Adapting communication with autistic service users: Co-produced adaptations for medical services, employers, and the third sector

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Abstract

Autistic people have a greater need to access services (e.g., health and social care, welfare, justice, etc.), yet face significant disadvantages when doing so, often due to poor two-way communication between service providers and service users. This study aimed to co-develop practical, evidence-based adaptations to facilitate communication between service providers and autistic people. Based on a review of current research evidence, an initial list of adaptations was developed, across four categories: (1) adapting the environment to reduce sensory stressors, (2) facilitating diagnosis disclosure, (3) adapting direct communication, and (4) modifying visual or written information. Second, we co-delivered (with autistic people) a workshop for service providers, tailoring these adaptations to their sectors. Finally, a large survey sample of autistic people and the autism community evaluated these adaptations and added their own suggestions. Workshop attendees' autism knowledge and confidence in communicating with autistic people significantly improved post-workshop, and they went on to implement the evidence-based adaptations. The autism community endorsed the adaptations and suggested some additional adaptations that they would like. Findings demonstrate that providing evidence-based adaptations in a workshop co-delivered with autistic people improves service provider autism knowledge and confidence in communicating with autistic people, and encourages them to offer adaptations.

Lay abstract

What is already known about the topic?

Autistic people need access to a range of services, including health and social care, welfare, and access to justice. However, research with autistic people and their supporters has identified several barriers when trying to access these services, including a lack of autism understanding, reluctance to make accommodations, and difficulties with communication.

What this paper adds?

Research has shown several ways in which communication can be adapted. The current study aimed to apply these research findings to real-world practice by working with service providers, autistic people, and the autism community to create a suite of practical adaptations. We developed an initial list of adaptations, under the categories: (1) adapting the environment to reduce sensory stressors, (2) facilitating autism diagnosis disclosure (where desired), (3) adapting communication, and (4) adapting visual/written information. With autistic people, we then co-delivered a workshop for service providers, tailoring these adaptations to each sector. Service providers who attended the workshop felt more confident working and communicating with autistic people, demonstrated improved autism knowledge, and implemented several adaptations in their services. We also surveyed the autism community, who agreed that the adaptations were helpful, and also suggested additional adaptations they would like to see offered by service providers.

Implications for practice, research, or policy

The findings demonstrate that adaptations autistic people find helpful can be tailored to specific services. This will help

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autistic people and their supporters to access crucial services, and will enable service providers to offer an effective service to autistic people.

Two-way communication forms the bedrock of the provision of most public services and must be effective in order for all individuals to receive appropriate access to services, including for example health and social care, employment, and justice. Services should be accessible and delivered in a way that respects the differing needs of the individual (Shattuck, Roux et al., 2012). This is particularly pertinent for autistic people, who have a greater need to access such services, yet face significant disadvantages when doing so. For example, autistic people experience significantly higher rates of almost all physical and mental health problems compared to the non-autistic population (Adams & Brosnan, 2019; Bishop-Fitzpatrick & Kind, 2017; Bowri et al., 2021; Cashin et al., 2018; Croen et al., 2015), have a higher proportion of unmet healthcare needs, and are less likely to utilise preventative healthcare (Doherty et al., 2020; Gilmore, Longo et al., 2022; Nicolaidis et al., 2013, 2015; Vogan et al., 2017; Weir et al., 2022), but are more likely to need to access primary care (Gilmore, Krantz et al., 2022).

Despite a wealth of evidence highlighting these disparities, and a desire within the autism community for better service access (Roche et al., 2021), service providers[1] can find it challenging to know how best to adapt their communication for autistic people. Evidence regarding the barriers faced by autistic people accessing crucial services has strengthened in the past few years (Bradshaw et al., 2019; Brice et al., 2021; Calleja et al., 2020; Malik-Soni et al., 2022; Mason et al., 2019, 2021; Nicolaidis et al., 2013, 2015; Raymaker et al., 2017; Shady et al., 2022; Shattuck, Narendorf et al., 2012; Walsh et al., 2020), from young autistic adults having difficulties accessing psychological, occupational, and employment-related services (Taylor & Henninger, 2015), to critical healthcare services such as Accident and Emergency Departments (Vohra et al., 2016), and social care in older age (Charlton, 2017; Hategan et al., 2017; Mukaetova-Ladinska et al., 2011; Perkins & Berkman, 2012). Indeed, service providers in the healthcare sector often lack understanding of autism and confidence working with autistic patients (Bradshaw et al., 2019; Brice et al., 2021; Chown et al., 2023; Corden et al., 2022; Unigwe et al., 2017; Zerbo et al., 2015), and can sometimes be reluctant to make fairly straightforward accommodations, including adapting written and verbally-presented information (Mason et al., 2019; Nicolaidis et al., 2015; Strömberg et al., 2022).

It should also be noted that although continuity of care and individualised communication are crucially important for maintaining good communication and ultimately successful service access for autistic people (Camm-Crosbie et al., 2019; Shady et al., 2022), providers often report system-level difficulties with enacting such good practice (e.g., Mason et al., 2021). Indeed, autistic people themselves frequently report problems communicating with service providers (Bradshaw et al., 2019; Brice et al., 2021; David et al., 2022; Gilmore, Krantz et al., 2022; Mason et al., 2021; Mazurek et al., 2023; Raymaker et al., 2017; Shady et al., 2022). For example, Muskat et al. (2015) reported that communication was a major barrier for autistic people using medical services, including problems with literal interpretation of questions (e.g., 'have you vomited' = 'no', rather than 'no, but I feel sick'), and difficulties with expressing pain (see also Brice et al., 2021; Crane, Adams et al., 2019; DuBois et al., 2016; Gilmore, Krantz et al., 2022; Mason et al., 2019, 2021; Mazurek et al., 2023; Moore, 2015; Nicolaidis et al., 2015; Shady et al., 2022). In addition, due to differences in the perception of one's own bodily sensations (i.e., interoception), it is not uncommon for an autistic person to be unaware of a symptom or sensation, or to be unsure of which symptom/s to report (DuBois et al., 2016; but see Nicholson et al., 2019). Autistic people and their supporters also note feeling that some staff, who are essentially 'gatekeepers' in the healthcare sector (e.g., receptionists) can be impatient with their speech and communication differences and difficulties (Shady et al., 2022). Autistic people note feeling uncomfortable that their slower processing speed affects communication and understanding during important consultations (Nicolaidis et al., 2015; Raymaker et al., 2017).

Ensuring services can adapt their approach for autistic people is critical, as effective communication reduces misunderstandings, ensuring people's needs are met. Effective communication also reduces service burden, by minimising

the need for repeated appointments due to misunderstandings, as well as reducing missed appointments (Brice et al., 2021). However, as many sectors are currently failing to make reasonable adjustments (Michael & Richardson, 2013), it may be that they need to be supported to use suitable, tailored, and evidence-based adaptations (Bradshaw et al., 2019; Shattuck, Roux et al., 2012). Indeed, Muskat et al. (2015) highlighted the importance of tailoring communication strategies to the individual, as well as consulting parents or carers where appropriate.

Direct verbal communication is crucial to gleaning important information during medical consultations. However, evidence shows that autistic people find it difficult to recall specific, personal episodic memories (Ben Shalom, 2003; Crane & Goddard, 2008; McDonnell et al., 2017), especially in response to open questions, or those consisting of complex, multi-step instructions, often used in vital services and in interviews (e.g., 'how can I help you today?', 'what happened yesterday?'), with this barrier to communication causing stress for autistic people (Dern & Sappok, 2016). Such open questioning is therefore likely to hinder autistic people's ability to recall personal memories relevant to, for example, medical consultations, whereby patients may need to recall information about the onset of symptoms, or an injury (Norris et al., 2020). Importantly, however, with more specific and supportive cues, autistic people can recall as much information as non-autistic people (Bowler et al., 1997, 2004), and adaptations to questioning based upon this evidence have been successfully tested in applied contexts (Maras, Norris & Brewer, 2020; Maras, Norris, Nicholson et al., 2020; Norris et al., 2020). For example, Norris et al. (2020) tested the efficacy of interview prompting techniques in supporting autistic adults' recall of specific personal memories relevant to interviews within the Criminal Justice System, healthcare, and employment, and found that the use of prompting resulted in more specific memories of past events being recalled. The findings offered several practical methods for service providers to facilitate their communication with autistic service users, and also showed that the participants valued receiving preparatory information as a gauge of 'what to expect' during the interview (which may also help alleviate concerns about being unable to process information quickly enough to participate fully in consultations with service providers; Raymaker et al., 2017).

Prior research therefore not only highlights the need for adaptations, but also demonstrates suitable methods for adapting communication to be more direct (e.g., using specific questions, specifying when communications require a response, checking understanding), and modifying visual and written information when facilitating service access for autistic people (e.g., sending clear and comprehensive directions, making written information clearer, allowing people to fill in forms in advance, providing photos of key people and locations, and offering 'walkthroughs'/familiarisation visits). In addition to supporting autistic differences in memory recall and communication, services also need to consider sensory differences (e.g., an aversion to busy, bright, and noisy waiting rooms, difficulties with identifying and communicating pain and sensation, etc.; Dern & Sappok, 2016; Doherty et al., 2020; Mason et al., 2019; Raymaker et al., 2017; Saqr et al., 2018; Strömberg et al., 2022). It is important therefore for services to also consider methods to effectively adapt the environment to reduce sensory stressors (e.g., by asking individuals about their sensory needs, adjusting sound and lighting, reducing waiting room time and/or giving the option to wait elsewhere), which in turn aids communication by reducing anxiety. These categories of adaptations broadly overlap with the findings of Nicolaidis et al. (2015), whose findings from the autism community regarding barriers to healthcare access were grouped into the following categories: *patient-level* difficulties; including verbal and non-verbal communication differences, sensory sensitivities, and difficulties with describing or explaining symptoms and bodily sensations; *provider-level* difficulties, such as poor service-provider autism knowledge, and a reluctance to offer accommodations for autistic service users; and finally, *system-level* barriers, including practical realities of the services available, as well as problems navigating healthcare systems (see also Mazurek et al., 2023).

Finally, autistic people can often find it difficult to know if or when to disclose their autism diagnosis when accessing a service, with some fearing that disclosure may negatively affect their interactions and care (Walsh et al., 2020). Clearly, diagnosis disclosure can be helpful in facilitating a conversation between the service user and provider about the difficulties faced, and which adaptations may be helpful. In addition, research within several real-life contexts shows that when an individual is made aware of a person's autism diagnosis, this can facilitate a more favourable perception of behavioural differences than would have been the case if the individual was unaware (Brosnan & Mills, 2016; Flower et al., 2021; Maras, Marshall et al., 2018; McMahon et al., 2020; Norris et al., 2023). Adapting initial questions (e.g., on screening surveys) to ask a direct question about autism diagnosis, and providing information about the benefits of disclosure, including how the service can help once they are aware, may help to reduce fear of stigma (McMahon et al., 2020; Romualdez, Heasman et al., 2021; Romualdez, Walker et al., 2021), and may therefore facilitate diagnosis disclosure by autistic service users.

The current study first aimed to build upon the extant research which has highlighted barriers to accessing services, particularly communication, as well as the sensory environment and service provider autism knowledge and understanding, by bringing together a set of evidence-based adaptations for service providers. Further, the evidence base

regarding these challenges was co-delivered with autistic people at a workshop for service providers, with a particular focus on how suitable adaptations could be made within each sector. The study also aimed to assess whether the provision of such adaptations in a workshop setting would be effective in improving service provider confidence in working and communicating with autistic service users, as well as autism knowledge. Adaptations were therefore tailored to each sector, and changes in attendees' autism knowledge and confidence communicating with and working with autistic people after attending the workshop were assessed. Secondly, these evidence-based adaptations were evaluated and extended by the autism community through a large online survey. Therefore, as well as generating a comprehensive list of adaptations that can be used by service providers across various sectors, the study also aimed to answer three research questions: (i) did workshop attendees' autism knowledge and confidence in working and communicating with autistic people accessing their services improve after attending the workshop; (ii) prior to the workshop, what were service providers' experiences in working and communicating with autistic service users, including challenges faced and current practice, and (iii) to what extent do the suggested adaptations align with those desired by the wider autistic community?

Method

Phase 1 – Workshop

A free in-person workshop[2] at the University of Bath, UK, was co-delivered by an academic team including one senior lecturer, one post-doctoral researcher, and one doctoral student in autism research, as well as three psychology students (one member of this team was autistic), and an autistic self-advocate. Members of the workshop team were paid for their time. The aim of the workshop was to design practical, evidence-based methods for facilitating communication. Information about autism (including for example diagnostic criteria, focusing on difficulties with social communication and interaction in the context of service access) and key research into adapting communication (such as how to adapt verbal communication and written information/ questions, and methods of supporting those with sensory needs) was disseminated, and the two autistic team members shared their experiences of being a service user, including the challenges they faced when accessing services, and the kinds of adaptations they had found helpful. Attendees then participated in extended group work with the assistance of the facilitators (autistic and non-autistic) to design adaptations tailored specifically for each service, whilst considering challenges and structural barriers specific to each sector. The workshop lasted around four hours.

Participants. The workshop was attended by 41 individuals from a range of sectors, including medical (e.g., surgical, occupational health, orthodontics), higher education, employment support (e.g., the Department for Work and Pensions), as well as from Non-Governmental Organisations (NGOs), third, and private sectors (Medical $N = 18$, Higher Education $N = 9$, Employment/employment support $= 5$, Social work/care $N = 3$, NGO/Third Sector/ Private sector $N = 6$). Attendees were invited via general advertising methods including social media, email lists, and professional contacts, and needed to be working in a service provision sector to be eligible to attend. Inclusion to the workshop was deliberately broad to encourage a variety of service providers to attend. Twenty-three of the workshop attendees completed a pre-workshop survey (1–2 weeks prior), assessing autism knowledge, and confidence in working and communicating with autistic service users. After he workshop (within 1–2 weeks), 20 participants completed questionnaires rating their autism knowledge and confidence, and indicated which adaptations they would be implementing.[3] Participants provided their typed informed consent to take part in the surveys. Ethical approval was obtained from the Psychology Research Ethics Committee at the University of Bath. Of those completing at least one survey, respondents reported that the proportion of service users they communicated, interacted with, or otherwise worked directly within their role who were autistic was on average 25.87% (SD = 29.50, range = 2–100), and 78.63% reported having some form of personal experience of autism (e.g., knowing an autistic person).

Materials and procedure. Pre- and post-workshop surveys were created using the online survey platform Qualtrics and aimed to examine autism knowledge and confidence in working with autistic people, as well as questions assessing standard methods of service delivery and communication, and/or adaptations and their perceived effectiveness, as well as perceived challenges to adapting services. At post-workshop, participants also rated the extent to which the workshop had addressed their perceived challenges to adapting services for autistic people, as well as endorsing the adaptations they intended to use from the workshop, and finally providing their evaluations of the workshop. Quantitative data were collected for self-reported confidence *working* with, and *communicating* with autistic people on sliding scales from 0% to 100% (in 10% increments, from 0% 'Not confident at all' to 100% 'Extremely confident'). Autism knowledge was assessed by asking respondents to select as many answers as they thought to be correct in response to the question 'Which of the below may be particularly difficult for autistic people?', with seven correct answers including *coping with unexpected change, organising appointments and treatment, gauging how much information to give during*

a consultation, understanding and answering open questions (e.g., 'what seems to be the problem?'), following complex, multi-step instructions, describing bodily sensations (e.g., pain), and *being in a noisy environment (e.g., with many people, frequent loudspeaker announcements).* As the workshop focused on supporting autistic people within specific communicative contexts, questions were developed to assess knowledge of autism based on factors identified in prior research as being difficult for autistic people when they were accessing services (e.g., bodily awareness, processing speed, and challenges related to the service itself; de Schipper et al., 2016; Nicolaidis et al., 2015), rather than using an existing but more general measure of autism awareness. In addition, five common strengths in autistic people, or factors whereby autistic and non-autistic people often show equal ability were added as (incorrect) filler response options: *paying attention to detail, analytical thinking, logical thinking, understanding, and answering specific questions (e.g., 'which doctor did you see on Tuesday afternoon at the hospital?'),* and *memory for facts.* Responses were scored as the total number of situations/factors endorsed by the respondent that would often be considered areas of difficulty for autistic people, with strengths that were not identified as weaknesses by respondents being reverse-scored, such that total scores could be calculated (out of a maximum of 12). Qualitative responses were also collected using optional free-text responses to explain their chosen score for confidence working with and communicating with autistic people, as well as free-text responses regarding communication adaptations respondents were currently using in their services, and their perceived effectiveness, service-level challenges in making adaptations, and the extent to which the workshop addressed these perceived challenges.

Data analysis. Quantitative data for confidence working and communicating with autistic people at pre- and post-workshop were analysed using Wilcoxon signed ranks tests, as some of the data violated assumptions of normality (data analysed for participants who completed both the pre- and post-workshop surveys; $N = 11$ for confidence, $N = 13$ for knowledge[4]). Although several reminders were sent asking workshop participants to complete both the pre- and post-workshop surveys, it was not possible to follow up with those who did not complete the surveys.

For qualitative feedback, participants were asked (both before and after attending the workshop) to explain their confidence in working and communicating with autistic individuals, and to highlight challenges and barriers to communication in their professional work context. Regarding confidence in working and communicating with autistic people, 21 participants responded pre-workshop, and 15 responded post-workshop (10 of whom provided feedback at both timepoints). Regarding

challenges and barriers of supporting autistic individuals in their professional context, 19 participants responded pre-workshop, and 15 responded post-workshop (nine of whom provided feedback at both timepoints). All responses were manually coded by the first and second authors independently, who then met and discussed similarities and differences in coding frameworks, before agreeing on a final coding framework for content analysis. We identified themes that captured codes from both pre- and post-workshop responses, to highlight changes in participants' attitudes regarding confidence and barriers to supporting autistic individuals in their respective professional settings. We completed directed content analysis (Hsieh & Shannon, 2005), as the open-text questions specifically asked participants to comment on the topics of interest in the current study, namely: (1) their knowledge about autism, and confidence in working with autistic people; (2) challenges and difficulties working with autistic service users; and (3) adaptations. This deductive approach allowed us to look for evidence for and against potential changes in attitudes in each of the questions when comparing pre- and post-workshop responses. A table summarising initial codes from each coder and the final agreed coding framework is shown in Appendix Table A1.

Phase 2 – Further developing adaptations with the autism community

Autism community participants. Alongside the delivery of the workshop, members of the autism community were recruited via posts on social media, promotion at autism-related talks in the UK, and existing participation networks to endorse which of the evidence-based, research-led adaptations applied in the workshop they would find helpful, and to also add any additional adaptations they would value. The sample was characterised as follows: 67 participants were autistic (self-reported), responding on behalf of themselves; an additional 12 were autistic and taking part on behalf of themselves and other/s; and 20 were non-autistic, and responding on behalf of someone else (for example, children and/or dependants). Respondents' ages ranged from 16 to 74 ($M = 39.04$, $SD = 13.04$), with 67 female, 22 male, 4 non-binary, 2 genderqueer, 1 agender, and 3 preferring not to respond about their gender. Participants provided their typed informed consent to take part in the survey.

Materials and procedure. The survey was created and circulated using the online survey platform Qualtrics. Participants were asked to endorse the evidence-based adaptations they would find helpful and to add any additional adaptations they would also value.

Results

Phase 1 – Pre- and post-workshop surveys

Quantitative analysis. Autism knowledge was significantly improved after the workshop (*Median* = 11) compared to prior to the workshop (*Median* = 10), Z = -2.354, p = .019. Attendees' confidence in working with autistic service users also increased significantly from pre-workshop (*Median* = 50) to post-workshop (*Median* = 70), Z = −2.965, p = .003. In addition, attendees' confidence in communicating with autistic service users also increased from pre-workshop (*Median* = 60) to post-workshop (*Median* = 80), Z = -2.814, p = .005. After the workshop, 59.09% rated it as Excellent, 36.36% as Very Good, and 4.55% as Fairly Good.

Qualitative analysis. Qualitative data at pre- and post-workshop were analysed separately to further elucidate changes in attendees' reasoning for their autism knowledge and confidence, the challenges faced, and adaptations made. Content analysis identified three overarching themes which applied across the pre- and post-workshop datasets from participants' open-ended responses to questions: *(1) knowledge about autism and confidence in working with autistic people*, *(2) challenges and difficulties working with autistic people*, and *(3) adaptations*.

Pre-workshop

(1) Knowledge about autism and confidence in working with autistic people. Before attending the workshop, participants expressed concerns about their knowledge and understanding of autism. For some, this stemmed from a lack of training which resulted in feeling unable to communicate with autistic people (n = 3):

> (I) have very little knowledge of autism and the different types… unsure of the best way to communicate (Employee at local hospital)

For others who had previously attended other workshops or training on autism, they also expressed a belief that one can never stop learning about autism because there are so many individual differences (n = 8):

> I teach in this field and I have read widely on the subject… However I'm aware that my learning and development continues to need improving and updating. (Business director)

> I have attended several training over the years that has certainly made me more aware of the needs and issues arising for those with autism, but I don't ever want to think or just assume that I know everything I need to know. (Employee at local college)

These comments were reviewed prior to the workshop to ensure that the workshop material addressed such concerns. In terms of attendees' confidence in working with autistic people, given that participants had a mixed level of autism knowledge and experience prior to attending the workshop, participants expressed varied levels of confidence (n = 5) when thinking about their ability to successfully work with, and communicate with, autistic people (n = 10). Participants reflected on the areas in which they felt less confident, and expressed how they hoped the workshop would further support their confidence when working with autistic people (n = 6):

> One can never be 100% confident, as one is not able to control all variables. (Employee from a regional autism service)

> I suppose for me a larger part of the 40% (of my lack of confidence) is what I don't know about the individual, and this is what I have to explore and find out about when I am working with an autistic service user. (Student information office coordinator)

(2) Challenges and difficulties working with autistic people. Participants also identified *challenges and difficulties working with autistic people* before attending the workshop. Respondents highlighted how, under the time pressures faced in healthcare, education, and commercial services, the structure of systems often leaves little room for practitioners to spend extra time appropriately assisting autistic service users (n = 5). This often led to feelings of frustration, further compounding the pressure of working with limited time and resources, managing client expectations, and ultimately ensuring meaningful adaptations can be offered:

> As symptoms can present in different ways, it can sometimes be difficult to open the initial lines of communication with the service user. (Student information office coordinator)

> Dealing with complaints adds pressure as, generally, patients are already frustrated when they speak to me which could heighten any problems that might occur. (Commercial analyst)

In particular, participants identified that when working with autistic children and young people, there was an added challenge of relying on their parents to provide accurate information about them, and to disclose their autism diagnosis to the professional in order to facilitate adaptations (n = 3):

I find that it can be difficult sometimes as parents don't like to give information regarding their child's diagnosis of autistic traits etc… (Orthodontist)

Other participants also expressed that their lack of direct experience and contact with autistic people meant that they found it difficult to put learning about autism into practice ($n = 8$). This was especially the case for respondents who were not front-line workers, or who worked in managerial roles. This led to further difficulties when it was felt that there was a lack of shared understanding between frontline staff who have identified an area in need of further improvement (i.e., adapting practice for autistic service users), but struggled to ensure that managers also recognised the necessity of implementing such changes.

(3) Adaptations. Prior to the workshop, participants demonstrated self-awareness regarding how much or how little they had been able to make use of their knowledge about autism to date ($n = 10$) to inform their daily practice and make adaptations for autistic people ($n = 17$). Respondents' comments suggested that they viewed gaining autism-related knowledge as just one component informing best practice, and that direct, practical advice and support on translating knowledge into adaptations (as was to be included at the workshop) was also needed:

I've not had any training or information on what 'normal' interactions/information could be a problem for someone with autism and therefore am unsure how to recognise their needs and give them a service that they will find helpful. (Staff from a local hospital)

Although I can sometimes recognise a service user with autism, I am not sure how best to communicate other than trying to be as clear and only speak in literal terms. I'm very keen to learn more. (Staff from a local college)

Post-workshop
(1) Knowledge about autism and confidence working with autistic people. At post-workshop, many participants felt that they had gained confidence ($n = 9$) from directly learning about more practical adaptations they could utilise in their work, as well as from recognising that treating autistic people with care and empathy as they would any other client is a key fundamental skill for improving communication ($n = 4$), as well as not being afraid to engage with the service user in order to explore how to offer the kinds of adaptations most suitable for their needs ($n = 6$):

I treat all patients as individuals and feel more confidence about caring for an autistic patient since attending the course. (Theatre nurse)

I know when communicating with anyone, autistic or not, it's important to take the time to listen, and to check understanding. I know that it's ok to ask someone about their specific needs – especially if it's done with no pressure, in a way that gives that person the choice of whether or not they want to say. The workshop helped me feel confident in asking about a service user's needs which makes it easier then to feel confident about adapting my approach to best suit each individual. (Student information office coordinator)

(2) Challenges and difficulties working with autistic people. In terms of the challenges faced in communicating with autistic service users, managers also attended the workshop alongside frontline staff, meaning that they were able to experience first-hand the challenges that autistic people can face when accessing services, and better understand the importance of making adaptations ($n = 10$). One manager reflected after the workshop:

I was especially pleased to be made aware of 'shutdowns' and also the presenter's ideas on autism styled free recall (for example – being specific in initial request and then expanding it topic by topic). (Director from a business co-operation)

However, some medical professionals still reported concerns about knowing when and which adaptations autistic children and young people may need, a group who may be unable to fully express their own needs, resulting in the need for practitioners to rely on their parent/guardians for communication ($n = 5$):

As all of the patients I see are under 18, what I do find difficult is if the patient is a new patient and the parent has not disclosed on the medical history form prior to the appointment that their child has autism. (Orthodontist)

(3) Adaptations. Participants broadly suggested that the workshop benefitted them in two ways – by directly providing helpful, practical advice on how to translate evidence-based autism knowledge into good practice and adaptations, and by providing a space for participants to reflect on their existing adaptations, highlighting areas for improvement ($n = 14$):

The biggest change I have made is to consciously ask the questions that are not too broad or open, and to not use phrases that could be wrongly taken literally… (Student occupational therapist)

I was able to recognise ways in which I am already adapting my communication with service users. The session helped

me recognise that the management of this intervention could be improved by providing support to students who may struggle with the format of an Exam performance interview… I will be adapting the information we provide to all students in advance of the meetings to make it more accessible, and allow students time to prepare answers to questions where possible… I already follow up with students following these meetings, and would look to ensure that any follow-up material is understood. (Student information office coordinator)

Participants also discussed how they had benefitted from connecting with colleagues from multiple disciplines at the workshop, sharing knowledge and good practice with each other to learn new strategies, as well as reinforcing effective adaptations they were already using ($n = 10$):

… Getting the chance to share good practice with workers from the University / Education settings on my table was really useful – as was sharing contact information allowing us to communicate in the future and to discuss ideas and any changes that we implement. (Employee at a local college)

Working in a university, we don't get a lot of opportunity to liaise with professional services staff from elsewhere, so this was a brilliant chance to find out what other institutions were doing, and how they would approach some of the examples I have dealt with in the past. (Student coordinator)

See Table 1 for adaptations endorsed by participants post-workshop. See also Figure 1 for an infographic detailing adaptations service providers could consider implementing.

Phase 2 – Further review of the adaptations by the autism community

The evidence-based adaptations created for the workshop were subsequently independently reviewed by the autism community, who were also invited to suggest additional adaptations they may find helpful when accessing services. Additional adaptations suggested included, for example, reducing noise in waiting areas (e.g., muting videos playing on repeat), prompting a service user to book their next appointment where relevant, using a visual cue (e.g., in waiting areas) that the service provider is ready to see the person (instead of only relying on calling out names), and sending a follow-up summary after medical appointments. The majority of the autism community's suggested adaptations, therefore, fell into the 'adapting the environment to reduce sensory stressors', 'adapting direct communication', and 'modifying visual information' categories (see Table 1), with respondents broadly agreeing with the initial list of adaptations presented. Although suggestions were also made within the category of facilitating diagnosis

disclosure, these were broadly similar to the adaptations already generated.

Discussion

With a disproportionate number of autistic people experiencing difficulties accessing crucial services (Nicolaidis et al., 2013, 2015; Taylor & Henninger, 2015; Taylor & Seltzer, 2011; Thompson & Emira, 2011; Vogan et al., 2017), it is vital that service providers facilitate successful engagement with autistic people by offering effective adaptations (Shattuck, Roux et al., 2012). Although there has been a recent increase in the number of studies examining barriers to accessing services (particularly within healthcare), there has until now been less research on the specific ways in which communication between autistic people and service providers can be supported, and how these adaptations could impact upon access to and use of services (Mason et al., 2019). The current study addressed the need for research which identifies, implements, disseminates, and evaluates a strategy for service improvement (Shattuck et al., 2020). Findings highlight the benefits of co-delivered activities such as workshops to stimulate the development of evidence-based adaptations tailored to services, whilst also addressing service providers' reluctance to offer adaptations (which is often due to poor understanding of autism, and low confidence working with autistic people; Mason et al., 2019; Nicolaidis et al., 2015; Unigwe et al., 2017; Zerbo et al., 2015).

A suite of adaptations was developed for the workshop, based on recent applied experimental research evidence on autism and communication (Crane & Maras, 2018; Maras, Mulcahy et al., 2018; Maras, Norris, Nicholson et al., 2020; Norris et al., 2020), which could be categorised within four broad categories: (1) adapting the environment to reduce sensory stressors, (2) facilitating diagnosis disclosure, (3) adapting direct communication, and (4) modifying visual information. These categories largely reflect those highlighted in recently published work, focusing on the sensory environment, clinical and service context, and service provider autism knowledge, understanding, and (effective) communication (Bradshaw et al., 2019; Brice et al., 2021; Mason et al., 2019, 2021; Walsh et al., 2020). In addition, this study highlighted the potential benefits of, but also barriers to diagnosis disclosure (Norris et al., 2023; Romualdez, Heasman et al., 2021). Broadly, our workshop adaptations and the findings from the autism community survey support those of Nicolaidis et al. (2015; see Introduction for full details), with our workshop focusing on facilitating diagnosis disclosure by highlighting what help *would* be available when a service user decided to disclose (i.e., supporting *system-level* barriers; Nicolaidis et al., 2015), as well as highlighting the benefits of offering adaptations such as maintaining person-consistency between appointments, sending clear, pictorial travelling directions, offering walkthroughs/familiarisation visits, and providing videos/other media to demonstrate procedures or broader

Table 1. Adaptations co-developed by the researchers and the autism community.

Researcher-developed adaptations	Additional adaptations suggested by the autism community
Sensory	
• Asking about individual sensory needs • Adapting the environment • Reducing waiting room time/giving the option to wait elsewhere • Checking sensory aspects of touch (e.g., warning a patient before about what will happen during an examination) • Signs in waiting areas telling people to ask for help if they need it	• Reducing noise and smells in waiting areas (e.g., videos playing on repeat, air fresheners) *For making appointments and waiting rooms:* • Offer flexible appointment times & flexibility on how to book an appointment (e.g., online/via email) • Update people on any delays to appointments/indicate the current wait time • Prompt the person if they need to book another follow-up appointment • Consider using a visual cue that the service provider is ready to see the person
Disclosure	
• Adapt initial questions (e.g., questionnaires and health screening) to encourage and facilitate disclosure • Provide information about the benefits of disclosure • Share disclosure with relevant staff (with service user consent) • In medical/inpatient settings, using an indicator, if acceptable to patient	
Direct communication	
• Maintaining person-consistency between appointments where possible/having a specified contact person • Using direct/specific questions (avoiding open questions) • Specifying when emails/letters you have sent require a response • Checking understanding • Avoiding phone calls if the person prefers • Giving plenty of time for people to process and answer questions • Showing & telling when filling in forms, using tools/instruments, etc	• Avoid speaking quickly • Consider offering printed instructions or notes to facilitate understanding of what you are saying • Consider speaking to a family member/supporter where this is requested (and keeping note of this for future appointments) • Offer the option to request a specific service provider
Preparatory/take-home materials	
• Sending clear travelling directions • Making written information clearer • Allowing people to fill in forms in advance if possible • Offering help and/or a quiet area for filling in forms, to plan & arrange multiple appointments, etc • Offering walkthroughs/familiarisation visits • Providing photos/videos of locations, key people, etc. • Providing an explanation of what will happen, who with, where, and when • Providing videos/other media to demonstrate procedures or broader systems	• Consider sending a follow-up communication summarising the appointment/meeting • Ensure preparatory information (e.g., paper-based sheets and websites) are visually accessible e.g., avoiding blocks of lengthy text • Improve transparency of access e.g., to patient notes

systems (i.e., supporting *patient-level* and *provider-level* difficulties; Nicolaidis et al., 2015). These findings also support those of Mazurek et al. (2023), whose qualitative work can be categorised across three themes also broadly mapping onto those by Nicolaidis et al. (2015): system- and service-level factors, aspects of the healthcare environment, and provider autism knowledge and practices (see also Dern & Sappok, 2016; Raymaker et al., 2017).

Our analysis of the pre- and post-workshop data indicated several benefits to service providers from attending: confidence in working with and communicating with autistic service users, as well as autism knowledge were all improved, although it should be noted that the quantitative data are limited by the small sample size (see *Limitations of the current study* below). In addition, feedback from attendees was overwhelmingly positive. Our qualitative analyses also indicated that, prior to attending the workshop, many participants felt they lacked the required knowledge and skills to effectively communicate with autistic people, and discussed challenges such as having outdated learning, and a lack of opportunities to apply their knowledge. In contrast, after the workshop, attendees discussed its benefits, in particular praising the value of hearing about autistic people's experiences, as well as being able to discuss the practical realities of adaptations with the facilitators and other service providers. Participants also cited gaining confidence in working and communicating with autistic people, in particular highlighting the value of learning about how to discuss which adaptations to offer with the individual themselves.

In terms of adapting written materials, many attendees discussed cumbersome processes required to change written information in their sectors, which they believed could be a barrier to adapting such materials. They also cited obstacles such as working with limited time and resources, finding it difficult to convince managers of the need for change, and having to rely on parents/guardians to facilitate communication with younger people and children (see also Mason et al., 2021), with many of these concerns remaining at post-workshop. However, respondents also highlighted that the practical guidance for creating adaptations was valuable in building upon autism knowledge to produce workable adaptations. Although barriers may exist in terms of adapting some written materials, service-provider willingness to assist the individual with understanding in other ways (e.g., providing extra time, checking understanding, etc.) can also be effective in scaffolding understanding. In addition, service providers should be aware of whether adapted materials are already available, such as easy-read information (indeed, NHS guidelines on reasonable adjustments already highlight a requirement for adaptations for many groups; NHS, 2020).

After conducting the workshop, we continued community involvement by surveying members of the autism community to generate further adaptations that autistic people and their supporters would find useful, adding these to the co-created list of adaptations. Suggestions included, for example, adapting waiting rooms by reducing noise and using a visual cue to indicate when a service provider is ready to see the person, adapting post-appointment communication by prompting an individual to book their next appointment, where relevant (Doherty et al., 2020), and providing a summary of what was discussed after appointments (see also Bradshaw et al., 2019; Dern & Sappok, 2016). Respondents also suggested that services could avoid relying on phone calls as their primary method of communication (a method often disliked by autistic people; Doherty et al., 2020; Howard & Sedgewick, 2021), and consider offering paper-based information to scaffold a discussion, and to support a service user's understanding after an appointment. Indeed, research has highlighted how providing information or questions on paper can help the person to focus on their responses, rather than having to hold in mind information about questions they are being asked, considering what they might be asked next, etc (Maras, Norris, Nicholson et al., 2020; Norris et al., 2020). The majority of the autism community's suggestions therefore fell into the adapting to the environment, direct communication, and written information categories developed for the workshop. This reflects the research literature indicating that autistic people face particular barriers when attempting to make appointments, as well as in waiting rooms due to difficulties with uncertainty about waiting times, crowding, and sensory sensitivities (Dern & Sappok, 2016; Doherty et al., 2020; Mason et al., 2021; Raymaker et al., 2017). These are important, low-cost, and fairly straightforward adaptations that service providers can implement. Importantly, although this evidence base is primarily from autism research, and some accommodations will be specific to a certain individual's needs, many of the adaptations could be useful to both neurodivergent and neurotypical populations (e.g., a less overwhelming environment, improved clarity of questioning and communication, and more explicit, detailed, and user-friendly directions). Implementing such adaptations across the board would therefore both reduce the burden on service providers of having to deliver their services in different ways, and also avoid the need for neurodivergent people to always disclose their diagnosis in order to access services (i.e., a neurodiversity approach; see for example Maras, Norris, Nicholson et al., 2020; Norris et al., 2020; see also Universal Design; Goldsmith, 2000; Milton et al., 2016; Steinfeld & Maisel, 2012).

Limitations of the current study

A limitation of the current study was that a fairly low number of the workshop attendees completed *both* the pre- and post-workshop surveys ($N = 13$; knowledge, and $N = 11$; confidence) out of 41 attendees (therefore, although 23 attendees completed the pre-workshop survey, and 20 completed the

Adapting communication for autistic people
Co-developed adaptations for service providers

Consider sensory adaptations

- Ask about sensory needs and adapt environment (remove ticking clocks or videos playing on repeat, adjust lighting, reduce smells and noise, etc)
- Reduce waiting time/provide option to wait elsewhere
- Update people on delays/indicate current wait time
- Consider using a visual cue that the service provider is ready to see the person
- Check sensory aspects of touch (e.g., talk through what will happen during an examination)
- Place signs in waiting areas telling people to ask for help if they need it
- Offer flexible appointment times & options for booking online

Facilitate autism disclosure

- Adapt initial questions (e.g., questionnaires/health screening) to encourage and facilitate disclosure of one's autism diagnosis
- Provide information about the benefits of disclosure
- Share disclosure with relevant staff (with service user consent)

Direct communication

- Ask what method of communication the person would prefer
- Avoid phone calls if the person prefers
- Maintain person-consistency/have a specified contact person
- Use direct/specific questions (avoiding open questions)
- Speak clearly, and not too quickly, whilst checking understanding
- Specify when emails/letters you have sent require a response
- Give plenty of time for people to process and answer questions
- Show and tell when filling in forms, using tools/instruments, etc
- Offer printed information to facilitate understanding in a consultation
- Consider speaking to a family member/supporter where this is requested (and make note of this for future appointments)

Provide preparatory/take-home materials

- Send clear travelling directions
- Allow people to fill in forms in advance and/or offer help
- Offer a quiet area for form filling, arranging appointments, etc
- Offer walkthroughs/familiarisation visits, and photos or videos of locations/key people
- Explain what will happen, who with, where, and when
- Provide demonstrations of procedures/broader systems (e.g., videos)
- Consider a follow-up contact summarising the appointment
- Ensure preparatory information (e.g., paper information & websites) are accessible
- Improve transparency of access e.g., to patient notes

Norris, J. E., Lei, J., Maras, K (2024) Adapting communication with autistic service users: co-produced adaptations for medical services, employers, and the third sector. *Neurodiversity*.

Figure 1. Infographic – adapting communication for autistic people: co-developed adaptations for service providers.

post-workshop survey, only 11 captured responses by the same individual across both timepoints). This means that our sample for the quantitative analyses was fairly small. It cannot be ruled out that those deciding to complete or not to complete the post-

workshop survey may be qualitatively different groups. For example, attendees who found the workshop most useful may have been more motivated to complete the post-workshop survey. Future research could therefore seek to improve the uptake of evaluation surveys, for example by asking attendees to complete these within the workshop session, rather than in the days following. However, it should be noted that although we were interested in pre- to post-workshop change in autism knowledge and confidence, another key focus of this research was on the qualitative adaptions made based on research evidence, those endorsed and suggested by the autism community, as well as the reasons given for attendee confidence, and which adaptations they would be taking forward into their service provision. Another limitation of the current study was that standardised measures of autism knowledge were not used. Instead, we selected questions about autism knowledge based on prior research in the field, the aim of which was to more directly reflect upon the learning from the workshop (e.g., around the aspects of communication autistic people may find difficult, and those where they may not differ from their non-autistic counterparts). Future research should therefore aim to also include some standardised measures of autism knowledge (e.g., the Autism Awareness Scale; Gillespie-Lynch et al., 2014). Finally, it should be noted that further research should and will continue to uncover additional and novel ways of adapting communication with autistic people, and some of the current results may be difficult to generalise due to the relatively small sample sizes present.

Practical implications and future directions

Although workshops and training can be enjoyable, and perceived as valuable at the time, they may not always lead to high rates of change in practice afterwards (the 'training transfer problem'; Burke & Hutchins, 2007). In order to try and capitalise on the enthusiasm of the workshop attendees in the current study, the authors encouraged them to register to become certified as *Ambassadors for Autism*. This involved attendees pledging to commit to make adaptations within their services. As a further incentive, services/teams received a certificate, which they were encouraged to display prominently (e.g., in waiting rooms/online/in email signatures, etc.) to encourage service users to request adaptations (Brice et al., 2021). Services/teams were also asked to encourage service users to provide feedback on their experiences, and also to provide their own feedback on the impact using the adaptations has had on their service. To date, several service providers and employers have pledged to make adaptations, becoming certified as *Ambassadors for Autism*. Such methods may be an effective way of converting workshop knowledge and training into real-world service change. Future research should also aim to build upon these initial

findings by testing the final list of adaptations created in the current study.

In sum, the current study built upon recent research (e.g., Bradshaw et al., 2019; Brice et al., 2021; Mason et al., 2019, 2021; Walsh et al., 2020) by focusing on assisting service providers to adopt practical, evidence-based methods for adapting communication with autistic people, as well as considering other barriers (sensory difficulties and diagnosis disclosure). Extending previous research on healthcare, this paper shows how these principles can also be applied across a variety of other crucially important services (Shattuck et al., 2020), and could also be extended to justice services, as autistic people are more likely to have interactions with police (Chaplin & Mukhopadhyay, 2018; Tint et al., 2017; Weiss & Fardella, 2018). The workshop led to improved confidence in working and communicating with autistic people, as well as improved autism knowledge, and encouraged services to implement adaptations, further supported by the *Ambassadors for Autism* scheme. A full list of these adaptations, successfully applied by many of the *Ambassadors*, and built upon by the autism community, is provided in the current study for use by relevant services and sectors.

Although this workshop focused primarily on service providers, many of whom worked in the physical health sector, the current findings have implications for a range of other services. For example, autistic people can struggle to access mental health services (Babb et al., 2021; Brice et al., 2021; Crane, Adams et al., 2019; Crane, Davidson et al., 2019; Nicolaidis et al., 2013). However, adaptations have been shown to successfully facilitate autistic people to participate (Cooper et al., 2018; Lang et al., 2010; Russell et al., 2019; Russell et al., 2013), with effective adaptations including incorporating behavioural strategies to introduce change, taking a more structured and concrete approach, including psychoeducation about emotions, and using more visual and written materials (Cooper et al., 2018).

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Notes

1. We use the term 'service providers' throughout the paper to describe a variety of staff and sectors providing a service to the public. This may include, but is not limited to, healthcare, social care and support, third-sector and charitable services, employment and welfare support, emergency services, the criminal justice system, etc.
2. The workshop was funded by the ESRC Festival of Social Science
3. Note that the overlap was $N = 11$ for confidence, and $N = 13$ for knowledge, as some people completed the post-workshop survey without completing the pre-survey, and vice versa.
4. Although 23 attendees completed the pre-workshop survey, and 20 completed the post-workshop survey, a total of 11 of these were the same individual completing pre *and* post.

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Appendix

Table A1. Coding framework for qualitative feedback from workshop participants.

Coder 1	Coder 2	Final agreed code and theme
• Existing knowledge, skills, and confidence • Autism knowledge and relevant skills • Weaknesses and gaps in knowledge	• Communication strategies • Knowledge sharing • Lack of autism-related knowledge	Theme: Knowledge Codes: (a) Autism knowledge (b) Communication skills (c) Knowledge sharing and training
• Difficulties with knowing who needs help • Weaknesses/gaps in knowledge • Practical issues in work context • Communication differences	• Difficulties and challenges of knowing who needs help • Contact and experience with autistic individuals • Infrastructure difficulties • Lack of resources and training • Communication difficulties	Theme: Challenges/difficulties (a) Diagnosis disclosure (b) Experience with autism (c) Infrastructure/lack of resource (d) Communication differences
• Workshop benefits • Self-awareness on current adaptation • One's own role in bridging communication differences	• Communication strategies and other specific adaptations • Awareness of current adaptation implementation • Personal strengths and development to facilitate communication	Theme: Adaptations (a) Existing adaptations (b) Workshop-based (c) Self-awareness (strengths and limitations)