Constantino and Gruber 2012), a 65-item measure to identify and quantify social challenges associated with autism. For each item, participants self-reported their behaviour over the previous 6 months on a four-point ordinal scale, ranging from 1 ('not true') to 4 ('almost always true'), with results converted to *T*-scores (mean = 50, SD = 10). The SRS-2 has high internal consistency ($\alpha = 0.94$ – 0.96) with content, predictive and concurrent validity reported as moderate to high (0.86–0.92) (Bruni 2014).

Interview schedule

There were six topics in the semi-structured interview schedule: (1) everyday communication, (2) communication preferences (e.g., different modalities and situations), (3) views on own communication (strengths and difficulties), (4) perceived impact of communication on day-to-day life, (5) desired changes to communication (own and others) and (6) support for communication. Each topic contained a number of probing questions

Table 1. Participant demographics

Demographic measures ^a	n (%)
<i>Age (years)</i>	
18–24	4 (22.2)
25–34	5 (27.8)
35–44	3 (16.7)
45–54	6 (33.3)
<i>Ethnicity</i>	
White	12 (66.7)
Black	1 (5.6)
Asian	3 (11.1)
Mixed	2 (11.1)
<i>Place of residence</i>	
Greater London	15 (83.3)
Rest of the UK	3 (16.7)
<i>Spoken communication</i>	
Yes	14 (77.8)
No	4 (22.2)
<i>Other means of communication^a</i>	
Gestures of behaviour (e.g., nodding, thumbs up)	9 (50)
n.a. (only speech)	7 (38.9)
Low-tech assistive technology (e.g., communication book)	4 (22.2)
Sign language (including Makaton)	2 (11.1)
High-tech assistive technology (e.g., voice output device, iPad)	1 (5.6)
<i>Other diagnoses^a</i>	
Anxiety	11 (61.1)
Depression	6 (33.3)
Obsessive compulsive disorder	4 (22.2)
Dyslexia	4 (22.2)
Dyspraxia	3 (16.7)
Seizure disorder or epilepsy	3 (16.7)
Attention deficit hyperactive disorder (ADHD)	2 (11.1)
Oppositional defiant disorder (ODD)	1 (5.6)
Bipolar disorder	1 (5.6)
Insomnia	1 (5.6)
Hearing impairment	1 (5.6)
Emotionally unstable personality disorder	1 (5.6)
Dysthymia	1 (5.6)
<i>Highest level of qualification</i>	
Primary school (ages 5–11 years)	2 (11.1)
GCSE (typically, ages 14–16 years)	6 (33.3)
A-Level (typically, ages 16–18 years)	3 (16.7)
Trade or vocational qualification	3 (16.7)
Undergraduate qualification	2 (11.1)
<i>Other qualifications identified by participants</i>	
Language course	1 (5.6)
Further education course	1 (5.6)
<i>Living</i>	
Living by oneself	8 (44.4)
Parents and siblings	4 (22.2)
Parents	3 (16.7)
Spouse/life partner and children	2 (11.1)
Spouse/life partner	1 (5.6)
<i>Marital status</i>	
Single, never married	11 (61.1)
Married or domestic partnership	5 (27.8)
Divorced	2 (11.1)
<i>Children</i>	
No	13 (72.2)
Yes	5 (27.8)

Note: ^aParticipants could select more than one response for these questions, which means that the total percentage exceeds 100%.

(average of four questions). The first author (C.C.) created the interview schedule, which was then reviewed by the co-authors (E.P. and L.C.). All have extensive experience of working with autistic people. The schedule was reviewed by one autistic adult and piloted with another autistic adult to ensure sensitivity and suitability of questions. The final version incorporated their recommendations, which included improving the specificity of questions and defining the term ‘communication’ (the sending and receiving of messages, thoughts and feelings), and the various ways people communicate (speaking, writing, signing, gesturing, etc.). Depending on participant preference, the interview schedule could include visuals throughout, providing a reference point for each question and supporting the accessibility of questions. We offered all participants the opportunity to see the interview schedule in advance, and during the interview itself. We also informed participants that questions might arise organically during interview, but they may decline responding to any question without giving reason, and without consequence.

Interviews were conducted in varying formats depending on participant preference; one of multiple strategies implemented to support successful participation (as per Nicolaidis *et al.* 2019). A total of 12 interviews took place in person, three via phone call, two via text message and one via e-mail. Synchronous interviews ranged from 10 min to 1 h in length, with text-based interviews taking place within 1 day, at each participant’s own pace. With permission, synchronous interviews were recorded and transcribed verbatim.

Analyses

We analysed interview data using thematic analysis, following Braun and Clarke (2006, 2019). An inductive approach provided a focus on meaning grounded within the data set. The analysis also took an experiential orientation, focusing on real-life experiences. The process included: familiarization with the data set (including transcribing and multiple readings), initial semantic coding (focusing on surface meanings), generation of themes from codes, review of themes (names and definitions), and reporting on themes. Stages were not completed in a linear manner, but involved an iterative process of moving backward and forward between different stages of analysis. One author (C.C.) worked through these stages independently and then met with another author (L.C.; who read a subset of transcripts) to collectively form final themes. C.C. and L.C. approached the analysis and discussions from the perspective of autism researchers and (in the case of C.C.) as a trainee SLT; neither of whom have a diagnosis of autism.

Results

We identified four themes from participants’ interviews: (1) complex views on communication; (2) communication difficulties arise due to internal and external factors; (3) we need personalised support but society needs to change too; and (4) the impact of communication difficulties is far-reaching (figure 1). Subthemes are shown in italics.

Theme 1: Complex views on communication

Participants discussed a *wide range of benefits but also negative consequences* that could arise from communicating with others. For some, views were steadfast; for others, this varied depending on the context. Participants with positive attitudes toward communication explained how it served as a protective factor against feelings of isolation: ‘I do like communicating with other people and want to make more friends, because I don’t like being on my own too much’ (P12); and allowed participants the opportunity to express and share their feelings: ‘sometimes I feel I need someone to talk to ... I suppose it’s almost like pouring my heart out’ (P1). Participants who expressed negative views toward communication knew what was typically expected within social interactions (e.g., eye contact, appropriate volume and intonation), but reported that it was an effortful and tiring process, with potential negative outcomes: ‘there is so much you have to consider when talking to people ... dealing with people is kinda fraught with pitfalls ... it’s always like an accident waiting to happen’ (P3).

Participants had an *awareness of their individual strengths, difficulties and preferences*. When explicitly asked, participants identified various strengths (e.g., making people laugh, using technology to communicate, reading environmental cues). However, these strengths often related to a specific modality of communication (e.g., face to face, phone call, text). For some, written communication provided the necessary time for reflection and editing: ‘I tend to be more articulate with the written word, cause obviously you’ve got time to reflect and time to think’ (P3). Contrastingly, participants with strengths in other areas (e.g., interpreting body language or tone of voice) had preferences for face-to-face or phone interactions:

I think face-to-face is more better and more easier ... by their facial expression, you can tell how they are feeling or how they sound like. If they’ve got a low voice you can tell they’re a little bit tired or a little bit moody or that kind of thing. (P18)

While preferred modalities used individual strengths, participants explained how other modalities presented specific challenges. For example, some

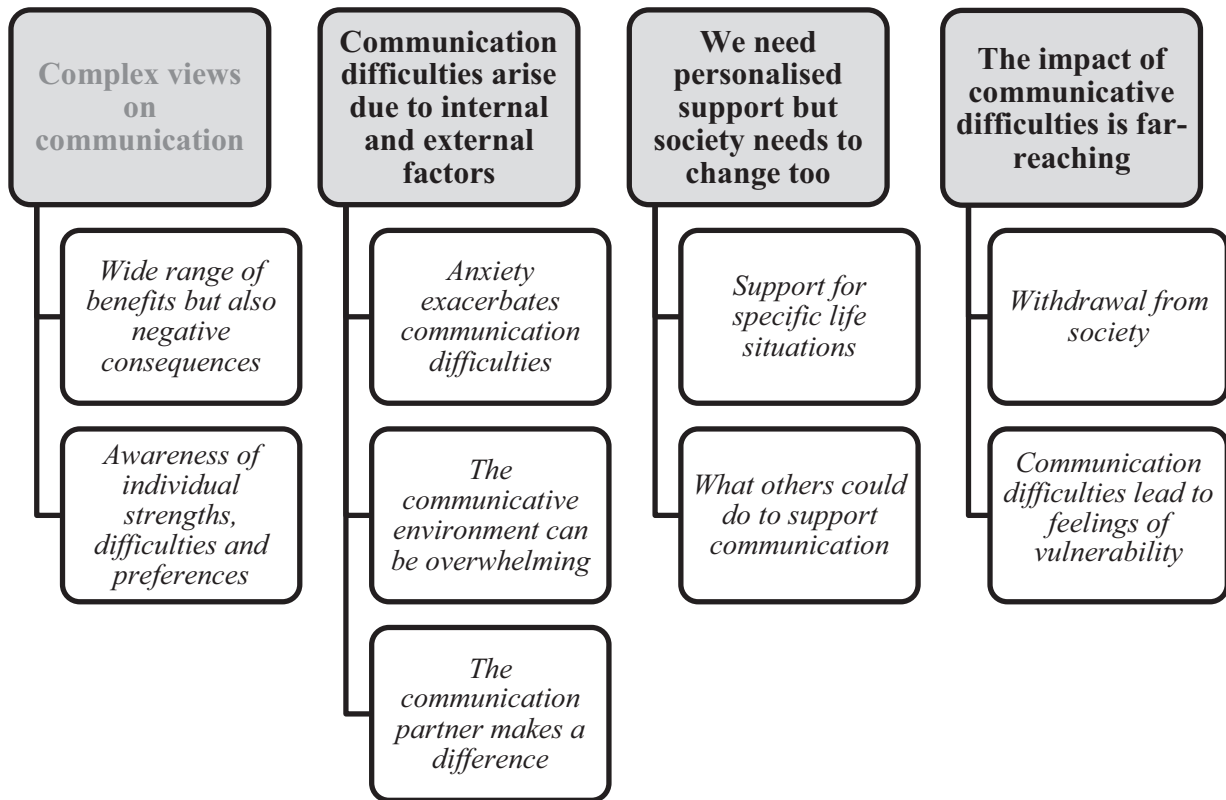


Figure 1. Themes and subthemes identified from interviews with autistic adults.

participants found the lack of conversational norms while texting difficult to navigate, particularly how to end a conversation or the duration between texts: 'I find text-messages hard because they can go on for hours. ... I suppose sometimes you just have to turn off your phone, or take out the SIM card' (P6). Similarly, difficulties were reported with particular aspects of social communication, such as initiating conversations ('I don't like making the first move ... if it's someone I don't know very well, I'll always expect them to make the first move'; P14), building on initiations ('I can do, "Hello, how are you?" quite confidently, but then I fall apart'; P10), and understanding jokes ('I find jokes hard to understand and I find it hard to know if people are joking or if they're being serious'; P7).

Theme 2: Communication difficulties arise due to internal and external factors

Views on communication varied depending on a range of internal and external factors. Internally, participants reported that *anxiety exacerbates communication difficulties*, with stress and anxiety altering abilities and desires to communicate. This could result in participants losing their ability to communicate verbally, find words or speak fluently: 'when I am really stressed out, I often lose the ability to speak. People don't under-

stand this and think I am just being purposely awkward but words will genuinely not come out of my mouth' (P4). Externally, participants explained how *the communicative environment can be overwhelming*, and was a barrier to effective communication. Group situations were reported to create challenging environments due to the intensity of the interactions, sensory overload and lack of privacy, for example. This impacted on participants' ability to concentrate and engage in conversation:

I find a group setting can be very intense and confusing because of a lot of noises and a lot of voices. I find it difficult to concentrate on one of multiple sound sources. And also I sometimes find myself focusing in on the wrong conversation if there is a whole load of conversations going on. And also I find it difficult to get a word in edgeways. (P1)

While identified as an issue within group situations, background noise was also reported as a barrier in one-to-one interactions: 'It can be something as innocuous as a ticking clock or an air-conditioning unit. Depending on how much energy I have, it can be the loudest thing in the room' (P1).

It was emphasized that *the communication partner makes a difference* in regard to desire, capabilities and preferred mode of communication. When identifying

what specifically about the communication partner had a positive or negative impact, participants identified a range of influencing factors (e.g., age, gender, appearance, mannerisms). While these varied between participants, they nevertheless emphasized the importance of finding common ground with the communication partner: 'I think in terms of barriers, I think it's, the only thing I could perhaps say is finding people that are similar enough to me to have meaningful conversations with' (P1).

Participants explained how common ground could be established through shared interests, hobbies, or likes and dislikes, which led to an ease of conversation:

if I can find common ground with that person, in talking to them, potential mutual likes and dislikes I think, as time goes on, I become a bit more comfortable with that person and suddenly this person feels like someone I've known quite a while. (P2)

Yet, as their interests often differed from those of the general population, they reported that finding common ground was not always easily achieved:

Because I don't have a huge amount of interest in popular things that are going on, I rarely watch television for example, it's difficult to have things to talk about, I suppose. I'm not interested in football and that's another thing that is often an icebreaker so I, I don't have a lot of common interests to have conversations about. (P1)

Engaging with an autistic communicative partner was reported to impact positively on communication. Participants noted that with other autistic people there was already a shared common ground, as well as differing (and preferred) expectations within interactions. Participants described how they did not need to interpret subtle communicative behaviours typically demonstrated by non-autistic people and, as a result, interactions with autistic people were less effortful and tiring:

it's the same with all of us, but us people on the spectrum, if they know there is someone else on the spectrum they tend to feel like they are in the same boat and they understand and they can communicate and there is no worry about being judged or being understood. (P15)

Theme 3: We need personalised support, but society needs to change too

While some participants reported not requiring or desiring support for communication at the present time, the potential benefit for future situations was recognized: 'I think at the moment I'm probably OK, if I'm honest. I mean if the need eventually arises then maybe, but at the moment I'm doing alright, I'm doing pretty

good' (P2). While these participants were communicating successfully within their current environments, they expressed an awareness of how situations change over time. However, some participants identified that *support for specific life situations* would benefit them now. These included demonstrating assertiveness, developing interview skills, and forming romantic relationships:

I joined up to an autistic dating site and it's sort of how to [communicate] like, how to approach someone there and how to sort of show interest in them rather than showing what, how to find interest in the other person rather than talking about your interests. (P11)

Looking beyond individual support, participants suggested *what others could do to support communication*, both in terms of adapting their communication style and respecting others' communication preferences. Participants emphasized the importance of having an awareness of what could make interactions easier or more difficult, and how others could adapt their communication style to support autistic people. Suggestions included avoiding speaking too quickly, or using abstract or vague language:

I wish people were more mindful of that—of things that are ambiguous in communication. And I think I am fortunate that I've memorized so many idioms and metaphors that I'm able to do an instant translation in my head. (P1)

Other participants highlighted the importance of understanding and respecting how autistic people communicate and how this might differ from non-autistic people. For example, understanding that verbal communication may not always be possible; or that individuals may need information clarified or repeated and that this does not always reflect levels of engagement or attention: 'not making me feel under pressure to verbally communicate just because that is their favourite way to communicate' (P4).

Theme 4: The impact of communicative difficulties is far-reaching

Participants repeatedly explained how their communicative difficulties impacted on other aspects of their lives, often leading to feelings of embarrassment, of feeling 'tolerated' and ultimately resulting in *withdrawal from society*: 'I hate going bright red, sweaty, and mumbling over a couple of words that barely make sense when I actually say them out loud. I then want to just run away home and be alone' (P10). While many participants had an awareness of social expectations and how their own communication might differ, having that awareness was not always beneficial, and sometimes led to negative self-views. As a result, participants reported

a lack of engagement with their local surroundings and social events, leading to feelings of isolation: 'especially within this hometown of mine, my local where I don't know anybody at all. This is the biggest mystery, and biggest challenge' (P18).

Participants also conveyed that *communication difficulties lead to feelings of vulnerability*. For some, these vulnerabilities arose from difficulties with higher level social communication skills, such as interpreting when a person is joking versus being purposefully unkind, or using eye contact appropriately: 'I used to stare at people and sometimes I would get into trouble for that, some people would become aggressive toward me' (P15). For others, their vulnerability was apparent with respect to particular skills such as demonstrating assertiveness:

I've often had times where there's been a particular person who's probably communicated with me in a way and they've made me feel frightened or nervous... my body acts in a way that I find it hard to speak up maybe. ... It's like being paralysed with fear you know. (P2)

Others demonstrated vulnerability as a result of difficulties accessing, sharing or contesting information in interactions with healthcare professionals: 'So yeah, asking questions and getting sometimes like ... speaking to a doctor or asking the nurse or, you know, an optician, I tend to just go along—I don't really ask questions, I don't really have anything to say' (P15).

Discussion

Eliciting the views of autistic adults on their communication skills and needs, this research identified what type of support they sought and how this could be provided. We identified four themes from our interview data: (1) complex views on communication; (2) communication difficulties arise due to internal and external factors; (3) we need personalised support, but society needs to change too; and (4) the impact of communicative difficulties is far-reaching. Next, we discuss each theme separately, before considering their collective implication for SLT practice.

Autistic adults who participated in the research presented complex views on communication, with communicative interactions having both benefits and negative consequences. Although some identified strengths in aspects of their social communication (e.g., reading body language or interpreting tone of voice), it was also the predominant area of difficulty reported by participants (as per APA 2013). The general preference for text-based interactions was consistent with previous research on access to healthcare, suggesting such interactions are beneficial for autistic individuals who find it difficult to interpret body language or process

auditory information (Nicolaidis *et al.* 2011). Yet, communication was considered both tiring and effortful, and participants reported a general preference for being alone. This diversity in views toward communication may be due to the current study being inclusive of individuals with a range of communication preferences (e.g., avoiding the need for face-to-face interviews if required), thus allowing for a broader representation of views and a more diverse set of experiences. The importance of a person-centred approach to healthcare is evident (NICE 2012).

Communication difficulties faced by autistic adults were explained as arising due to internal and external factors. The communication partner was a key external factor, with participants reporting preferences for communicating with other autistic (as opposed to non-autistic) people. Milton's (2012) Double Empathy Problem reframes the notion of an autistic deficit in social interaction to a two-way breakdown between communication partners; acknowledging that while autistic people may lack insight into the social world of non-autistic people, the reverse is also true. Milton adds that autistic people, out of necessity, have gained greater insight into the world (and communication preferences) of non-autistic people, comparative to the insight gained by non-autistic people into the world and preferences of autistic people.

This disjuncture between autistic and non-autistic groups has been supported by recent experimental research. Crompton *et al.* (2019) used information transmission tasks to examine the efficiency of message transfer between groups of autistic people, groups of non-autistic people, and mixed autistic/non-autistic groups. While similar amounts of information were shared by groups of both autistic and non-autistic individuals, mixed alternating chains of autistic/non-autistic individuals shared less information; highlighting a breakdown in communication specifically between autistic and non-autistic populations. Using the more real-world context of short dyadic social interactions, Morrison *et al.* (2019) additionally found that, following 5-min interactions, autistic people reported a greater willingness to live near conversation partners who were also autistic, as opposed to those who were not. These studies are consistent with the findings of the current study, with participants' reporting preferences for interacting with those who have minds more aligned with their own.

Considering this influence of internal and external factors, it is understandable that participants not only sought personal support for their communication difficulties/differences, but also wanted to see changes at a societal level. On a personal level, some participants desired support in areas such as employment and

romantic relationships, which are recognized areas of difficulty for autistic adults (Hurlbutt and Chalmers 2004, Orsmond *et al.* 2004) that directly impact on quality of life (García-Villamizar *et al.* 2002). Yet, not all participants wanted or required such support. These differing views on social support are aligned with previous research, indicating a benefit to adapting interaction styles (in specific situations) for some people. For others, however, this can negatively impact on their sense of self (Milton and Sims 2016) or increase social understanding without improving the ability to implement targeted skills (Gates *et al.* 2017). Participants in the current study reported similar experiences of knowing how to interact socially but experienced difficulties implementing changes.

Individual SLT support could, alternatively or additionally, be provided through supporting self-advocacy strategies. One such strategy, diagnostic disclosure, has been shown to positively influence first impressions toward autistic people (Sasson and Morrison 2019), and to impact on employment rates for this population (Ohl *et al.* 2017). Yet, the stigma and fears that can exist around disclosing an autism diagnosis (Crane *et al.* 2019a, Krieger *et al.* 2012) mean that this may not be a desired approach for all. These mixed views towards individual support, and challenges regarding its implementation, indicate the importance of considering individual differences and preferences, as well as looking beyond support at this personal level.

In line with participants' desire for societal change, recent research has argued for a paradigm shift away from individual support that changes behaviours, toward a system that provides support at an environmental level (e.g., peer mentoring, adapting tasks, using individual strengths; Black *et al.* 2019); and conceptualizing autism using the social, rather than medical, model of disability (den Houting 2019). The government strategy Think Autism (2014) also highlights the importance of recognizing difference and providing such support, with a strong emphasis on autism awareness training. Professional bodies in the UK (such as the Royal College of General Practitioners and the Royal College of Psychiatrists) have endorsed such training packages, and are engaging in other initiatives to increase practitioner knowledge and confidence when working with autistic people (Crane *et al.* 2019b, Unigwe *et al.* 2017). The potential impact of such training has been demonstrated in research, with increased autism knowledge positively influencing raters' first impressions of autistic adults, alongside the aforementioned diagnostic disclosure (Sasson and Morrison 2019). This suggests that societal awareness alongside individual support (either to self-advocate or to form positive initial impressions) would be optimal for those who want such support; demonstrating how personal

and societal approaches to support can complement one another.

Importantly, the current study demonstrated that communication difficulties did not occur in isolation, with such difficulties often posing wider (and negative) consequences on other aspects of participants' lives. Beyond previously mentioned areas (e.g., employment, relationships), communication difficulties were reported to impact on both physical and mental health. Raymaker *et al.* (2017) highlight the difficulties faced by autistic people when sharing information in a medical context; a finding echoed in the current work. Acknowledging these difficulties, Think Autism (2014) supported the development of 'hospital passports' to aid autistic people in their communication with healthcare professionals (My Hospital Passport n.d.). These adaptable documents enable autistic people to share relevant information within a hospital setting (e.g., key information relating to medical problems and allergies, information on communication preferences). This form of augmentative and alternative communication (AAC) can be implemented in adulthood, and used intermittently as needed (Nicolaidis *et al.* 2014), for example, when verbal communication is not preferable or possible (Bradshaw 2013).

Yet it is unclear whether such support would alleviate the impact on mental health, with participants reporting feelings of embarrassment and being 'tolerated' as a result of their communication difficulties. Furthermore, mental health difficulties (e.g., feelings of stress or anxiety) were also found to impact on communicative abilities and preferences. Considering the high rates of co-occurring psychiatric conditions in autistic adults (Lever and Geurts 2016), this has particular relevance. Similarly, the impact of communication on mental health may reflect the wider societal context, with research indicating that mental health difficulties in autistic people may relate to challenges in navigating a non-autistic world (Crane *et al.* 2019a). Acknowledging the complexity of the relationship between communication and mental health, and professional guidance indicating the role of speech and language therapists in minimizing such difficulties (RCSLT 2018), these findings confirm the professional duty of the SLT in supporting autistic adults.

Limitations

First, this study included autistic adults over 18 years of age. Wright *et al.* (2019) argue that this age classification is overly broad, as individuals have varying needs at different life points, and data are often skewed toward those in their twenties. While this study had a relatively even distribution of ages, interviews were analysed as a whole, and therefore may be lacking

insight into the priorities of specific age groups. This is an important consideration for future research. Second, this study specifically included a population without intellectual disabilities, who do not qualify for access to Adults with Learning Disabilities (ALD) services, and are (currently) unable to access SLT services. As a result, the findings speak to a specific subgroup of the autistic population, and cannot be generalized to autistic people with intellectual disabilities. Future research should elicit the views of autistic people with a wider range of intellectual functioning; to ensure the SLT provision is representative of what autistic people more broadly want/desire.

Implications for SLT

The results highlight how autistic adults generally want support for communication: both on an individual basis (for specific life areas), and at a broader societal level. Regarding how such support could be provided, it is important to consider all modes of communication to encompass the range of individual strengths and difficulties autistic adults display. There is no prescriptive approach that can be recommended for this population; SLT should be tailored to meet individual needs, circumstances and preferences. Yet, not all autistic adults want individual support for communication and not all will necessarily benefit from such support.

In accordance with previous research, participants reported that they can learn communication skills, but have difficulty implementing or generalizing these. For those who could do so, this was effortful and could have negative impacts on mental health. The role of SLT includes minimizing difficulties associated with communication and mental health. As such, speech and language therapists—working with adults *and* children (Fuller and Kaiser 2019)—have a professional duty to consider these potential negative implications.

Framing individual support through a social model of disability (Hughes 2010, Oliver 1996) is one solution; empowering autistic individuals, as opposed to changing specific behaviours that are traditionally viewed as deficient. This reflects the approach implemented with people who stammer, where SLT includes encouraging openness and acceptance of stammering (Cheasman *et al.* 2015). Whilst this form of empowerment is reflected in the aforementioned 'hospital passports' for autistic individuals, this document has a function in a specific setting that is not representative of the range of environments autistic adults may encounter. Equally, some autistic people choose not to disclose their diagnosis (Crane *et al.* 2016, Krieger *et al.* 2012) and this should be respected.

The Double Empathy Problem (Milton 2012) emphasizes the two-way nature of communication, and it

is imperative to look beyond the individual when identifying communication difficulties and proposing solutions. Positive change is occurring through the implementation of current legislation (e.g., Think Autism 2014), yet societal change is a slow process. To further the development of societal awareness and understanding, the involvement of autistic people is paramount. Speech and language therapists may play a crucial role in eliciting the views of autistic people, facilitating the sharing of their views with the wider community, and proposing appropriate accommodations with respect to communication.

Note

1. Identity first language (i.e., an autistic person) as opposed to person-first language (i.e., a person with autism) is used throughout, as this is preferred by many autistic adults (Kenny *et al.* 2016) and considered to be less stigmatizing (Gernsbacher 2017).

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