An Auternative Research Project: Strategies, Barriers, Good Practice and Recommendations – Results from Questionnaire

Marion Hersh[1a], Sharon Elley[2b], Cal Watson[1c], Panda Mery[1], Michael Dawson[1] David Cowan[1], Zyggy Banks[1]
[1]Biomedical Engineering, Rankine Building, University of Glasgow, Glasgow G12 8LT, Scotland
[2]School of Sociology and Social Policy, University of Leeds, Leeds, LS2 9JT, England.
[a]marion.hersh@glasgow.ac.uk; [b]S.T.Elley@leeds.ac.uk;
[c]callumwatson@hotmail.com.

Executive Summary

The idea for the An Auternative research project came out of concerns by several autistic participants at a Scottish Autism Research Group seminar about the lack of understanding of real autistic lived experiences. This understanding and the involvement of autistics are crucial for both good research and real change.

The project funded by Disability Research for Independent Living and Learning is autistic-led and the majority of the project team are autistic. The team was suported by an Advisory Board of autistic people who provided advice on all aspects of the research and piloted the questionnaires.

The research project investigates the following two research questions:

1. How do autistic people use strategies, including logic, reasoning and rules, to understand social situations and other people's reactions, and to empower themselves?
2. What are the barriers, including stereotypes, misconceptions and systemic issues, to autistic people using their strengths and appropriate strategies to participate in decision making, the economy and the community?

The report discusses the results of the questionnaires carried out by the project. Previous work has included a literature review and subsequent work will include a questionnaire and a diary exercise. The questionnaire could be completed on line or using an electronic or hard copy document. Participants were recruited through email lists and online forums used by autistic people, social media, organisations supporting autistic people, students and other groups for autistics and the partners' and Advisory Board members' contacts, which included autistic people from diverse backgrounds. A flyer and video were used to publicise the research and particularly encouraged the participation of underrepresented groups of autistic people identified by analysis of the personal data as results were submitted. The video was also tweeted and put on the project website. Ethical approval was obtained from the University of Glasgow College of Science and Engineering Ethics Committee.

Our results are based on 223 interviews, all completed online. The participants were reasonably diverse, though participants over 70 and those with cognitive impairments were not represented and there were few non-verbal people.

All participants used a number of different strategies. The strategies presented were used effectively by at least some and frequently a majority of participants, but also had disadvantages and/or costs. We consider them a resource to be used by autistic people, but are not recommending specific strategies. What works best will depend on the individual autistic person and the situation. The main strategies identified were a trusted or a support person, hiding autistic traits and imitation, research and preparation, using technology, logic and reasoning, stimming and relaxation and using humour, interests, personality and strengths. These strategies were generally all used, though to differing extents, with service providers, in employment and job search and in social interaction. Further details about these and other strategies are provided in the body of the report.

Participants experienced a wide range of different barriers with several participants experiencing barriers in most or all the following categories. They included communication barriers, expectations of and lack of alternatives to phone use, noise and other sensory issues, stereotypes and misunderstandings, negative experiences, disadvantageous and discriminatory treatment and internal barriers. Further details about all the barriers are provided in the body of the report.

Some good practice was identified, but was relatively sparse and mainly in the area of diagnosis. We used the results to draw up a number of recommendations to improve the experiences of autistic people and enable them to participate more actively in society. This will have benefits to society as a whole as well as autistics. Following a number of summary recommendations, the recommendations covered a wide range of areas, including summary, communication, sensory issues, training, service providers (general), health service, benefits, diagnosis, employment and suggested research topics.

1. Introduction

The research project was motivated by a seminar organised by the Scottish Autism Research Group in 2016. Several autistic participants were concerned by the focus on 'interventions' which showed limited if any understanding of real autistic lived experiences. The researchers felt that this understanding and the involvement of autistic people need to be the starting points for both research and any real change.

This led to the An Auternative: A society fit for autistics project, which was successful in receiving funding from Disability Research for Independent Living and Learning (DRILL). It is autistic-led and the majority of the project team are autistic. Marion Hersh and Sharon Elley are a senior lecturer and lecturer at the Universities of Glasgow and Leeds. Michael Dawson and David Cowan are involved in projects for autistic people in Glasgow and Panda Mery in London. Zyggy Banks supports autistic students at the University of Leicester. Callum Watson is an assistant psychologist who has formerly supported autistic students. Michael, David, Panda, Callum and Zyggy are all employed as research assistants by the University of Glasgow.

An Advisory Board of autistic people has supported the project throughout. They have provided us with advice on all aspects of the project and also piloted the questionnaire.

We will use the term autistic or autistic people to cover everyone on the autistic spectrum, as the terms most frequently preferred by autistic people themselves (Kenny et al., 2016). However, we recognise that some autistic people may have other preferences. Our approach to autistic people is based on the social model of disability (Johnstone, 2012; Swain et al., 2003) and the compatible neurodiversity model. This leads to an understanding of autistic people as experiencing social, attitudinal and infrastructural barriers and frequent social exclusion (social model of disability). This is a result of the lack of acceptance and valuing of differences in thinking patterns, moving, interacting, and sensory and cognitive processing due to neurological differences from the majority 'neurotypical' population (neurodiversity model). This differs from the more commonly used deficit based medical definitions and approaches. Much of the research is very strongly deficit based, to the extent that several members of the project team found working on the literature review a negative and depressing experience. It also continues to affect attitudes to autistic people and lead to very negative perceptions. This is also, unfortunately borne out in our research.

As is discussed briefly in Hersh et. al., (2020a) our research is also influenced by the disability literature on self-determination, autonomy, independence and interdependence e.g. (Deci, 1992; Sprague and Hayes, 2000; Wehmeyer, 2005; Wehmeyer et al., 2010; White et al, 2010), particularly autonomy. This has been defined as the ability to 'make meaningful decisions about [one's] life and have also them happen' (Knight, 2007).

The project aim is to investigate the following two questions:
1. How do autistic people use strategies, including logic, reasoning and rules, to understand social situations and other people's reactions, and to empower themselves?
2. What are the barriers, including stereotypes, misconceptions and systemic issues, to autistic people using their strengths and appropriate strategies to participate in decision making, the economy and the community?

The research is intended to cover all autistic people, whether they have received a formal diagnosis, self-identified as autistic or are in the process of seeking an autism diagnosis. This report will discuss the responses to a questionnaire. We previously carried out a literature review (Mery et al, 2018). Subsequent research will include interviews and a diary exercise.

The report is organised as follows. A brief overview of relevant literature is given in section 1.1. Section 2 presents the methodology and section 3 an overview of the interview participants. Strategies are discussed in detail in section 4, a brief overview of the barriers is given in section 5 and good practice is presented in section 6. Conclusions are presented in section 7 and detailed recommendations in section 8.

1.1 Brief literature overview

There is relatively little existing research on the strategies used and barriers experienced by autistic people. The relatively limited literature on strategies has tended to focus on masking and imitation e.g. (Hull et al., 2017; Livingston et al., 2019) rather than trying to identify the full range of strategies used by autistic people. There has been some discussion of autistic women, in particular, using camouflaging and imitation to mask social and communication barriers (Lai et al., 2017). The negative impacts of masking on mental health, particularly depression have been considered and it has been suggested that they are due to the power dynamics, negative stereotypes, prejudice and discrimination experienced by autistic people (Hull et al., 2017). However, these factors are likely to have a negative impact on autistic people whether or not they use masking.

Discussion of the barriers experienced by autistic people has generally focused on particular domains such as the health service and/or particular groups of autistic people, such as students. Studies of autistic students have shown they had a high level of negative experiences, including bullying, humiliation, social exclusion, loneliness and unpredictable changes in social group and that this had resulted in depression and anxiety in levels from being able to cope up to overwhelming (Hastwell et al., 2017). In addition many autistic university students have had limited support in social situations and experienced difficulties in understanding the behaviour of non-autistic students (Beardon et al., 2008)

Autistic people have been found to experience a number of employment related barriers. They experience structural barriers and discrimination in the labour market (Rosqvist and Keosi. 2012) and their experiences in work have generally been negative, though a few had obtained good jobs, particularly when they matched their autistic skills, key interests and strengths, such as attention to detail (Müller et al., 2003). Particular barriers included a lack of adaptations of job content and working conditions, such as flexible hours, special lighting, exemption from customer-facing tasks and tailored supervision strategies (Baldwin et al., 2014).

In the area of healthcare sensory issues have been found to affect healthcare use (Muskat et al., 2015; Nicolaidis et al., 2015), communication issues between autistic people and professionals to be a problem (Nicolaidis et al., 2013) and healthcare professionals not to understand the needs of autistic people (Westminster Commission on Autism, 2016). Autistic people were generally dissatisfied with the support they received post-diagnosis (Jones et al., 2014).

2. Methodology

2.1 Ethics

Ethics were central to our research. We obtained initial overall approval for the project and then specific approval for the questionnaire from the University of Glasgow College of Science and Engineering Ethics Committee. Further advice on ethical issues was obtained from the Project Advisory Board. In line with ethical procedures, participation was voluntary, with the option to withdraw at any time, and participant confidentiality, anonymity and data protection were assured. However, participant anonymity meant that data could not be withdrawn once submitted.

All versions of the questionnaire, online, hard copy and electronic, were accompanied by an information sheet and a consent form. In the online questionnaire this formed the first page of the questionnaire and participants needed to answer the initial compulsory consent question before they could proceed to the survey.

Contact details for the researchers were provided at both the start and end of the questionnaire and participants were encouraged to contact them with questions and to ask for additional information. There was a link to a separate brief questionnaire where participants could leave contact details to be sent the research results. This was separated to preserve anonymity.

2.2 Questionnaire

Drawing up the questionnaire involved all partners and comments by the Advisory Board of autistic people. There were several stages of piloting, including online piloting to ensure that to ensure usability as well as appropriateness for the audience and lack of ambiguity. A number of changes were made as a result of piloting.

The resulting questionnaire consisted of seven different sections, Sections included a mixture of open and closed questions to investigate participants' experiences, strategies and suggestions for improvements in the areas of: 1) diagnosis; 2) health service; 3) job search and employment; 4) benefits and 5) social interaction. A further section comprised open questions to investigate participants' use of technology in interaction with service providers, social and other situations and suggestions for new technologies and improved/new uses of existing technologies. The final section collected personal data on factors such as gender, age, ethnicity and class to allow investigation of the relationship between these and other factors and to determine the extent to which the whole autistic community was covered. This section was put at the end rather than the start, as is most common, as it could have been offputting for some autistics to start with personal information. The final question asked for permission to store anonymised responses in the University of Glasgow Enlighten data repository. All questions, other than the initial consent question were voluntary.

2.3 Recruitment of participants

In addition to the on-line version, options were provided to complete the questionnaire in hard copy format and as a WORD file. The questionnaire was publicised as widely as possible and all project team members were involved in doing this. This included through email lists and online forums used by autistic people, social media, organisations supporting autistic people, students and other groups for autistics and the partners' and Advisory Board members' contacts, which included autistic people from diverse backgrounds.

In order to try to recruit participants with diverse characteristics, the flyer and other publicity materials both invited all autistic people to participate and specifically encouraged the participation of autistic people from some of the groups we considered likely to be underrepresented, including non-verbal autistic people, autistic people with learning disabilities and autistic people from ethnic minorities. Groups of autistic people with cognitive impairments or who were non-verbal were contacted. As results came in, we analysed the personal data to identify the groups of autistic people who were underrepresented. This led to us adding autistic people over 70 and those with physical and sensory impairments to the groups we were specifically targeting for recruitment. One of the researchers produced a short video clip to publicise the research which was tweeted, put on the website and sent to contacts. It also highlighted recruitment of groups of autistic people who were underrepresented in the data so far.

2.4 Analysis

Initially the results of the open and closed questions were analysed separately. Analysis of the open questions was based on thematic analysis (Braun & Clarke, 2006) and driven by our interest in understanding autistic experiences of barriers, strategies and good practice, as well as suggestions for recommendations. Questionnaire data from different sections was divided amongst the researchers who coded it independently of each other. The coded data was examined for patterns and then organised into initial themes. The initial themes generated by each team were compared, discussed and revised.

The themes were then reorganised using a framework of strategies, barriers, good practice and recommendations in order to answer our research questions. Further analysis identified that there were some themes were specific to particular domains such as employment, but that the majority of them covered all the domains of services, job search and employment and social interaction. This led to a further analysis stage of combining themes across different domains. This was followed by discussion and revision by all the researchers to reach a consensus on the themes which described the data within the framework of strategies, barriers, good practice and recommendations.

Simple statistical analysis of the closed questions was carried out. This involved calculation of the percentages of participants with each response relative to the total number of participants who answered that question. Other than for the questions which were not relevant to all participants, only a few participants did not answer any given question. This was followed by comparisons of the percentages of participants giving each response. Subsequent work will examine the relationships between personal characteristics, such as gender, age, ethnicity, class etc and participants' responses.

A further stage involved combining the analyses of quantitative and qualitative data together and investigating how they were related and qualitative data expanded on the quantitative data.

3. Results: Sample Overview

223 responses were obtained, including eight from the initial piloting stage.
Over half the participants (58%) were female, a third (33%) male, 6% non-binary and 4% other. 10% had changed their gender from that assigned at birth. The relatively high percentages of non-binary and trans participants follow the literature on the high percentage of autistic people who are trans and/or reject binary gender (Walsh et al., 2018). Another recent study had an even high percentage of female participants (Livingston et al., 2019), indicating that some studies may be attractive to autistic women. The previous low representation of autistic women in research makes this very welcome.

There was good age distribution, though only a few participants were aged 65 and older and none over 74. Nearly two fifths (37%) were in the 25-40 year age range and about a fifth in each of the 16-24 (19%), 41-50 (23%) and 51-64 (18%) age ranges. A combination of factors was probably responsible for the low representation of older people, including their lower diagnosis rates compared to the rest of the population and the possibly greater difficulties in contacting them, particularly by electronic means. The overwhelming majority (89%) were white, a very similar figure to that for the UK population (87%). 8% were black or mixed race and 3% other.

There was a much greater representation of middle class (47%) than working class people (37%), with a few considering themselves upper class and 14% other, generally because they were unsure where they fitted on the class spectrum or rejected the concept of class. The overwhelming majority (97%) of participants used spoken language most of the time. However, nearly a fifth (19%) used another form of communication, either together with speech or on its own. 12% use the most popular alternative communication approach, a system on a mobile device or PC.

The results will now be presented in sections 4-6. They are divided into strategies, barriers, and good practice. However, this has the disadvantage of splitting topics across sections. Thus, for instance, barriers and bad practice in diagnosis are presented in section 5 and good practice in section 6.

In the interests of reducing the length, the strategies presented in (Hersh et al., 2019) are only summarised at the start of section 4 and not presented in detail.

4. Results: Strategies

This section answers our first research question on the strategies used by autistic people. It does this by providing details of the strategies discussed by participants in their interviews. While the strategies presented were used effectively by at least some and frequently a majority of participants, all strategies have drawbacks or disadvantages, which will also be discussed. We are providing the strategies as a resource to be used by autistic people rather than recommending specific strategies. What works best will depend on the individual autistic person and the situation. It is for each autistic person to choose the strategies that they think will work best for them in the given situation.

A number of the main strategies identified have been reported in (Hersh et al., 2019) and will therefore only be discussed very briefly. They are:

- A trusted or support person: used to access services and use them effectively. Comments were generally positive. The disadvantage was the need to find a suitable person.
- Hiding autistic traits and imitation: comments were varied, but overally more participants found these approaches effective than otherwise. In general experiences were positive when participants chose to hide their autistic traits, but could impact mental health when they felt forced (or believed they were being forced) to do this.
- Research and preparation: used to improve access to diagnosis and other services and chances of obtaining employment, as well as in social interaction.
- Using technology: this included the use of email and online booking systems to access services and games and other technologies to support social interaction, as well as to support face to face interaction.
- Logic and reasoning: used to understand situations and emotions. It could help some participants work out what they should and should not do, but there was a need to avoid overanalysis and few of the participants found these approaches helpful, particularly in social situations.
- Stimming and relaxation: used to cope with stress, with stimming generally carried out discreetly using objects rather than body movements.
- Humour, interests, personality and strengths: humour and interests were popular strategies in social situation. Humour and personality use were generally effective. Using strengths included using valued workplace skills such as reliability, dedication, honesty and intelligence to obtain and keep meaningful employment.

These strategies can generally be used in a variety of circumstances, including social interaction, looking for jobs and in the workplace and interacting with service providers. The other strategies identified by participants will now be discussed. Unlike the above strategies, several of them are situation specific. However, others can be used in a variety of contexts, though discussed here in a specific one.

Participants used several communication support strategies. Whilst they were reported in the context of medical appointments, there is no reason why they could not be used in other circumstances. 35% asked the doctor to repeat things and 32% to write them down. These strategies illustrate that participants understood their own communications needs and were able to act autonomously to ensure they were met.

Participants also used communication-based strategies in job search, namely networking (22%) and using contacts in the organisation (21%). However, unlike the communication support strategies used with doctors, these strategies were used by only a minority of participants, possibly because strategies based on communication and knowing people are more difficult for autistic people. Networking and using organisational contacts have applications beyond job search but, as indicated by the small percentage of participants using them, may not be suitable strategies for many autistic people. Mentoring was a workplace strategy used by only a small percentage of participants (10%) which could have wider applications. The very low number of participants using this strategy was probably due to lack of availability, though further research would be required to confirm this. However, the need to get to know the mentor initially may have acted as a barrier to using this strategy for some participants.

Several strategies reported in a job search or employment context are applicable in a range of situations. These included asking for a quiet room, used by 38% of participants for interviews, disclosing you are autistic (38%), asking for reasonable adjustments (28%) and asking for feedback. A generally applicable strategy reported in a health service context was asking what (the doctor) knew about autism, used by 22%. Participants also used social avoidance strategies in the workplace, such as ‘avoid social breaks and chats’, ‘not trying to talk to people’ and avoiding networking These strategies are also more widely applicable, but could lead to isolation.

Employment-specific strategies included volunteering, self-employment, freelancing and choosing autistic-friendly workplaces. Volunteering was successful to some extent and included charity work and only working for autism charities and recruitment agencies. However, participants’ expectations of reduced barriers and greater understanding in these organisations were not always borne out. Typical comments were that organisations sometimes ‘don’t follow reasonable adjustments’ at interview and are ‘autistic-unfriendly’. Unfortunately, supposedly ‘autistic’ organisations do not always understand and follow good practice in employing autistic people. Several participants considered part-time volunteering roles a useful way to gain experience and eventually securing paid employment. However, volunteering can easily lead to exploitation, with volunteers used as a source of cheap labour. Volunteering can also become the expected norm for disabled people and frequently not result in secure paid employment.

Some participants considered ‘self-employment’ or ‘freelancing’ to be a good alternative employment strategies which enabled autistic people to adapt employment to fit their own needs. This is borne out to at least some extent by the relatively high percentage of participants (18%) who were self-employed and the fact that 25% had set up their own businesses. However, we do not obtain information on how many of these businesses were flourishing or even still operating. Further research is required to investigate both the benefits and the difficulties, as well as how successful self-employed and freelancing autistics are in earning a living.

Autistic-friendly work-places were considered to include both specific types of work and workplaces with specific characteristics. Suggested types of work included support work, menial work (as less expectations), working with animals to ‘destress’ and drawing on special interests, such as a love of books. While support work, menial work and working with animals are not suitable for all autistic people, probably quite a lot of them could transform a particular interest into a possible career. Workplaces with specific characteristics included working with an ‘excellent manager’ (e.g. could email problems, reminded to take breaks) and ‘home-working’. Where participants have a manager, there are strong advantages in them being understanding and supportive, though it is not always easy to find out a prospective manager’s characteristics in advance. However, the value of trying to identify good employers and supervisor and management style as part of job search has been suggested in the literature (Hagner and Cooney, 2005).

5. Results: Barriers

This section answers our second research question on the barriers experienced by autistic people by discussing the barriers identified by participants. It may therefore seem rather negative. However, it is important to note that this is because it is purely about barriers and not intended to give a balanced perspective of the life experiences of autistic people.

5.1 Communication

Appropriate communication was an important issues for participants. Inappropriate communication was a particular problem and participants experienced a number of different communication barriers in accessing services. In particular, communication barriers were amongst the main problems leading to poor access to the health service and the difficulties experienced in obtaining benefits. The barriers experienced covered both direct and technology mediated communication.

Participants often felt pressurised to communicate in particular ways that were unsuitable for them. This included providing visual and emotional cues, and body language and tone of voice which were considered to be consistent with their words. In the employment context they frequently felt penalised for communications illustrating traits that are considered typical of autistic people, such as ‘honesty’, ‘bluntness’ and ‘lack of social awareness’.

Communication with receptionists could be difficult, for example, with some participants experiencing them as hostile, intrusive and requiring unnecessary personal information before allowing them to make an appointment. It should be noted that any requests for information can be very stressful for autistic people to negotiate. They can be experienced as gatekeeping barriers even if intended to support signposting to appropriate services.

This led to difficulties in making (medical) appointments and sometimes a failure to obtain one, as well as the inability to communicate effectively about their health and health conditions if they managed to make an appointment. A typical participant comment was: ‘Greater ease in obtaining appointments without having to explain detailed private information to receptionists.'   Hostile reactions could lead participants to give up on trying to get an appointment. For example, 'being met with a blunt or rude person on the phone makes things harder to articulate, can make me flustered. If I'm feeling close to a meltdown, can make me give up on accessing treatment altogether.’

Overcoming the communication and other barriers to obtaining an appointment was only the first step. Participants frequently also encountered further communication once they had accessed health and other services. Rather than listening to what they actually said, doctors and other professionals often (mis)interpreted it in terms of 'contradictory' body language. Typical participant comments included: ‘Making sure that my doctor understands that I will not respond the same way as other patients, and that if I tell him something verbally, he should not interpret my body language or tone as contradictory.' The converse of this was difficulties arising from expectations of being able to read other people's body language.   For instance, 'being unable to read body language' could act as a barrier in interviews.

A related issue was particular expectations of understanding and experiences of physical pain and lack of knowledge that at least some autistic people experience pain different from neurotypicals. A typical response was 'Train medical staff how to gather information with autism friendly questions that do not assume understanding/experience of concepts such as pain.' Otherwise, health conditions can be missed, as autistic people are not responding in the expected way about being in pain.

These communication barriers can have very serious consequences in preventing autistic people from having access to appropriate medical advice and treatment. They are therefore a contributory factor in the poor health, particularly mental health of many autistic people (NICE, 2012, 2017).

Lack of flexible communication options and lack of clear communication again raised problems with benefits. In this case, written as well as oral, communications presented barriers. The need for face to face interaction was a barrier for 41% and the need to complete forms for 42%. The demands of complicated forms with ambiguous questions which they did not know how to answer were frequently highlighted as a particular problem. There were repeated demands for 'clearer questions ... better understanding of how to phrase questions … including unspoken things'. Participants also commented on the need for a wider understanding of disability and the problems arising from assessment forms which were just for physically disabled claimants and did not include questions for autistic claimants and claimants with mental health issues and cognitive impairments.

Another issue was the need for assistance in completing the forms and problems and possibly very negative consequences when this was not available. 'When I had DLA [disability living allowance] forms were done for me, with PIP [personal independence payment] such people were no longer employed by NHS and I had to do it myself and lost it, no help on appeal either.' A related issue was lack of understanding of expectations and difficulties in completing the forms in 'the "right" way'.

Participants also experienced problems with forms when looking for employment. These included difficulties in preparing application forms and 'honesty on application forms'. This indicates a probable barrier due to a lack of knowledge of expectations. This parallels participants' experiences with accessing health services where there is an expectation of 'emoting' to confirm experiences of physical pain and mental distress. Lack of 'emoting' may then be interpreted by doctors and other medical professionals as the autistic personal not really being ill and therefore not needing advice and treatment. This is clearly a problem, particularly in view of research showing autistic people's poor health outcomes particularly in the area of mental health (NICE, 2012, 2017).

Communication and other barriers can lead to equally serious problems in accessing benefits. Participants were disadvantaged by ambiguous forms and communication expectations that were difficult or impossible for them to meet, with very serious consequences of not being able to jump over these hurdles. One participant expressed this contradiction very clearly. ‘Many forms are difficult to understand what is being asked for specifically and then the penalties for getting it wrong are frightening.’

In one case not being listened to and lack of assistance in completing forms resulted in a participant experiencing the horrendous situation of being accused of fraud, leading to a criminal investigation and finally being vindicated. This could have been avoided if they had been listened to and assisted in completing forms. ‘Being accused of fraud because, when I was struggling with a difficult council tax benefit form, I decided to pay the full council tax rather than fill in the form - the council then assumed that I had been claiming fraudulently up to that point as I hadn't told them i had had a change in income (because I hadn't had one)- rather than ask me about it they put me through a full criminal investigation only to discover that they owed me over £1000.’

Particular barriers were experienced by participants in employment interviews, an area where being able to meet communication expectations is very important. The barriers included lack of understanding interview expectations, bluntness and communication differences during interviews, lack of ‘social awareness in the interview’, and expectations of ‘social interaction as part of the interview process’. The expectation barrier is probably a result of implicit assumptions that job applicants should be familiar with (unwritten) expectations and a consequent lack of anywhere that participants can look them up.

Communication and social interaction continued to present barriers in employment. Specific issues included ‘networking expectations of the job’ not ‘fitting in’ and ‘relating to others’. Both forced socialising and social isolation were problems experienced by a majority of participants, 61% and 57% respectively, with some participants experiencing both.

There has been some discussion in the literature e.g. (Kurtz and Jordan, 2008) of the communication barriers experienced by autistic people. However, although solutions have been suggested, the perspective is that of individual communication and social interaction deficits rather than barriers resulting from the mismatch of neurotypical and autistic communication styles.

5.2 Expectations of Phone Use and Lack of Alternative Email/Online Communication

The majority of participants expressed a very strong preference for using email or online systems rather than phone. For many of them this was not just a preference and phone use was very difficult and stressful or even impossible. Typical comments included: ‘Anything without voice’, ‘I cannot make phone calls’, ‘I rarely answer phone’, ‘phone is always horrible’ or simply ‘NEVER phone'.

In addition to being stressful, phone calls were not necessarily useful, as participants could have difficulties understanding what was said. ‘If it's urgent enough then I might phone, but it's horribly stressful and I can hardly understand anything said to me over the phone which makes phoning nearly useless'. Although difficult, some participants were sometimes able to phone. For instance, 'I will phone if I am up to it on the day'. There were considerably more comments about the difficulties of phone use than explanations of what made phoning so difficult. However, one participant did specify that 'phone requires a lot of quick mental processing that I'm not good at'.

Control over how, when and where calls took place could make phoning easier. Typical comments included 'I like to use the telephone too but only once written details are available/confirmed' and 'they have to call me'. Unexpected phone calls could result in limited understanding of the call. 'If I'm called out the blue usually a lot is missed so it's better to be arranged in that case.' Psychological preparation was frequently important, for instance 'will phone if required to (I need an hour to work up to it and to be in a private space)' and 'have to psych myself up to call'.

As well as psychological preparation phone calls sometimes required practical preparation, for instance 'ideally write it down first so I don't get confused and miss all the points'. Some participants required recovery time due to the negative impact of phone calls. Typical comments show the very draining effect of using the phone. 'Phoning as a last resort for simply conversations in an utter emergency because it means no work for the rest of the day while I recover.' A related issue was the conditions under which phone calls could be made when an answer was required 'really fast'. These included knowing 'who and what to expect on the other end' and 'on good days'.

Uncertainty in phone arrangements could be very stressful. For instance, 'I do get GP phone appointments, but vague appointment time – e.g. "Dr will call anytime between 12:00 & 18:30" - is very stressful.' This can also make it difficult to organise other commitments and is probably also a problem for neurotypicals. The other person's manner could also make a difference. For instance, 'I don't mind phone calls as long as the person calling has a calm and pleasant voice'.

The requirement for phone use as a barrier to accessing benefits was mentioned by several participants. Comments included 'there is no reason I should be forced to make phone calls when I am disabled in a way that makes them intensely difficult for me.' Specific issues including 'anxiety about phone calls' and 'the need to complete a long form over the telephone'. In the case of long forms phone completion seems particularly unsuitable and likely to lead to errors. Adding this to the additional barriers experienced by autistic people, the requirement of form completion by phone could be considered to be also a deliberate attempt to prevent autistic people receiving the benefits they are entitled to, in line with the (Hampton, 2019).

In the case of diagnosis obtaining an appointment is just the first stage in the process. However, the need to phone for appointments eliminated some participants at this first stage in the diagnosis process. For instance, 'I cannot access a GP due to the requirement to phone for an appointment'.

Several participants appreciated online booking systems. For instance 'Online appointment booking for doctors and dentists are usually very easy to use'. In view of the comments above about the difficulties of using the phone for appointments and other types of ‘official’ communications, the lack of options for online and email communication, including appointment booking could be considered a barrier. This was expressed directly, for instance ‘there should be more options to do things online, as using the telephone can be difficult … and minimise in person contact to essential interactions only’. It was also expressed slightly more indirectly, for instance ‘more access to online booking NOT complex automated phone systems’. Some participants were actively discourage from using email and put under pressure to phone, ‘appointments/contact in general by mail, not telling my carer that I have to call myself’.

Benefits (appeals) were another area where barriers were experienced due to the lack of flexible communication options, including electronic written communication, web based services and the ability to sign up for benefits online without the need for face to face or telephone communication. These barriers were frequently expressed in terms of suggestions for improvement, such as ‘online chat facility', ‘electronic forms & communication … and a digital helper where you can enter all your info’ and ‘manage … cases online – submit evidence etc’.

5.3 Lack of Attention to Noise and Other Sensory issues

Poor sensory environments acted as a barrier in a variety of situations, including employment and accessing services. For instance, in the workplace 77% of participants experienced problems due to noise and 51% due to having to share an office.

Sensory needs not being met were one of the two main barriers to participants accessing the health service. Particular barriers included the lack of quiet waiting rooms with subdued lighting, with a typical comment ‘waiting room often busy n loud. Lots of bright light.' The resulting sensory overload frequently led to increased stress and the risk of meltdowns and being unable to communicate. Sensory overload could also affect participants' subsequent ability to communicate effectively or even at all with medical professionals. Typical comments included ‘I become overwhelmed by the sensory environment before I even see the doctor, so then I'm less able to communicate.’ and 'can struggle to communicate problems and stand up for what I think is required.'

The way many autistic people are made incapable of fully articulating their health concerns by the unfriendly sensory environment of the waiting room further adds to the factors which lead to autistic people’s poor access to the health system. There is also an element of the unfairness of first forcing autistic people to struggle through a very unfriendly sensory environment and then not even receiving the health care they require as a result of the consequent communication problems. Problems of not being listened to and misinterpreted have already been discussed in section 5.1..

In the case of one respondent, waiting room stress had a negative impact on their health, at least in the short term. ‘V noise sensitive, waiting rooms cause my B.P. to rise and already have hypertension so by the time I see doc it’s significantly higher than it was an hour before!’

The lack of accommodations to take account of sensory issues was a major barrier to obtaining benefits for many participants. Many of them mentioned the negative sensory environment of benefits offices and assessment centres. Concerns included ‘Noise levels in Jobcentre, WCA [work capability assessment] & PIP assessment centre’ and demands for a ‘better environment’, ‘quiet times’, ‘quiet space in job centres’, ‘quieter offices’ and ‘sensory sensitive rooms/areas at benefit offices’. Demands for ‘separate room’ and ‘more private rooms’ raise issues of privacy and dignity when applying for benefits as well as sensory issues. Other sensory issues in accessing benefits in addition to noise included the presence of a lot of people (31%), smells (31%) and lighting (25%).

The potential for sensory overload was again a problem in the buildings where diagnosis were carried out. Despite being used for a service aimed spec,,,,,,,,ifically at autistic people, they were frequently not chosen or designed to take account of their sensory needs and could be very inaccessible. A typical comment was ‘The only barriers for me were the assessment centre itself, which the assessor acknowledged and apologised for seemingly almost designed to massively overload anyone significantly on the spectrum’. The recognition by diagnosis personnel of poor sensory environments in diagnosis centres is not particularly useful if it does not lead to changes.

5.4 Stereotypes and Misunderstandings of Autistic People

Stereotypes and misunderstandings about autistic people are still very prevalent and can have a negative impact on their access to a wide range of services, as well as reasonable adjustments in the workplace.

This could lead to particular problems in accessing an autism diagnosis. For instance, participants had experienced difficulties in obtaining an autism diagnosis for a number of reasons. The following difficulties indicate stereotypical perceptions of autistic people: previously given another diagnosis than autism (30%)
told that I do not meet the right criteria to be autistic (18%) and being female (16%). For instance, there is no reason that a person cannot have more than one diagnosis. In one case a mental health diagnosis or label prevented further investigation, although a very high proportion of autistic people have mental health issues (NICE, 2012, 2017). ‘I was just treated as mentally ill all my life and people said I appeared to have some autistic traits but not one single professional took this further’. Being told they did not meet the right criteria again indicates stereotypes about how autistic people should present themselves to receive a diagnosis, which is further developed by some of the comments. Stereotypical perceptions that autistics are not female had affected 28% of female participants). Comments included ‘autism doesn’t really seem to be on the radar for quiet girls’.

Some of the participant comments indicate very unprofessional prejudgements and stereotypes. They included ‘was met by the doctor informing me that if I was an Aspie, I was the most well adjusted Aspie he’d ever met’. Participants also commented on the continuing influence of expectations of stereotypical behaviour: ‘the myths out there still have far too much influence - the whole, "you looked at me so you cant be autistic" you didn’t flap enough’. This type of stereotype would almost be humorous if it were not for the very real negative consequences on participants' lives. Positive experiences of diagnosis are presented in the good practice section.

85% of participants hid their autistic traits in at least some social interactions and two thirds imitated other people. Experiences of hiding autistic characteristics could make it difficult to obtain a diagnosis and necessary support. For instance. 'I think because I wasn't brought up being seen considered autistic, I had to conform more and learned to assimilate better. However, this was detrimental in other ways as my need for help, my struggles were hidden to an even greater extent.' Use of masking as a strategy is presented briefly in the strategy section and discussed in more detail in (Hersh et al., 2020a).

Further stereotypical perceptions about who is and is not 'entitled' to experience communication issues also acted as a barrier. For instance autistic people could be labelled as 'professionals', leading to assumptions that they could not possibly have communication barriers in a healthcare context. This was commented on in the context of the need for training: 'rigorous autistic training so people who are articulate but always reply I'm fine are questioned again and understand that professional autistic people have just as many barriers to accessing health as LD.'

Barriers also resulted from stereotypical assumptions about the behaviour of people in physical pain or mental distress. 'People don't believe how much physical pain or mental distress I am in because I don't emote in the typical way.'

Benefits personnel frequently had stereotypical perceptions of autistic people and expected them to present in a particular way. This led to participants feeling judged, their real difficulties being ignored and a total lack of understanding and support for 'day to day problems'. Typical comments included "You don't look autistic" I get this a lot, or "you seem fine." I feel judged, and it's upsetting, I feel a massive sense of injustice. Because I seem 'fine' doesn't mean that I haven't struggled. Every day is a challenge in striving to assimilate in a world that will never accommodate me.'

Workplace barriers resulted from employers stereotypes, 'fear and misunderstanding' of autistic people. This sometimes resulted in a lack of even the most basic courtesy in their treatment of autistic employees. For instance, one participant was asked if they 'hear voices in the head' and if they were 'dangerous'.

Whether due to ignorance or other factors, employers also show a reluctance to accommodate autistic people in the workplace. Employers frequently lack understanding of diversity and workplace inclusion: they are in practice ill-informed about autistic abilities and strengths and rely on textbook understandings of autism. For instance, disclosure met with lots of restrictions and being treated like a textbook example made everything worse'. In some instances, this has resulted in autistic people experiencing stigma, stereotyping and trauma in the workplace. This confirms the negative experiences in the workplace found in previous research (Müller et al., 2003).

A lack of understanding of the needs and stressors of autistic people resulted in participants being forced into difficult situations, further adding to their stress. There was also a lack of understanding of the importance of considering autistic people's interests in matching them to jobs and the possibility that with training they might be suitable for better paid jobs. Typical comments included ‘I got forced into a role play group to train for job situations and it got really angry and I had a breakdown. I get in trouble being late sometimes. Staff at Jobcentre really don't get that autistic people can't just be forced into the files others don't want . That we might be able to train for higher paid posts . For us it's really important to know what interests we have or could apply to gain truly successful employment we can stick. Given existing daily stressors it's unreasonable for them to add more with unreasonable expectations.’ This is in line with the literature on the importance of appropriate types of employment for autistic people e.g. (Baldwin et al., 2014). However, it is important that the job is matched to the specific autistic individual rather than stereotypical assumptions being made about suitable employment. Lorenz and colleagues (2016) provide a categorisation of barriers encountered and strategies used in the workplace. However, other than noting that their external help category is similar to the trusted/support person strategy presented briefly in section 4.1, they provide too little detail to compare their strategies to those identified here.

5.5 Negative Experiences, Disadvantageous and Discriminatory Treatment

Both the benefits system and the workplace were experienced as negative or even hostile environments by many of the participants. The benefits system made participants feel negative and that their claims were discouraged by benefits and other personnel. Particular barriers included ‘confusing’ experiences, ‘conflicting or illogical advice’, ‘hard to deal with’ and ‘disrespectful’ staff, ‘blatant lies’, ‘being judged’ and being ‘set up to fail’. Comments included ‘Job centre & DWP (department of work and pensions) staff who are hostile to all claimants and have zero understanding or empathy for difficulties faced by autistic people.' Difficulties in obtaining benefits and hostility were such that some participant(s) were left with the impression that 'bonuses'were being used to encourage benefits assessors to 'lie in their reports to ensure benefits are denied.’

Participants' experiences bear out those of other disabled people’s involvement in a deliberately hostile system intended to discourage claimants (Hampton, 2019).

Poor sensory environments, a lack of privacy, badly designed forms and high levels of anxiety make claiming benefits a difficult experience. As suggested by participants reduced frequency of assessment or lifetime awards as well as options for managing benefits online would reduce stress and anxiety. There is also a need for a change in attitudes to encouraging rather than discouraging claimants, publicising entitlements and benefit calculators in a clear format. Hostility should become a thing of the past. Forms should have clear, unambiguous questions and those for disabled applicants include questions aimed at a much wider range of disabled people, including autistic people.

The requirement to sign on for benefits regularly in person (62%) was a further barrier. It also illustrates hostile attitudes to autistic (and other) disabled people in terms of repeatedly requiring them to prove they are still disabled despite autism being a life-time condition. Typical comments were ‘Class autism as a lifelong disability (because it is) and stop requiring frequent reassessments.’ and ‘Not having yearly assessments, in which the assumption is that you've improved a lot.' The need to queue was noted as a barrier by 33% of participants. This clearly contributes to negative experiences and indicates the lack of priority given to resources for disabled and unemployed people. For many autistic people the problem probably also relates to barriers resulting from sensory overstimulation, stress, chaotic environments and the presence of large numbers of other people.

Benefits could be turned on and off repeatedly without reason, leading to insecurity. 'They were totally dishonest ... the system was crap and they'd stop benefits for non-reasons ... I had friends and enough money that I was not scared of being destitute but if I didn't have those resources it would have been seriously scarey.'

The workplace was also a difficult environment for autistic people and this is probably a significant contributory factor and their very low employment rates e.g. (Office for National Statistics, 2016). A comment indicative of this negative environment was that employers 'did not want people with 'problems'. Being made to feel a 'person with problems' rather than a useful employee who requires reasonable adjustments is in itself symptomatic of a major problem. Bullying or harassment were major problems experienced by half the participants. Participants commented on being 'intimidated', 'forced out', 'bullied' or 'being made redundant'.

UK legislation entitles disabled people to receive reasonable adjustments or adaptations to overcome the barriers and disadvantage they would otherwise experience in a variety of situations, including the workplace and access to services. However, the majority of participants in employment experienced barriers and difficulties in getting workplace reasonable adjustments implemented. Participants highlighted the lack of space in which to negotiate about reasonable adjustments even when working for an autistic company. 42% did not receive reasonable adjustments as they were not diagnosed when they started work and 35% did not receive them as they did not identify as autistic when employed.

The de facto need to disclose that they were autistic could act as barrier to obtaining reasonable adjustments. A number of participants had concerns about disclosure, both in the context of obtaining reasonable adjustments and more generally. The issues identified included feeling 'too many RAs [reasonable adjustments] needed' or 'being forced to disclose to avoid misinterpretation'. Problems in obtaining reasonable adjustments are in line with the literature on the lack of support in the workplace and the desire for additional support (Baldwin et al., 2014).

Disclosure could have negative consequences, including job loss, for instance 'disclosing has cost every job'. Several other participants felt that they could disclose as long as they did not ask for any reasonable adjustments out of fear of losing their jobs. However, one participant felt that disclosure had led to employment. Promotion was also an issue, with 38% noting not being promoted under negative employment experiences. Problems in obtaining promotion are one aspect of the underemployment identified in the literature for autistic people without an intellectual disability (Baldwin et al., 2014). It should be noted that people with intellectual disabilities are poorly represented in this study.

Several participants highlighted what they conceived to be disability discrimination

For instance, one participant has been fired for reporting their manager.

Organisational barriers often took the form of excessively demanding duties e.g. ‘being overloaded with tasks’ or duties which made demands which were difficult for the particular participants e.g. ‘time-keeping’ and ‘multi-tasking’, as well as ‘a lack of suitable jobs’. For example, one participant was offered evening hours only and another ‘unpredictable short work’. There was also a tendency to assign participant unpopular duties. For instance 45% had been assigned tasks no-one else wanted and 13% were not allowed to do particular tasks because they were autistic. Both of these are examples of discrimination.

Some participants also voiced the emotional costs of being employed in feeling ‘scapegoated and invisible’ or ‘isolated’ in the workplace and a lack of knowledge about Access to Work by employers and employess and that this sometimes resulted in discrimination. This included ‘being removed from my job when I disclosed being autistic’, ‘no reasonable adjustments’ because the employer did not put these in place DESPITE having a diagnosis’ and being repeatedly laid off without understanding why.’

5.6 Internal barriers

Participants also experienced what could be called internal barriers, including a lack of self-understanding, poor executive functioning and verbal articulation due to a lack of self-motivation. Participants also experienced burn-out, stress, exhaustion and distress, as well as anxiety, lacking confidence and assertiveness, low self-esteem and being nervous, particularly in employment. While these issues can be seen as internal, they may be at least in part a response to external circumstances. The previous sections presented the difficult and sometimes hostile environments many participants experienced in the workplace and when claiming benefits. In addition, many participants experienced barriers accessing health services and were often not listened to and what they said misinterpreted when visiting the doctor. There is also a mismatch between the behaviour, thinking etc of autistic people and the expectations of the rest of society. There is therefore a need for research on the role of these and other external factors in leading to internal barriers, as well as the changes in external factors and support required to prevent this happening.

To some extent, discussion of these barriers indicated a tendency for participants to blame themselves and consider themselves inadequate rather than also considering the role of barriers in the workplace and other external factors, such as lack of understanding and reasonable adjustments. The tendency to self-blame, which could be considered a further barrier, is shown strongly in comments from some participants about being ‘arrogant’ and ‘confrontational’ and these characteristics causing workplace difficulties. Anxiety was also a significant issue in the context of benefits. It cover both general anxiety and anxiety about being refused benefits, both experienced by over half the participants (56%).

Several participants had other disabilities and/or ill-health, such as repeated cycles of illness. However, at least some of these other conditions were a direct consequence of external barriers, such as the pressures participants experienced and the lengths they went to in order to succeed in the workplace. Examples included high levels of stress leading to an inability to perform tasks quickly, neglecting themselves and their own safety and reducing contacts. They also mentioned masking as frequently leading to ill-health.

Much of the discussion of barriers in the literature has been in the context of employment e.g. (Kurtz and Jordan, 2008) rather than a wide range of domains and focused on these and other internal barriers expressed as deficits.

5.7 Other Barriers

Participants experienced a number of others barriers, including those resulting from lack of information, lack of resources and lack of finance.

In the area of lack of information barriers included being unsure of (workplace) entitlements (62%) and not knowing how to obtain a diagnosis (28%). Lack of knowledge about reasonable adjustments was also a barrier, with autistic people commonly ‘not understanding rights’ to reasonable adjustments. ‘Unwritten rules, requests and expectations’ in the workplace also presented barriers for some participants. Where information is not (easily) available online participants could experience barriers finding out about things.

Lack of resources and facilities, probably resulting from the low priority given in reality to support autistic people, were found to be major barriers to obtaining a diagnosis. This led to long waiting list for diagnosis, experienced by 39% of participants, NHS diagnoses not being available (8%) or only being available for people with additional conditions (6%). It should be noted that these figures are in line with reports of long and increasing delays in obtaining a diagnosis (Lamb, 2018). Barriers in accessing a health service diagnosis were exacerbated by lack of money for a private diagnosis, with 18% indicating that being unable to pay for a private consultant was a barrier.

A further barrier was difficulties in obtaining a diagnosis referral from their doctor (26%). Typical comments included . ‘Its not the people diagnosing who need to change in my personal experience, it’s the people who refer you to the specialists’.

6. Results: Good Practice

Most of the reports of good practice were in relationship to diagnosis. They could be summarised as taking a person-centred and wholistic approach which considered all aspects of the person, had real understanding of their needs and made any necessary adaptations. However, this type of good practice is more widely relevant.

Such adjustments frequently related to sensory issues and/or encouraging the autistic person to feel as comfortable as possible from the start. However, both of these types of adjustment could also be considered to fit under the person-centred approach. Examples of adaptations for sensory issues included: ‘Diagnosing psychologist made sure the room was suitable for my sensory needs (e.g. away from noise, kept light off) and told me that I didn't have to remain seated if I didn't want to. This meant I could carry out repetitive behaviours that helped me stay calm. Gave me lots of time to process information and offered me multiple opportunities for breaks' and 'the assessor was very understanding when I explained eye contact is really unpleasant to me'.

Examples of being put at ease from the start included: 'Psychologist emailed that they would come out to the car park to meet me. That was really good'. Putting participants at ease could also include empathising with their experience: 'they made me feel at ease and they empathized with my life long difficulties in socialising, not liking big crowds, noise, smells etc'.

Another important factor was (diagnosis) professionals actually listening to what participants were saying and not assuming that as experts they knew everything. Examples of this included: 'It was the first time I felt like a doctor or psychiatrist actually understood what I was talking about and listened to me.' and 'the psychologist actually listened to me and didn't decide that I couldn't be autistic if I could look people in the eyes'.

The barriers resulting when autistic people are not listened to have already been discussed. One participant appreciated the opportunity to have a long and well organised assessment: 'It was worth it to have a 5 hour assessment with a senior and specialised clinical psychologist, which was a lovely process and very positively framed'.

Participants also appreciated questions being explained and rephrased in a more respectful way. 'They also made sure to explain the questions in the questionnaires a little more, and to rephrase them in a less demeaning/dehumanizing way which I think helped a lot'. Having an autistic psychistrist who was able to go beyond the limitations of traditional approaches was also appreciated. 'The psychiatrist who assessed me was autistic himself and knew how to think outside the DSM's biased literature.'

7. Conclusions

7.1 Overview

The results presented here were obtained from a questionnaire distributed by the autistic led An Auternative project to investigate the barriers and strategies which affect participation by autistic people. 223 useable responses were obtained. Some questions were not relevant to all participants, giving reduced response rates. In addition, small number of respondents did not answer all the questions. Where percentages are given they are based on the number of participants answering the question. The participants represented a wide section of the autistic community, though there was limited representation from older people and people with learning disabilities.

The results show both the great diversity and the commonality of autistic people's experiences. There were also a number of common themes across participants' experiences of interaction with different service providers and social interactions. In particular they experienced a number of different barriers and used a range of strategies to try to overcome them.

The contributions of this research include the following:

1. Identification of the barriers and strategies experienced by autistic people across social interaction, different services and job search and employment. Existing work has generally focused on one of these areas, frequently employment.
2. Taking a neurodiversity and social model perspective rooted in the experiences of autistic people rather than a deficit perspective.
3. Identifying a wide range of different strategies and barriers, as well as some good practice. The literature has tended to focus on the strategies of masking and imitation e.g. (Hull et al., 2017; Livingston et al., 2019) rather than trying to identify the full range of strategies used by autistic people. There has also been a lack of attention to both barriers and strategies.
4. Determining which strategies are context specific and which can be applied in a variety of contexts.
5. Using the results to determine detailed recommendations.

7.2 Strategies

Strategies used with different service providers and in social interactions included hiding autistic traits (and imitation), research and preparation, obtaining support from a ‘trusted’ person or organisation and technology (Hersh et al., 2019). Hiding autistic traits was used when trying to get a job and in social interactions. However, disclosing an autism diagnosis was also used when applying for a job, with some participants possibly using both strategies at different stages in the process. On the one hand, participants were generally positive about hiding autistic traits and imitation and found them effective. On the other, they could lead to exhaustion, (repeated mini) burn-outs and mental health issues, particularly when participants felt forced to use them. In addition, the habit of hiding autistic traits could be problematical when applying for a diagnosis, disability benefits or support.

Obtaining support from another person, who could be a family member, friend and/or professional, was a commonly used and generally successful strategy across services and in social situations. In some cases, including job search, support was provided by organisations. Support was provided in various ways, including making phone calls, providing assistance in completing forms, accompaniment to appointments and acting as an ‘interpreter’ for them. In some cases support from another person was essential in overcoming communication blockages that would otherwise occur and either prevent access to services (e.g. the requirement to phone for appointments) or prevent useful outcomes through communication misunderstandings. In the diagnosis context support also included putting pressure on medical professionals to obtain a referral and speed up obtaining a diagnosis appointment. Analogous forms of support could probably be used with other service providers. In social interactions the person provided support by going with them to social events, providing a known person to talk to at events, reducing anxiety and making them appear more ‘socially acceptable’. However, unlike most of the other strategies, this could not be used independently and the relative isolation of many autistic people meant that they did not always have contact with a suitable person.

Research and preparation were used by participants with both service providers and in social interaction. In the case of social interaction it took the form of learning small talk and preparing social scripts. Reasoning about situations could possibly also fit into this category. In preparation for referral and diagnosis many participants carried out extensive research about autism, listed the reasons why they thought they were autistic and wrote notes as a communication aid. In the job search and employment context participants researched prospective employers, practiced interview techniques and trained on managing in a work environment. However, it should be noted that the first two are approaches likely to be used by many nondisabled job seekers and participants did not indicate whether they carried out the research and practise in a particularly focused way. In the health service context some participants prepared a list of questions and, where permitted, emailed information about their condition to the doctor in advance. In benefits appeals nearly half the participants asked for information about the appeal and the questions in advance, presumably to allow them to prepare.

Technology was used very widely in all contexts. Although not always specifically stated, research and preparation presumably often involved the internet as a source of information and making notes on an electronic device. Many participants enjoyed using technology for socialising and preferred it to face-to-face interaction. Where possible, participants used email, texts and online booking systems to make appointments and email to send information about their condition to doctors in advance.

7.3 Barriers

Common barriers included sensory and communication issues, stereotypical assumptions and lack of understanding of the diversity of autistic people, and hostile environments. In particular, most service providers lacked quiet waiting rooms and frequently had sensorily overwhelming spaces which stressed participants and sometimes affected their ability to communicate.   Workplace noise was a problem for three quarters of the participants. In addition, there was little evidence that this need was understood or an attempt had been made to accommodate it. Noisy waiting rooms in doctors' surgeries were a particular problem. Noise and lack of private space was also a major issue in benefits offices and assessment centres. The situation in diagnosis centres was more mixed. There were both examples of reasonable good practice and centres which seemed designed to cause sensory overload. However, there was little mention of sensory issues as a barrier to social interaction. It would be useful to investigate further whether and, if so, the extent and ways in which sensory issues affect social interaction and whether there is any relationship between many participants’ preference for online and other technology mediated forms of socialising and sensory issues.

Common communication issues across service providers included preference for email and online text communication to phone, misunderstandings due to inappropriate expectations and not listening to what participants were saying and the difficulties in communicating where immediate responses were required. The lack of availability of email and online booking systems and insistence on the use of phone caused many participants problems. In the case of both the health service and benefits system problems resulted when what participants said was not taken at face value, but misinterpreted because participants did not ‘emote’ or ‘exaggerate’ or there seemed to be a mismatch between their facial expressions and word. In social interaction problems included lack of small talk and participants feeling that they had to prepare appropriate dialogue.

Stereotypical assumptions and lack of understanding of the diversity of autistic people were also problems. In the diagnosis and benefits context they were disadvantaged by assumptions they could not be autistic because they were too ‘well adjusted’ or did not ‘flap enough’. In employment this resulted in bullying and discrimination, not being allowed to do certain tasks and being assigned to undesirable ones and being asked if they ‘heard voices’ or were ‘dangerous’. In social interactions this led to the overwhelming majority of participants trying to hide they were autistic and frequently also trying to pretend to be someone else. Lack of understanding of autistic people and their diversity was a major factor in their needs rarely being met across all service providers.

Hostile environments were unfortunately typical of many service providers, though their manifestations were different. In employment hostility was experienced through disproportionate experiences of bullying and discrimination, including being assigned tasks no-one else wanted and not being allowed to do certain tasks due to being autistic, as well as experiences of forced socialisation and social isolation. In the context of benefits, the hostility was probably directed at all claimants, but may have been experienced more strongly by autistic people. It worked in combination with stereptypical perceptions about autistic people to make them feel they were being judged and found wanting. There were also instances of participants being forced into difficult and unsuitable situations, such as role play groups to train for job situations. Unnecessary demands for information by medical receptionists and not being listened to contributed to making doctors’ surgeries less than welcoming. The evidence for social interaction being experienced as a hostile environment is more indirect. It includes the facts that many participants preferred to socialise online. In addition, nearly 90% tried to hide their autistic traits and two thirds imitated other people. While participants generally found this a useful strategy, the fact that they need to apply it raises the questions of them not feeling acceptable as their real selves and whether this contributes to the low self-esteem and confidence of many autistic people.

8. Recommend**ations**

Consideration of the empirical survey data and the discussion in the conclusion section leads to the recommendations below. The categories of recommendations are ordered by a combination of generality and relevant point in the lifespan e.g. education before employment. It should also be noted that the ordering and numbering are not intended to indicate the relative importance or priorities of different recommendations.

8.1 Summary

1. Treating all autistic people with respect, empathy and acceptance and avoid assumptions.
2. Listening to what the autistic person is saying and do not reinterpret in the light of their body language or your assumptions.
3. Providing a variety of contact options, including email and online systems and accept different types of communication e.g. use of notes in meetings and appointments.
4. Providing sensorily quiet waiting and meeting rooms which have various lighting options, quiet decor and no smells or scents as well as no internal or external noise.
5. Using person-centred approaches with individuals seen as fully rounded people and adaptations tailored to individual needs.
6. Clearer and more widely available information in a variety of formats on the legal rights of autistic and other disabled people and the duties and responsibilities of service providers to them.

8.2 Communication

1. A variety of options with guaranteed fast response times to contact service providers and make appointments, including email, text, online booking and chat and phone. This should include a dedicated email address and phone line staffed by a person trained to work with autistic and other disabled people.
2. Provision of information and questions in advance.
3. The use of writing during meetings/appointments where requested.
4. Options to provide information to health and other service providers in advance of meetings/appointments where appropriate.
5. Increased use of technology for consultation.
6. The use of clear unambiguous language, including in forms.
7. The inclusion of questions relevant to autistic people, people with mental health issues etc in disability related forms.

8.3 Sensory issues

1. Provision of separate quiet areas or rooms for both waiting and participating in private (and other) activities, such as benefit interviews, as well as specific quiet times.
2. Email and/or text notification of delays to reduce waiting times.

8.4 Training

1. For service provider personnel and (potential) employers on the diversity of autistic people, the different ways in which they communicate and their diverse sensory accessibility requirements.

2. For service provider personnel and (potential) employers on the social model of disability and neurodiversity.
3. Information on workplace adjustments and Access to Work for potential employers.
4. Production of training materials to identify and counter common stereotypes
5. Assertiveness training and confidence building for autistic people.
6. For health and other service provider personnel on listening to what an autistic person is saying rather than how the say it, looking for visual or emotional cues or misinterpreting it based on perceived mismatches with body language etc.
7. For health and other service personnel on the differences in the (sensory) perceptions and experiences of sensory stimulation of autistic and non-autistic people.
8. For health professionals on the differences in understanding and experiences of pain between autistic and non-autistic people and that not emoting in a particular way or at all does not imply that autistic people are not experiencing pain and/or mental distress.
9. For receptionists on communicating with autistic people, including providing additional time and not asking for unnecessary information and repeating information if necessary.
10. For health service and other professional to overcome stereotypes, including the assumption that autistic people who appear 'professional' do not have communication and other problems.

8.5 Service Providers (General)

1. More welcoming, for instance through removal of gatekeeping and demands for information or other conditions before receptionists will book an appointment.
2. Encouragement of the development, implementation and monitoring of neurodiversity policies in conjunction with autistic and other neurodiverse people.
3. Quiet waiting rooms with appropriate lighting and no TVs or music.
4. Clear and unambiguous signage and instructions in buildings.
5. Support in finding a suitable advocate and automatic entitlement to the presence of an advocate during interactions with service providers and funding to cover the advocates’ expenses, if any.

8.6 Health Service

1. The option to book appointments by email and an online booking system.
2. The availability of regular health checks, similarly to what is available for people with learning difficulties.
3. Doctors asking structured questions to obtain information about health conditions rather than expecting the autistic person to report their symptoms
4. Telemedicine-type options for obtaining advice at a distance
5. A notification system for delays to enable autistic (and other) health service users to time their arrivals to avoid unnecessary waiting.
6. A tactile paging system to avoid the need for participants to look at screens or list for their names and, if it had sufficient range, might allow them to wait outside if that were quieter.

7. The option to email the reasons for the visit, a list of issues and/or symptoms to medical practitioners in advance of the appointment.

8.7 Benefits

1. Holistic approaches to providing meaningful support for autistic people.
2. Provision of a job by the government after a period e.g. six months of unemployment. The job would need to be matched to the individual's interests and skills and not at too low a level.
3. Employment of some autistic people in the benefits system, including to provide advice and training to other members of staff and ensure that the needs of autistic claimants are fully understood and that they are properly supported.
4. The provision of appropriate information about voluntary work, without any compulsion to engage in it or any suggestions that it will necessarily lead to paid employment.
5. Clear and unambiguous forms.
6. Assessment forms based on a wide understanding of disability and which questions for autistic claimants and claimants with hidden disabilities, mental health issues and cognitive impairments, drawn up in consultation with autistic people and members of the other groups.
7. Remove sign-on requirements for autistic amd other disabled people or providing the option to sign on online.

8.8 Diagnosis

1. Encourage, including through training, a person-centred approach with individuals seen as fully rounded people, adaptations made on an individual basis, as appropriate to the person, and neutral attitudes which avoid stereotypical perceptions of how autistic people behave.
2. Provision of additional resources and diagnosis facilities to significantly reduce waiting times.
3. Provision of a range of different options for post-diagnosis support with the options developed in conjunction with autistic people and including face to face support.
4. Provision of mentoring and specialist counselling to deal with pre-diagnosis issues.

8.9 Job search and employment

1. Structured meetings in the workplace with papers provided in advance and a minimum of oral reports.
2. Quiet offices with a choice of single offices or offices shared with a small number of other people
3. Easy access to reasonable adjustments which are implemented rapidly.
4. Provision of appropriate support tailored to the individual's needs.

5. Trade unions, unions of unemployed people, advocacy groups and disability rights groups becoming more knowledgeable about autistic people and more proactive in reaching out to them, as making links can be difficult for autistics.
6. Encouragement of autistic people to make links with the above organisations for more support options, including additional ‘trusted people’ and collective action where appropriate.
7. Appropriate work-place mentors.

8.10 Research topics (general)

1. Effectiveness of the different strategies used by autistic people and the individual, circumstantial and other factors that affect this.
2. Investigation of the details of the ways different strategies are used in different situations.
3. Investigation of the reasons individuals mask/camauflage, the factors that affect effectiveness of this strategy and the impacts on self-perception.
4. The role of external factors, including hostile environments, not being listened to and/or misinterpreted and the mismatch between societal expecations and autistic thinking and behaviour, in leading to internal barriers.
5. The changes in external factors and support required to prevent external factors contributing to, exacerbating or causing internal barriers, such as anxiety and low self-esteem.
6. Whether and, if so, the extent and ways in which sensory issues affect social interaction and whether there is any relationship between many participants’ preference for online and other technology mediated forms of socialising and sensory issues.
7. Investigation of how factors such as gender, class, ethnicity, age and other impairments affect the barriers autistic people experience and their strategies and approaches to decision making.

8.11 Technology research topics

1. Development of personal virtual games for online socialising
2. Improved technology systems with different communication options
3. Improved sensory monitoring and protection systems.
4. Improved and affordable noise cancelling headphones
5. Improved and less costly sound proofing
6. Reduced glare screens and glasses that reduce flickering
7. Technologies to support virtual meetings in interesting locations.
8. Multi-function apps to support different types of communication, (visual) schedules, calendar and maps
9. Stress monitoring and management systems.
10. Technologies to support interaction with medical professionals

References

Baldwin, S., Costley, D., & Warren, A. (2014). Employment activities and experiences of adults with high-functioning autism and Asperger's disorder. *Journal of Autism and Developmental Disorders*, *44*(10), 2440-2449.

Beardon, L., Martin, N., & Woolsey, I. (2009). What do students with Asperger syndrome or high functioning autism want at college and university?(in their own words). *Good Autism Practice (GAP)*, *10*(2), 35-43.

Benford, P., & Standen, P. J. (2011). The use of email - facilitated interviewing with higher functioning autistic people participating in a grounded theory study. International Journal of Social Research Methodology, 14(5), 353-368.

Braun,V., & Clarke,V. (2006) Using thematic analysis in psychology, Qualitative Research in Psychology, 3:2, 77-101, DOI: 10.1191/1478088706qp063oa

Davidson, J., & Orsini, M. (Eds.). (2013). *Worlds of autism: Across the spectrum of neurological difference*. U of Minnesota Press.

Goering, S. (2015). Rethinking disability: the social model of disability and chronic disease. *Current reviews in musculoskeletal medicine*, *8*(2), 134-138.

Hagner, D., & Cooney, B. F. (2005). "I do that for everybody": Supervising employees with autism. *Focus on Autism and Other Developmental Disabilities*, *20*(2), 91-97.

Hampton, J. (2019). Crippled: austerity and the demonization of disabled people. *Disability & Society*.

Hersh, M. Elley, S., Banks, Z., Mery, P., Dawson, M., Cowan, D. and Watson, C. (2019). Accessing Services and Social Interaction: Strategies Used by Autistic People. Neurodiversity reader. Milton, D., Murray, D., Martin, N., Ridout, S. and Mills, R. (eds.) (to appear).

Hillier, A., Campbell, H., Mastriani, K., Izzo, M.V., Kool-Tucker, A.K., Cherry, L., & Beversdorf, D.Q. (2007). Two-year evaluation of a vocational support program for adults on the autism spectrum. Career Development for Exceptional Individuals, 30(1), 35-47.

Hull, L., Petrides, K. V., Allison, C., Smith, P., Baron-Cohen, S., Lai, M. C., & Mandy, W. (2017). "Putting on My Best Normal": Social Camouflaging in Adults with Autism Spectrum Conditions. *Journal of Autism and Developmental Disorders*, 1-16.

Kenny, L., Hattersley, C., Molins, B., Buckley, C., Povey, C., & Pellicano, E. (2016). Which terms should be used to describe autism? Perspectives from the UK autism community. *Autism*, *20*(4), 442-462.

Knight, J. (2007). Spaced out and smiling, CSUN, https://spacedoutandsmiling.com/presentations/index.php?s=autism-technology-csun-2017%20:, accessed 4,9.2019

Kurtz, A., & Jordan, M. (2008). Supporting individuals with autism spectrum disorders: Quality employment practices. *The Institute Brief*, *25*, 1-12.

Lamb, N. (2018). The autism diagnosis crisis FoI responses briefing. All Party Parliamentary Group on Autism. https://www.autism.org.uk/get-involved/media-centre/news/2018-07-18-autism-diagnosis-postcode-lottery-exposed.aspx, assessed 13.12.2019.

Livingston, L. A., Shah, P., & Happé, F. (2019). Compensatory strategies below the behavioural surface in autism: a qualitative study. *The Lancet Psychiatry*, *6*(9), 766-777.

Lorenz, T., Frischling, C., Cuadros, R., & Heinitz, K. (2016). Autism and overcoming job barriers: Comparing job-related barriers and possible solutions in and outside of autism-specific employment. *PloS one*, *11*(1), e0147040.

Nicolaidis, C., Raymaker, D., McDonald, K., Dern, S., Boisclair, W. C., Ashkenazy, E., & Baggs, A. (2013). Comparison of healthcare experiences in autistic and non-autistic adults: a cross-sectional online survey facilitated by an academic-community partnership. Journal of general internal medicine, 28(6), 761–769. https://doi.org/10.1007/s11606-012-2262-7

Nicolaidis, C., Raymaker, D. M., Ashkenazy, E., McDonald, K. E., Dern, S., Baggs, A. E., … Boisclair, W. C. (2015). "Respect the way I need to communicate with you": Healthcare experiences of adults on the autism spectrum. Autism, 19(7), 824–831.

Office for National Statistics (2016) Dataset: A08: Labour market status of disabled people, 20 July 2016. https://www.ons.gov.uk/employmentandlabourmarket/peopleinwork/employmentandemployeetypes/datasets/labourmarketstatusofdisabledpeoplea08, accessed 5.4.2018

Oliver, M. (1995). *Understanding disability: From theory to practice*. Macmillan International Higher Education.

Piskorz-Orgorek, K., Ogorek, S., Cieslinska, A., & Kostyra, E. (2015), 'Autism in Poland in comparison to other countries". *Polish Annals of Medicine*, Vol. 22 No.1, pp. 35-40.

Shah, A., Frith, U. (1993). Why do Autistic Individuals Show Superior Performance on the Block Design Task?. J. Child Psychology and Psychiatry, 34(8), 1351-1364

Swain, J., French, S., & Cameron, C. (2003). *Controversial issues in a disabling society*. McGraw-Hill Education (UK).

Thomas, P., Gradwell, L. and Markham N. (1997). Defining impairment within the social model of disability. https://eu-browse.startpage.com/

Walsh, R. J., Krabbendam, L., Dewinter, J., & Begeer, S. (2018). Brief report: Gender identity differences in autistic adults: Associations with perceptual and socio-cognitive profiles. *Journal of autism and developmental disorders*, *48*(12), 4070-4078.

Wee, R.Y. (2017), "Countries with the Highest Rates of Autism", available at: http://www.worldatlas.com/articles/countries-with-the-highest-rates-of-autism.html. Accessed 1 May 2017.

World Health Organization. (1980). International classification of impairments, disabilities, and handicaps: a manual of classification relating to the consequences of disease, published in accordance with resolution WHA29. 35 of the Twenty-ninth World Health Assembly, May 1976.

World Health Organization. (2001). *International classification of functioning, disability and health: ICF*. Geneva: World Health Organization.

Acknowledgements

We would like to thank our funders Disability Research for Independent Living and Learning (DRILL) for their generous funding and Josie Isles for the support she has provided us throughout the project. We are also very grateful to the Advisory Board for all their advice and support. We would also like to thank all our autistic research participants - without you there would have been no project. We would like to thank

all the research and other support staff at Glasgow University - you have made our lives a lot easier.