

## **An Auternative Research Project: Strategies, Barriers, Good Practice and Recommendations – Results from Interviews**

Marion Hersh<sup>1a</sup>, Sharon Elley<sup>2b</sup>, Cal Watson<sup>1c</sup>, Panda Mery<sup>1</sup>, Michael Dawson<sup>1</sup> David Cowan<sup>1</sup>, Zygy Banks<sup>1</sup>

<sup>1</sup>Biomedical Engineering, Rankine Building, University of Glasgow, Glasgow G12 8LT, Scotland

<sup>2</sup>School of Sociology and Social Policy, University of Leeds, Leeds, LS2 9JT, England.

<sup>a</sup>marion.hersh@glasgow.ac.uk; <sup>b</sup>S.T.Elley@leeds.ac.uk;

<sup>c</sup>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 supported 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 interviews carried out by the project. Previous work has included a literature review, a questionnaire and a diary exercise. Participants were recruited from both those who had left contact details after completing the questionnaire and using publicity material, including a video which were widely distributed through organisations and the researchers' contacts. The video was also tweeted and put on the project website. Identification of underrepresented groups in the questionnaire responses helped us target this publicity material, including to try and recruit older people, non-verbal people, people with intellectual impairments, people from ethnic minorities and with sensory and/or physical impairments. Ethical approval was obtained from the University of Glasgow College of Science and Engineering Ethics Committee.

Our results are based on 21 interviews. The participants were reasonably diverse, though participants over 74, non-verbal people and those with cognitive impairments were not represented. Having an autistic interviewer helped to establish rapport with the participants and to encourage them to speak freely.

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 most commonly used strategies were a trusted or support person, masking and imitation and research, preparation and planning. Other strategies were using technology, analysis and reflection, using dialogue and managing disclosure, strengths and interests, managing energy and sensory issues, communication and social interaction and employment strategies. The trusted person could be a family member or friend or a professional. The trusted person had a variety of roles in supporting the autistic person to facilitate access and effective use of all services and in job search and the workplace. Masking included constantly monitoring and, if necessary correcting, behaviour and facial expressions, presenting yourself in a certain way, putting on a 'persona' or mask, forcing yourself to make eye contact and avoiding the use of adaptations. Research and preparation were used to improve access to diagnosis and other services and the chances of obtaining employment, as well as in social interaction. This included obtaining evidence to support diagnosis and medical visits, researching prospective employers and the use of notes, lists and (social) scripts. Further details about all the 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, social interaction barriers, expectations of phone use and lack of alternatives, lack of (appropriate) support and resources, stereotypes and lack of knowledge, noise and other sensory issues and energy drain, internal barriers, diagnosis and disclosure, barriers to obtaining benefits and job related barriers. Further details about all the barriers are provided in the body of the report.

Some good practice was identified, but was relatively sparse. It was generally based on seeing autistic people as complete individuals with strengths and weaknesses and as people rather than diagnoses. It included acceptance, clear explanations, meeting sensory needs and supporting skill development, with all support and adaptations provided without stigmatising the person or making them feel different. It frequently involved proactive approaches.

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 general recommendations, the recommendations covered a wide range of areas, including communication, overcoming stereotypes and misinformation, technology, leisure activities, all services, health services, benefits, diagnosis, support, education and support for students, preparation for entering employment and post-school education, employment, reasonable adjustments, and research.

## **1. Introduction**

The idea for the research project came out of a seminar organised by the Scottish Autism Research Group in 2016. Several autistic participants were concerned about the approaches presented, which focused on 'interventions'. In addition, the types of intervention indicated 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 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. Zygy 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 Zygy 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.

Previous research activities by the project team have included a literature review (Mery et al., 2018), questionnaires (Hersh et al., 2020ab) and a diary exercise. This report presents the results of the interviews we carried out. The final project activity is a questionnaire about the impacts of the project on the project team, members of the Advisory Board and research participants.

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 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. This focus on deficits has unfortunately affected researchers. 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.

As is discussed briefly in Hersh et. al., (2020) 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 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?

These questions recognise the importance of the barriers encountered by autistic people in leading to many and possibly most of the problems they experience. They also recognise that autistic people can show agency and take action to improve their lives through the use of strategies. However, this does not reduce the responsibility on society to make significant changes to remove or at least very significantly reduce these barriers. We make a number of recommendations for doing this both in this report and the report on our questionnaire (Hersh et al., 2020b).

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 is 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, with a focus on 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 (Muskat et al., 2015; Nikolaidis et al., 2015) and/or specific groups of autistic people, such as students (Beardon et al., 2008; Hastwell et al., 2017). 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 had limited

support in social and experienced difficulties situations 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). Specific 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; Nikolaidis 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).

The project's previous questionnaire-based research (Hersh et al. 2020ab) has identified wide range of barriers experienced and strategies used by autistic people. The most commonly used, but not the only strategies identified included a trusted or support person, masking and imitation, research and preparation and technology use. They were used with different service providers, in job search and employment and in social interaction. Although they were used effectively by many of the participants, these strategies also had drawbacks. The project identified a number of barriers, with the most common ones sensory and communication issues, stereotypical assumptions and lack of understanding of the diversity of autistic people and environments which were perceived as hostile.

However, there are still numerous unanswered or incompletely answered questions. This includes a more in-depth understanding of the factors which affect choice of strategy, details of how it is used and effectiveness. The interviews drew on the results of the questionnaires to investigate these issues.

## **2. Methodology**

### **2.1 Aims and previous project activities**

The project aims to investigate the two research questions presented towards the end of section 1. Previous project activities include a literature survey, a questionnaire to autistic people and a diary exercise completed by autistic people. The interviews drew on and followed up the results obtained in the questionnaire. However, unfortunately strict anonymity of the questionnaire results prevented direct investigation of issues arising from them when participants who had completed a questionnaire were interviewed.

### **2.2 Ethics**

Ethics were central to our research. We obtained initial overall approval for the project and then specific approval for the interviews 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 and data protection were assured. The practicalities of organising interviews means that total anonymity is not possible. However, each participant's identity was only known to the researcher(s) carrying out the interview and the analysis was carried out anonymously, using aliases. All participants were sent an information sheet explaining the research in advance and given the opportunity to ask questions both before the interviews were arranged, before the start and at the end of the interview.

We aimed to approach the interviews from a position of respect which acknowledged and communicated to participants the value of their time and the information we were sharing with them. We had initially intended to acknowledge this by giving participants small thank-you payments or vouchers. Unfortunately, we encountered practical barriers to doing this and, in the event, were only able to provide vouchers to two participants.

### **2.3 Recruitment of participants**

The questionnaire provided the option for participants to leave contact details and indicate whether they wished to be contacted for interviews and other follow-up research and/or sent the research results. To protect the anonymity of the questionnaire data these contact details were on a separate survey. All the participants who provided contact details were contacted to participate in interviews. A brief video clip was produced by one of the researchers to publicise the research. This was sent to several organisations and contacts of the researchers to distribute to their contacts to publicise the research. It was also tweeted and put on the project website.

Analysis of the questionnaire had indicated which sections of the autistic community were less well represented. This included older people, non-verbal people, people with intellectual impairments and, to a less extent people from ethnic minorities and with sensory and/or physical impairments. Therefore, approaches to recruiting a diverse sample focused on these groups. For instance, one of the researchers approached a group involving autistic people with intellectual impairments several times to try and organise interviews. The interview invitation and video highlighted our interest in recruiting members of these groups. However, shortness of time until the end of the project limited what we could do to ensure diversity.

### **2.4 Organisation of interviews**

A semi-structured approach was used, involving a list of topics or themes and following up issues raised by participants to investigate them in depth. How questions were formulated and their order depended on the participants and their

previous responses. The response format was open (Boeije, 2010). A semi-structured approach was chosen, as it provided both sufficient structure to ensure that all relevant topics were covered and sufficient flexibility to enable participants to raise issues and these issues to be covered. It also made it more likely that participants would present their own views and perspectives rather than reflecting back those of the researchers (Boeije, 2010).

Drawing up the list of themes/topics involved a multi-stage process starting with drawing up a list of themes arising from analysis of the questionnaires. This was followed by several iterations of modification and discussion. Further discussion occurred after each interview, leading to some further modifications.

A single research carried out all the interviews, except one where there were two researchers. All the interviews, except one email one, were carried out by phone or in person. Interview locations included the offices of the Glasgow researchers and offices of other organisations and were chosen based on convenience for participants and availability. Participants were asked to complete a personal data form in advance of the interview. This comprised a mixture of data requested by the funder and additional data of relevance to autistic people.

Interviews started with an open question about participants' lives and what they did or what had attracted them to the project. Subsequent questions investigated the themes and issues arising in more depth with a focus on strategies, barriers and good practice in order to answer the two research questions. The themes presented in an arbitrary order and noting that not all of them were relevant to all participants, included (i) job search and employment; (ii) benefits; (iii) access to mental and physical health services; (iv) disclosure of autism diagnosis/being autistic; (v) the impact of diagnosis; (vi) self-confidence and self-esteem. In a few cases questions were asked about information in the personal information sheet.

Two phone interviews took place in two sessions with a break between them. The other phone and face to face interviews used one session. In the email interview the participant completed the initial question in advance and answered further questions over three sessions.

All but two of the phone and face to face interviews were recorded on a digital recorder. The recordings were then transcribed verbatim. In two cases the participants refused permission for recording. In one of them the researcher typed the interview at the time and the participant spoke more slowly and provided breaks to facilitate this. The transcription was accurate enough to use quotations, but did not include repetitions and the full details of the researcher's questions. This was one of the two interviews which took place over two sessions, as providing time for typing extended the time required. In the other case the researcher took hand written notes which were subsequently typed up. The questions and answers from the email interview were combined in one document to provide the 'transcript' of this interview.

## **2.5 Analysis of the results**

Analysis was largely based on the transcripts. However, several of the researchers also listened to the recordings. The approach taken was based on thematic content analysis. Each interview was coded separately, in the majority of cases by two researchers, but in some cases by one. The nature of the research questions led to the coded sections of data being organised into strategies, barriers, good practice and recommendations rather than the more common determination of first order themes. Some coded data was included in more than one of these categories. In each of these categories second-order coding was used to organise data in the first three categories into groups, equivalent to higher level strategies, barriers and good practice.

Data was then combined across interviews. For the strategies, barriers and good practice this involved combination of data in existing categories, creation of new categories and moving data between categories. This resulted in a number of categories of strategies and barriers, frequently with a number of sub-categories. In addition it led to the identification of the main strategies used by and the main barriers affecting participants, as well as strategies and barriers relevant to smaller numbers. Unfortunately, good practice was generally based on isolated examples or similar good practice experienced by a small number of participants. Therefore, the distinction between main and other good practice was not particularly relevant.

Recommendations were added at both the second level coding and the combination of data across interviews stages. For instance, good practice led to recommendations to follow this practice more generally, for instance to generalise person-centred approaches. Barriers led to recommendations to overcome these barriers, for instance to increase the number of centres providing autism diagnosis for adults and reduce waiting times. Analysis of the recommendations therefore took place after combination of data from the different interviews. It involved second-level coding to identify themes and further organisation within these themes.

### **3. Overview of Participant Data**

22 interviews were carried out. However, one participant asked for their data to be withdrawn, leading to the audio file being deleted. The analysis is therefore based on 21 participants. To preserve anonymity aliases are used in the results in the subsequent sections other than for one participant who requested that her real name be used at the time of interview. One of the researchers confirmed that this was still the case shortly before the report was finalised.

A third (33%) of participants were female, 62% male and 5% non-binary. This is a considerably higher percentage of male participants than in the questionnaires, where there were more female participants, but a lower percentage than amongst diagnosed autistics in the general population. 5% had changed their gender from that assigned at birth and 5% were questioning this. 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).

There was a good age distribution in the range 20-24 to 65-74, but no participants were aged over 74. The low representation of older people may have been due to a

combination of 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 (90%) were white and 10% were black or mixed race. 95% had other impairments or a long term health condition and 86% had mental health issues, including anxiety and post traumatic stress disorder (PTSD). The percentage with mental health issues is particularly and worryingly high. This is in line with, but considerably higher than estimates of co-occurring mental health conditions in autistic people of about 70% (NICE, 2012, 2017). The difference may be due to the relatively small sample or underreporting in previous research.

43% of the participants were working class compared to 29% middle class and 5% other, with the remainder not providing this information. All participants used spoken language most of the time and there was no representation of non-verbal people. However, 62% used another form of communication at least some of the time, either together with speech or on its own.

## **4. 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.

### **4.1 Trusted or Support Person**

Similarly to the questionnaire responses, this was a common strategy, used by the overwhelming majority of participants, with those not currently using it suggesting ways in which they would like to. The responses also provide more depth and detail to those obtained from the questionnaire.

Both professionals and friends and family members were involved. Some types of support required particular expertise, making the use of a professional preferable unless a friend or family member had relevant expertise. For instance, Betamax had mentoring and study skills support to, amongst other things, 'help me interpret the language being used by my tutors' and 'help me to hone my critical thinking skills'. Jas was assisted in an unsolicited call to university admissions by their boyfriend's mother who was 'headteacher of a primary school' making a follow-up call on their behalf. 'I made the first call and they were a bit unsure [about admission], and then she made her call and ... they sounded much more kind of ready to do it. So I guess she was able to kind of work that'.

Otherwise, parents or other family members and partners seemed to be preferred if available and professionals or volunteers from organisations were used when they were not. For instance, Bill's partner is his main support 'I am really reliant on my

partner'. Clare is generally supported by her mother and Falcon and Brad by their fathers.

Most of the examples given by participants related to support in accessing and effectively using services, including mental and physical health, diagnosis and benefits, making complaints when things went wrong, in job search and in the workplace. There were only a few examples related to support in social interactions. These included Jim going to football with his mum 'every couple of weeks'. Her presence together with the fact he had been going to football for 25 years enabled him to feel 'safe' despite the noise and crowds, which in other situations were a major problem for him.

The trusted person had several different roles, depending on the situation, including providing moral support, advocacy, speaking or phoning for the person when they felt unable to, intervening in situations when they became difficult, and providing expert advice and support and practical support. Examples involving family and friends will be given first.

Alice generally took her wife to doctor's appointments with her, largely to relieve stress in the waiting room by talking to her. 'I try not to do doctor's appointments and stuff like that alone ... I get very stressed ... What helps more is ...to have someone with me to talk to, because I'm really not good at talking and listening ... So as long as I talk, I have something of a filter for what is talked around me.' Bill's partner accompanied him to the diagnosis. She provided both moral support which helped with anxiety and provided a different perspective on his experiences. 'Some of the questions I might not consider repetitive behaviour ... She would say yes it is... We would go on holiday to same place ... same B&B every year .... same meal.' Although not discussed as a strategy, doing things in the same way may be a supportivel approach for a number of autistic people. However, in the context of diagnosis, it is useful to reinterpret this as 'repetitive behaviour' which meets diagnostic criteria rather than as a 'strategy'.

Brad's father accompanied him to the doctor and benefits and would speak for him if he started 'shutting down' and it became 'really hard to talk ... He knows when to speak up for me, and how to. So yeah, he's a great help'. Jim's parents took over when communication about insurance for damage to his flat became impossible for him. 'I've actually had to pass him [person chasing the insurance] onto my parents ... I ask him clear questions and I don't get clear answers, and I've just decided to wash my hands of him because of just that kind of persistent lack of clarity which is really bugging me.'

Chris's mother accompanied him to a meeting with his support worker to explain his difficulties and the support he required. 'She tried to help get across some of the problems I'm having, which was really good for me because it sort of made the support worker take them seriously.' She also helped him communicate in medical appointments and be taken seriously: 'get my point across without just rambling, and I think having two people there makes someone take it more seriously and them not just thinking it's...like, how much is hypochondria?'

Some examples of support from organisations and professionals will now be given. Yumi received support in writing his CV from both parents and professionals and Leon from a charity. Falcon could get support from another worker in the charity shop where he worked by pressing a button if he felt 'uncomfortable with a particular customer or in a specific social situation ... someone will come out and help the social situation.' Support from professionals could also take the form of information about the adaptations required. For instance, 'the person who's supporting me from them has come in and had a chat with the directors of the company ... They were, kind of, just expecting to be told things about how to support me.' [Sophie]

Clare used a pre-meeting with the trusted person to clarify what was going to be happening and the support she wanted, 'discuss about okay, here's what's going to happen, asking things like is there anything you want me to talk about or anything I should say to this person before they come in' to try and make her 'feel more comfortable'. She used a post-meeting to 'talk about what just happened.' Although Clare did not mention this explicitly, post-meetings are probably useful in determining what, if any, further action will be necessary and how evaluating how well the support worked and what, if any, changes would be required in future. Izzy had preliminary discussions with an advocate supporting her in a meeting about mental health support and therapy. 'We agreed an agenda for the meeting and how we would make sure that I got my perspective across.'

Participants are again generally very positive about this strategy. However, several potential drawbacks were mentioned. They included the potential lack of availability of appropriate trusted people indicated in the questionnaire report. For instance Sam discussed the disadvantages of reduced availability of her friends. 'I have two friends who used to come to the tasting quite a lot ... and where they live now it's not as easy for them to get in, so they don't tend to be at the tastings any more. And having been used to being seen as part of a little group with [two friends] and now I'm back to being on my own ... that is quite hard because it's difficult to get into the conversations.' Bill's partner is an architect, 'always working, really important person at work ... never available, always busy', but will prioritise his needs when he asks: 'She will prioritise me if I say prioritise me.'

These examples indicate a further potential drawback not mentioned in the questionnaires, but which emerges explicitly in the interviews. While support from a trusted person was generally considered very useful, several participants commented on the need for self-reliance or expressed concerns about becoming dependent. Falcon considered that 'there's a line between being entirely independent and not being able to do what you want to do and being able to use people as support whilst also doing a thing for yourself'. Sam was worried about dependence and not being able to do things without another person. 'I would be wary of going about with other people too often in case I ended up dependant. I'm terrified of ending up in a situation where I just can't face at all leaving the house on my own'.

Most of the participants did not seem concerned about possible imbalances in a family or friendship relationship resulting from the friend or family member acting as a support person. For instance, Phil considered 'my family will be my biggest support. I can always go to them. ... my parents, more than anybody. ... I know

unconditionally that they'll always be there to help me.' However, Chris felt that sometimes needing help from his sister, for instance in contacting the plumber to install a new shower, unbalanced the relationship. 'But it feels like I'm never quite her equal now because I need help sometimes with these completely stupid things.' While Chris recognised that 'I give a lot back as well' in terms of supporting his mother and nephew, he seemed happier to receive support from his mother and that giving support to some family members did not even the balance with others. 'I suppose it's hard with family who don't need help from me because I never get to redeem myself.'

A related concern was retaining control of the situation, including being able to leave it whenever the participant wanted. For instance, Brad generally preferred to drive himself. 'I never go out, [Dad] always offers to pick me up whenever I want, if he can. I generally like to drive myself, 'cause it means if I need to leave, I can leave when I want, you know?'

The final potential drawback was the potential impact on the trusted person. Thus, Bill was careful what he told his partner about his involvement in post-diagnosis groups for autistic people which he had found quite difficult. 'I could talk a little bit to my partner what it was like [groups], but did not really want to burden her with horror stories ... not really fair on her'. Izzy noted the impact on her husband from supporting her 'when I got very agitated about the whole ... debacle' and 'such a look of relief on his face when I said, the advocate wants to bring someone else to the meeting with her', relieving him of the need to attend.

Organisations did not always provide promised support. For instance, after diagnosis a local autism organisation told Jim 'yeah, we can support you, we'll follow up'. However, he received an email about 18 months later saying 'oh, do you still want a mentor? We can put you onto a six-month waiting list'. He suspected this was probably due to lack of resources. The lack of examples of negative experiences of support from family members may be due to participants not asking them to act as a 'trusted person' when relationships were difficult (see section 5.8 for more details of problems with family). The most crucial factor in choosing a trusted person (or organisation) is probably determining that they can really be trusted, both to provide the necessary support and not to take advantage of the person in any way.

## **4.2 Masking, Imitation and Self-Monitoring**

Masking and imitation were used or had been used by a significant majority of participants. However, their views, particularly of masking and imitation, were more critical than those of the questionnaire participants. Several participants recognised that masking had helped them to be successful, for instance in obtaining jobs, being accepted onto university courses or participating in social interaction. However, many of them would have preferred not to mask, several had stopped or were trying to and the motivation was frequently negative, for instance to avoid bullying.

Masking was defined by Betamax as vigilance and control over himself combined with not using sensory objects: 'Watching what I say, watching how I say it; being

aware of my facial expressions; appearing interested; appearing to be still ...as in be formal ... being business-like when I ask questions or respond to questions. ... trying to minimise my use of adaptations that I would normally use to help me to be sensorially calm as well.' This is in line with the literature (Hull et al., 2017) on masking involving following strict rules on behaviour, in this case in social interaction, whereas Betamax is referring to work and study. Alice had a similar approach, particularly in groups (which she did not like) of constantly monitoring her behaviour and reactions to it. 'I'm ... constantly monitoring my behaviours, I'm constantly monitoring the reactions to my behaviour, was it right, did I talk too much, did I talk too fast, shouldn't I have laughed, wasn't that a joke, did she take that seriously what I meant as a joke. I'm constantly doing that in my mind.' Possibly unsurprisingly she found this 'a lot of work.'

Clare's approach was closer to playing a role. She noted that she was 'relatively good at' 'creat[ing] a persona or put[ting] on a mask'. However, she recognised that, although 'a lot of the techniques are similar in certain areas' the two were different and 'acting on stage, for example, is very different to somewhere like ordering a coffee at Starbucks, for an example.' Izzy also used a 'role play' approach, including consideration of costume and dialogue. 'I think a lot about the clothes I wear in the context. I think about topics for conversation. I think about who I'm having the conversation with.'

Jas's approach to imitation was 'very focused on my self-image'. She seemed to have two different approaches. One involved 'find[ing] someone that I admire for some reason and ... adopt[ing] one or two things about how they do things'. The other involved 'referencing to people with similar body types, people with similar colouring ... in terms of what colours and shapes and things look good'. Anne considered that imitation was a gendered issue. 'I think that especially women on the spectrum tend to mimic others.' This is in line with comments in the literature on autistic people, particularly women, using camouflaging and mimicry to mask social and communication barriers (Lai et al., 2017). However, there is a need for further research on gendered aspects of the use of masking and imitation, as the results and the literature do not provide sufficient information.

Izzy and Jim had both used masking successfully in interviews. For Jim it involved eye contact and presentation. 'In those kind of situations that seem a bit more formal and feel a bit more really important that I do make a big effort with eye contact. It's really hard for me to do. ... you have to kind of present yourself in a certain way, like you have to sit properly, you can't cross your legs ... You have to do your hair nice; you have to wear nice shoes. ... I put on this professional face, on all sorts of levels.' This parallels the literature on masking involving eye contact and behaviour (Hull et al., 2017) Izzy 'had quite a good track record of converting interviews in to job offers', but this had involved 'heavy masking'.

However, they found that continuing to mask in the workplace was not sustainable in the long-term. In Jim's case as he 'got a bit more comfortable or kind of the mask slips a little bit' 'the real me' became visible, making things 'maybe a little tricky and maybe a bit more difficult'. Izzy found that 'having masked in the interview and presented myself in a particular way, I was then almost obliged to maintain that'. Trying to do this made excessive demands on her. However, the strategies she

used to manage these demands, which were not sustainable in the long term, were related to managing sensory issues and will be discussed in section 4.9.

Betamax considered masking essential to get through his nursing course, including to be accepted on placements. 'And I mask in professional settings to get through the course at the moment. No two ways about it, if I didn't mask, people would think that I was unsafe to be on placement. ... I'd be seen as professionally unsuitable and potentially unwell, and I wouldn't be able to be on a nursing placement if I was my actual self currently. That's how bad things are.' He masked in other situations as a safety measure and to avoid ridicule. 'I try to be myself when I am in social spaces, such as shopping. But I am the subject of ridicule ... I am looked at, I am laughed at, I am followed, if I act naturally, ... it happens probably once a month. ... I mask for my personal safety.'

Chris had masked successfully for several years while working in sales which he was 'good at'. This involved 'conscious mirroring their body language, adjusting my vocabulary to fit into theirs ... a lot of kind of jokey masculine not quite joking humour ... constantly, kind of, processing what does this person want from this interaction, how do I provide that' and 'social processing hyperdrive'.

As a trans woman, Clare engaged in gender as well as autistic masking. She felt gendered cues did not come naturally to her and that this was more difficult for autistic people. 'And I think someone who is autistic it's kind of difficult'. As a result she 'researched a lot on, and I tried to copy and imitate that other person ... so in time it can hopefully become more natural to me. ... Not just necessarily the tone of your voice and the pitch of your voice. ... but also ... your word choices, the way you choose to word things. The clothing you wear, obviously, and how you wear the clothing. Her motivation was a mixture of avoiding transphobic violence and being outed and wanting to 'feel comfortable in my own clothing and in my own presentation, and ... the cues that I give to other people'.

Several participants noted the costs, particularly exhaustion, of masking and imitation, even when they were successful, and to a lesser extent mental health issues. For instance Jim often left an interview 'totally drained as I had to spend half an hour just talking and looking at people'. Clare found it exhausting and emotionally distressing. 'It does take a huge toll on me. I become tired very quickly as a result. I think it can almost be very emotional at times in terms of sometimes if I'm actively trying to not be autistic I do tend to have some of those PTSD like ... come back to me'. She attributed the tiredness to 'not really being myself'. Masking could also lead to feelings of loss of identity or confusion about what participants were really experiencing and feeling. Chris did not 'feel like a real person at work'. Sophie lost the ability to 'tell how I felt in most situations because I'd trained myself to respond by not having a response, by being quiet and nice and polite'.

Several participants had stopped masking or were trying to reduce or eliminate it. Chris had largely forgotten to mask 'especially having a few years out of work ... a lot of that stuff's really fallen away.' He also felt that his new autistic identity should negate the need for masking, though it might require smaller changes. 'I have this new kind of autistic identity, which in theory shouldn't require masking...or creating

an artificial persona and enacting it. It might require moderating certain behaviours and some ways of thinking in order to gel with society.'

Izzy now wanted other people to accept her communication style. 'I've spent nearly all of my life having to adjust to your style of communication. In the last few years that are left to me, I actually want to spend my time communicating with people who are prepared to come my way a bit. So that's how I feel, you know.' Sophie wanted to mask less and was realising that one of the barriers was anxiety about being herself. 'I'm slowly finding ways in which I don't need to mask as hard ... don't want to keep having to hide who and what I am. So, I'm going to, like, just throw it out there and then see what happens. ... I realised that the thing that I'm actually anxious about is being too much myself.'. This was a reaction to negative comments. 'I would realise that I'm getting really, really anxious about being myself just because I've been told so much that who I am isn't right or good enough'. Having an autism diagnosis was helping her deal with this and she was also finally allowing herself to experience her feelings and be upset and angry.

It has been suggested in the literature that the negative impacts of masking are a result of stereotypes, prejudice and discrimination (Hull et al., 2017). Our interviews indicate that these factors and particularly the resultant bullying are a significant factor in leading to masking. However, the reasons for its negative impacts are more complex and include identity confusion and tiredness from making eye contact and talking. As these authors indicate, this is one of the areas where further research is required.

### **4.3 Research, Preparation and Planning**

The related strategies of research and preparation were again used by the overwhelming majority of participants. However, planning was less popular. Research was used in a number of different areas, particularly diagnosis, medical conditions and benefits. Researching about autism could be triggered by a relative, friend or colleague being diagnosed. This could then lead to seeking a referral and diagnosis. For instance, Chris started researching autism after it was suggested for his nephew. 'But seven years ago my nephew was born ... autism was suggested for him and that's when I started kind of researching it heavily and ... realised how much I fit the picture for some aspects of Asperger's.... when I'd done this, kind of, reading about autism I started to recognise myself more seriously and I asked a psychiatrist to refer me.' Izzy started researching after receiving an email from a recently diagnosed colleague. 'A former university colleague emailed me and said, guess what, I've just got diagnosed as autistic, age 56. I thought, but we were so similar. ... And I read Samantha Craft, a few other women's accounts. I started googling everything I could find about how autism presents in women and thought, my goodness, this is it.'

Izzy and Alice had both researched medical treatments to ensure they received appropriate treatment and that doctors took them seriously and avoided mistakes. In Izzy's case this was a response to dissatisfaction with what she was being told: 'with my Dupuytren's disease, the medical view was ... come back and see us when your fingers are contracted. ... I'd got radiotherapy ... because I went behind my doctor's

back and found a research trial and got in'. Alice researched extensively 'just to be able to recognise when doctors were talking over my head, when they weren't taking me seriously, or when they were just dismissive, or when they made obvious mistakes. ... I just studied. I just went online and got books and just learned what I could to kind of guard myself against that.'

Several participants had researched benefits. Jas had additionally researched immigration law as part of finding out her rights to benefits as a person with 'settled status'. 'I'm having to print off the law and I'm having to print off the Government issued guidance and stuff like that and I've highlighted the bits that I'm talking about, and I'm trying to explain to people, look, it says here this is what you have to do.'

Sam kept a diary of difficult experiences, which could then be used to, for instance, support benefit claims. 'for years ... I keep examples, of evidence of some of the kind of glitches, some of the kind of situations I've mentioned, the negative ones.' Because the experiences were negative she had an 'absolute rule' of not looking back at the material or keeping the file open longer than necessary. This diary enabled Sam to provide very detailed information in her PIP (personal independence payment) and she considered this an important factor in its success. 'When I did my PIP claim as well as filling in the form and giving them pages of supplemental to all the questions, more than fit in the boxes, I also cross-referenced to specific examples. ... I think that was a big, a big contributing factor in why I got the best possible award of PIP'.

Several participants prepared notes, lists and scripts for doctors' visits. For instance, Bill prepared a script with a list of questions: 'I knew I would be anxious as soon as I went in the surgery ... I wrote myself a script. ... I just wrote down the questions I wanted.. it feels like there is one ailment per session but I had three or four questions building up. ... I would say I've got these worries about these things. Can you answer these questions one to ten. I would literally say what can you do to relieve my anxiety about these issues, like an interview.' To avoid having to provide explanations to the receptionist in the busy waiting room, Jim wrote down what he required. 'I don't want to have to explain to the receptionist that this is why I'm doing this ... it's quite a humiliating thing ... My way was to actually write down on a piece of paper and say ... I don't want to talk because I don't want these people in the waiting room to know what I'm doing ... and dispose of it as soon as ... you're done'

Betamax proposed that students find out different universities' reasonable adjustment records. 'Try and investigate from other students whether the university has been good in terms of reasonable adjustments previously. ... Even if it's not to do with your course, just to know what their track records like in general, because it gives an idea of the strength of the disability and support department, if not the tutors on your course.' This strategy could possibly be extended to workplaces. He also investigated and selected a particular Disabled Students' Allowance assessment centre rather than going to the nearest one. 'I went to a different university for my assessment which proved a good thing.'

Several participants researched firms they were applying to for jobs and/or prepared interview strategies. Izzy had strategies for trying to find out the interviewers' identities in advance in order to research them before an interview. 'I might ring up

and say, oh I'm bringing a handout, I just wondered how many people are on the panel because I want to make sure I have enough. And they'd say ... there's Professor Jones and so-and-so ... But then I go off and find out who Professor Jones was... it was my way of trying to tilt things to my advantage, that I would find out about people.' Brad and Yumi both researched the organisations they were applying to be able to 'say something that's non-generic' (Brad) and 'talk[ed] to them about their company' (Yumi). Anne 'made sure that I prepared the answer to as many questions as I could that I thought they may ask me.' Yumi practiced responding to 'likely interview questions'. Brad had also prepared a covering letter that he could adapt for different employers: 'a template for a covering letter that sort of will adjust based on the description of the job or the company.'

To try and overcome some of the difficulties associated with change Anne also prepared for her first few days in her first job. 'I think there's a few little things that I did to make my first few days better. Just things like taking a packed lunch so I wouldn't have to worry about the type of food that was there (I can be a bit picky) and wearing comfortable clothing (certain textures can agitate me). Planning my route to work beforehand.'

Several participants prepared for social interactions of different types. Bill preferred to investigate new groups before joining them: 'if I was going to go to a new exercise class, I would probably go and have a look, see what kind of people went and then go the next time ... I am not the kind of person who would just rock up.' Sam prepared for social interaction in various ways, including watching episodes of popular TV programmes. 'A TV programme everybody is talking about that I am not particularly interested in, but I might watch an episode just so that I'll know ... just enough to be able to maybe ask a few questions just for the sake of joining in and showing an interest in what other people are interested in.'

Several participants had prepared dialogue to use in different situations they were likely to encounter. For instance, Anne tried 'to plan out what I would say in terms of making conversation to the other new starters. I prepared a few 'small talk' type questions. ... I try and remember certain phrases or ideas to use in the future with other people to help me socialise with them'. She also planned dialogue for workplace meeting, including answers to small talk questions. 'For example, if I know that I need to go ask somebody for help at work then I try to plan how I will answer questions they may ask me such as 'how are you today?' and 'did you have a nice weekend?'

Both Anne and Izzy tried to remember something about other people they could use in conversation. Izzy tried to 'remember something that matters to the person and ask them about that. So, I did remember to thank him [boss] for recommending a gadget that I got for my dog which he told me about. But I find that quite hard work, trying to remember stuff about people and say it.' Anne used this information to have something she can use to 'ask them about' in the case of 'an awkward silence'.

Anne and Betamax engaged in detailed planning, particularly of their work and studies respectively and frequently using technology to support this. Anne: 'I plan my time out for the day so that I can get everything I want to done in that day. ... I just set up a certain amount of time each week for longer term projects and focus on

short term as my main focus each day. ... I tend to plan things out with diagrams and sketches which tends to help me a lot. ... online planning tools such as Trello ... I tend to plan out the bigger picture first and then focus on the details of each section.' They were both positive about planning, whereas Chris seemed less so and now plans less than he used to. On a recent visit to Glasgow 'everything was really clearly planned out up until arriving in Glasgow', but he just had a 'basic level plan' for getting across the city, whereas previously he 'would've had written down in a notebook, sort of, what time the Subway trains come and I'd have written myself directions or I may have even printed off the Google maps'. However, he felt that 'doing all that planning it doesn't actually make me less anxious'. This raises questions as to the value of planning if it does not reduce anxiety. A further question relates to the potential for autistic people with executive functioning issues to use planning with the support of a trusted person.

Participants did not directly mention any drawbacks of research and planning. Implicitly indicated drawbacks included the possibility of overcomplicating issues. For instance, Bill considered that 'getting the diagnosis is like having to do a PhD or something. You have to go away and do loads of work. ... some of the ... stuff I find really hard. Have to learn about the Bayesian brain.' A further implicitly indicated drawback was producing a list of issues which does not fit in the available appointment time. For instance, Chris 'tried making a list of things I want to talk to the GP about ... but my list was, like, 13 points long. And I can understand in retrospect that turning up for a ten-minute appointment with a 13-point list, to the GP looks like... I was kind of hoping ... the GP would help me really figure out actually which of these things is bad.' However, the problem is less with the strategy than a combination of too short appointment times and difficulties in prioritising. A further implicit difficulty relates to the time involved, though it could be enjoyable. For instance, Izzy 'love[d] researching stuff'. In addition the success of these strategies is likely to be affected to some extent by the ease of availability of information and participants' abilities in finding and interpreting it.

#### **4.4 Using technology**

Many participants used and were positive about a number of different technologies. The most frequent mentions were of commonly used technologies, such as email, internet, Whatsapp and Facebook. Several participants preferred email or other written communication to phoning and in some case also to speaking, though Jim preferred either email or face to face contact to phone. Brad used texting, Whatsapp and Facebook Messenger extensively. He found written communication easier than spoken, particularly for explaining his feelings or why he was upset about something. He considered this was because in spoken conversation people tended to interrupt before he had explained fully. 'I think a lot of that is because ... it takes me a few sentences to make my point, and people tend to interrupt the second something affects them emotionally, rather than hearing me out.'

Leon preferred typing as he found it less 'mentally challenging' and any hostility less painful. 'With phones, you're listening ... involves more concentration and ... it's more tiring. ... And also, if you're on the receiving end of hostility, especially when you hear it verbal, ... it's more gut wrenching.' Alice felt that using email led to better

understanding than phone. 'I cannot collect and ... get my thoughts into order when I call, as I can do while writing and rewriting an email, and just making it perfect before I send it. ... I just... say what's on my mind and ... I can't correct it before it reaches the other side. ... I understand others better because I can re-read it ...in the first reading, I just get the usual context and then I try to read between the lines.'

Sam preferred email for similar reasons, as it provided 'time to think, having time ... to choose how to word things'. She also liked the fact that email and text messages could be read at a 'convenient' time for the recipient. However, she was experiencing difficulties with the small size of the phone keypad, so preferred her laptop or iPad for longer messages and used a small Bluetooth keyboard with her phone when she was away. Dinah preferred to engage with people making 'prejudicial judgements' in writing, whether on screen or on paper, than in person. 'I worry that if I try and engage with passion, then it will be interpreted as anger'.

Clare had been using Skype and Facebook and more recently Discord 'to talk a lot' to maintain her long distance relationship with a partner in the USA and Sam used Facebook, text and email to keep in touch with friends who had started as penpals. Clare and her partner used the technology 'to just talk about how our days are and we just try and sort of have a very loose conversation where any of us can just reply whenever we want.' This helped overcome the time difference and their different schedules. Brad and George both used technology to socialise. Brad played online computer games with a small group of friends and they talked using Skype. He considered 'that's when I'm at my most comfortable socialising'. Dinah did jigsaws on her iPad, 'which, actually, is fantastic, you can't lose the pieces.' This discussion parallels the literature on the use of apps by autistic people to support social interaction and computer mediated communication and overcome some of the barriers they would otherwise experience (Hull et al., 2017).

Participants also used online chat for contact with services, online ordering for shopping and takeaways and the internet to obtain a wide range of information, including to plan journeys. Both Chris and Sophie used the internet to maintain contact with other autistics. Chris used Facebook and mailing lists to obtain advice from other autistics, for instance on resolving sleeping problems and buying a winter coat. Yumi intended to use the internet for marketing videos in a small business he hoped to set up.

However, this preference for technology mediated written communication was by no means universal. For instance, Brad preferred phone or audio Skype to face to face or audiovisual communication, as he found it easier to process audio than combined audio and visual signals and experienced difficulties in processing visual signals. 'I would even think that I could participate in a conversation with more people, if it's just over the phone or by Skype, than if it was an actual face to face encounter, because then there's all the visual data my brain can't handle.' Lola preferred to use skype with video in only one direction, as this gave him more control and allowed him to exit from the conversation. 'I can see his face or her face, but they can't see me ... I can go.'

Specialised software was also used, mainly by two participants. Anne used online planning tools including Trello, to help her 'be more creative in planning my time'.

Betamax used Claroread's screen tinting software and its text-to-speech function to read research papers, as he found this 'more accessible to me than trying to read through the print, even if I do enlarge it.' He also found it easier to understand and work with papers with statistics or multiple perspectives that he had listened to. 'If there are lots of statistics or lots of viewpoints, I tend to find that I can work with them better, I can manipulate them better if I've heard them, rather than I try to read them all.' He used mindmapping software to help him 'literally structure my ideas visually from the question' and was proposing to use it to plan an invited speech. He had also 'summarised all of my findings for ... my recent life discoveries on a mind map, which has been amazingly useful for me' and which could be printed on A3 paper.

There was also some use of specialised hardware. Alice had been using a wheelchair for about 10 years and considered she had 'adapted to that quite well'. Betamax had Irlen lenses 'to help with the lighting ... 'because the artificial lights are really hard work' He used a livescribe pen 'to link what is written with the recorded audio'. Anne, Jim and Alice had noise cancelling headphones and Bill had applied to Access to Work for them. Jim had obtained his from his work budget and was particularly satisfied with them. 'I've got a colleague who has a really squeaky chair ... and if I have headphones on with no music playing, I can still talk to her, but I don't have to listen to the chair. ... I would say that the noise cancelling headphones have actually made a bigger difference than I think anything could really.'

#### **4.5 Analysis and Reflection**

Several participants engaged in analysis and reflection and a few explicitly used logic. However, the overall view was that these strategies could be useful in some circumstances, but that many participants had a tendency to overthink and overanalyse, though this could also sometimes be useful.

Sophie generally found analysis useful, including to determine if you would be able to deal with any possible negative consequences of a particular action. 'Can I deal with all of the consequences that come from this thing if they go badly. I need to constantly assess all of this because I cannot afford to make a mistake in this, because when I make a mistake, everything falls apart.' She also used step by step analysis to work out strategies. 'I can't be part of this hobby because I get terrified anytime I'm in it because of things that have happened. ... well what if I make this hobby something I can do by myself and then maybe eventually I'll feel like I'm more confident being back in that context.' However, she found the process of constantly having to come up with 'potential solutions ... on top of everything else ... overwhelming sometimes'. Having decided that 'making romantic decisions based on the heart was a folly in my case'. Izzy had successfully used a 'spreadsheet' to help her choose her current partner. She had produced the equivalent of a 'job spec/person spec', followed by 'analysing people against this'.

Alice 'constantly' used logic, but recognised its limits in complex emotional and social situations, as they were 'not predictable' and did not follow 'absolute logic and rules'. She noted that 'I still sit beside my wife when she's crying, why are you crying, it doesn't make sense', but did not seem to have applied analysis and logic to try and work out why her wife was crying. Anne and Chris reflected on conversations and

interactions, though Chris did so less now than in the past. They found this was sometimes helpful and could lead to them dealing with the situation better in the future. 'The next time I have a similar situation I approach this better' (Anne). Chris could find it helpful to realise that his anxiety was 'irrational'. They both noted a tendency to 'overthink' or 'overanalyse'.

Anne found that overanalysis could make her 'more upset' and Chris found that overthinking 'gets in the way of what I am trying to do' and that 'I waste so much energy thinking about it [doing things]'. Jim considered that he needed to overthink to function and that 'if you took that away from me, I kind of don't really function anymore. I can't be impulsive, that's completely unnatural to me, because I can't be impulsive or spontaneous.' He considered that overthinking had both advantages and disadvantages. On the positive side it made him 'not prone to rush judgements ... less prone to ... extreme thinking' and 'very conscientious'. On the negative side it impeded 'gett[ing] things done' and was not useful for 'general everyday stuff' like deciding an appropriate type of answer to colleagues asking 'how was it?' about a recent holiday.

#### **4.6 Using Diagnosis and Managing Disclosure**

Obtaining a diagnosis was not always easy or straightforward and several participants had needed to use strategies to obtain one. The main problems were the lack or extreme scarcity of facilities for diagnosing adults in the particular area and difficulties of various types in obtaining a doctor's referral for diagnosis. Jas had to get a private diagnosis as there were 'practically no NHS services ... that would diagnose you ... if you were over 18' in their area. This involved saving up over several years, as well as obtaining a contribution from the university they were studying through their support for disabled students and an existing registration as a disabled student with other diagnoses.

Diva and Jim both successfully referred themselves for diagnosis, Diva because his doctor said he was not autistic and Jim because he 'just couldn't get in to see him [doctor]'. Jim contacted the Autistic Diagnostic Service directly, whereas Diva paid for a diagnosis in another service area. Izzy decided 'I'm not even going to bother to contact the GP', as she had 'very little energy' and felt 'they're just going to dismiss me again 'cause they dismissed everything else'. She therefore contacted a specialist centre but got turned away as she was from 'outside the area'. She then found a not for profit community interest company that provided autism diagnoses. Anne had to find a solution when the professional diagnosing her wanted her to bring her parents with her, as she no longer spoke to them.

All the participants who commented on the impact of having being diagnosed were overall very positive and glad they had obtained a diagnosis. Diagnosis was both a strategy with positive outcomes and something participants used to increase self-understanding, make sense of things, improve self-esteem and self-worth, provide explanations to family and friends and obtain reasonable adjustments.

Understanding themselves and their issues better was the most frequently expressed benefit. For Leon 'it just answered so many questions' and Jim had 'an

understanding that kind of almost instantly spoke to me. I realised, oh, wow, okay, that is my experience and that's maybe why I struggle with this thing that makes me feel bad.' It helped Izzy understand why she changed jobs so frequently and 'wasn't able to sustain myself in any particular role for any length of time.' Alice used diagnosis to understand and explain to her carers why she needed a particular routine and became very stressed otherwise. 'And I had a lot of ... very, very difficult, long discussions about why I needed things to happen in a certain way ... It was not taken seriously because people did not see any real reason behind that ... And since the diagnosis, I'm like ... I'm autistic and I need a certain routine, ... a certain way of doing things or else I'm stressed out ... you're needing longer ... and I will have two or three days afterwards to recover ... And that changed things.' Anne used it to understand sensory overload and 'limit the effects by avoiding flashing lights and wearing headphones more often.' George used it to improve his understanding of how he communicated with neurotypical people and this had made him more 'relaxed'. 'It's changed how I feel about any difficulties ... in communicating with neurotypical people ... But it's maybe easier for me to contextualise what's going on in how I'm perceiving their behaviour and my interactions with them.'

Several participants used this increased understanding to improve their self-esteem and challenge their own or others' negative narratives. Chris used it to help 'erase this ... narrative I had for myself beforehand ... that I wasn't, like, a real person ... I used to just call myself, like, a shit person and that was my mental self-identification.' Leon was using it to maintain his self-esteem when he left a job. 'Self-esteem would hit rock bottom when I left a job, ran away ... but now it's on an even keel.' Alice obtained 'peace of mind and more importantly ... self-respect'. She was able to challenge the narrative she 'been trained to believe' that she was 'just broken and difficult and bad' by recognising 'that there was a very logical, very sound and scientifically reasoned answer to why I was the way I was'.

Jas was able to use the diagnosis to improve relations with their mother, at least to some extent. 'One positive impact of it was I went to my mum and I told her about it and I explained what it was and sent her some resources. ... And she actually responded with, like, such regret... She apologised for all the physical abuse.' Alice used the diagnosis to increase her wife's understanding of her and improve their relationship. 'I can talk about the books I read with her. ... we've been a couple of 13 years now, and I got the diagnosis last May. ... she really started to understand me on a level she never had understood me before. ... And a lot of stuff that had been difficult in our relationship that had caused arguments, that had caused strife and pain, were pretty much resolved by understanding my autism.'

While most participants were positive about diagnosis, there were a few potential drawbacks. Izzy noted that 'the fact the diagnostic process deliberately exposes deficits, weaknesses, things I wasn't good at was quite distressing and undermining.' While there is a need for diagnosis to investigate difficulties, it can be demoralising if the autistic person, who may already be feeling vulnerable, is made to feel that they only have weaknesses and not strengths as well. Izzy overcame this and put the diagnosis into perspective using a strategy of actively recognising that she 'was very capable and intelligent and sensitive and empathetic and that this diagnosis was just looking at very specific things from a very particular angle.' Dinah was concerned by the possibility of inappropriate communication of the

diagnosis, leading to a negative impact. 'The way the diagnosis is delivered by these very powerful people, it can make a very significant difference to how that person feels for the rest of their life. Jim had become 'much more cautious since being diagnosed' and went out 'a lot less now'. He was ambivalent about this, feeling both 'very comfortable not doing that' and concerned that he was 'missing out on stuff' and that 'friends can be a bit annoyed with me that I don't want to expand the social circle beyond them.' He had not yet worked out a strategy to resolve this.

Most participants' disclosure strategies were based on management of some sort, for instance on a need to know basis and/or to trusted friends. No participants stated they had strategies based on total non-disclosure. For instance, Anne and Sam disclosed on a 'need-to-know' basis. Anne had only told two people at work, her manager and her manager's manager. Sam had told a few close friends, her office manager and team leader in her previous employment. Her strategy in disclosing to friends was to make it clear she was still the same person. 'I made it clear ... it's news but ...it doesn't mean I've changed, I've always had this. I've just only just found out.' At work her strategy was providing necessary and relevant information - 'giving them information that they needed to be able to supervise or line manage me in a constructive way'.

Jim had disclosed at work, to his circle of six friends and his immediate family. His decision to disclose at work was based on 'damage limitation' motivated by bad experiences in previous jobs which were probably due to misunderstandings resulting from autistic differences and a lack of support. 'I pretty well always had fallings out with people to things that I would probably attribute to autistic traits . ... in the previous job, it was two years of kind of pure misery, at not understanding what was really going on'. He hope that disclosure would lead to 'a bit more kindness and a bit more compassion' in the case of any future difficulties.

Sophie had disclosed in the application for her current job and in any future jobs would prioritise getting her needs met over being seen as 'the best kind of employee'. She also disclosed when she made new friends. Jim had not disclosed to wider family and Sophie to any family due to feelings that they would not understand. Jim considered 'I don't think they'd get it. They don't know the history of the mental health problem either. .... why I felt different and or why that made me feel bad.' Sophie thought that 'they dealt really badly with me talking about dealing with mental illness ... And I don't want to deal with their anxiety about what my existence means for me'.

Participants were less likely to disclose to people with whom they had minimal contact. Phil considered 'it didn't feel always appropriate' when he was delivering one-hour music sessions to people with dementia and in end of life care. However, he would be open to having conversations with people where a 'to and fro conversation about it' is possible. Jim had not disclosed to casual acquaintances and considered doing so pointless. 'If you're on kind of terms with people and it's only platitude and ... how are you doing, kind of thing ... there's very little point to telling this kind of really personal stuff about you, because, ultimately, what is it going to do?'

Brad seemed keen to disclose in all circumstances and found this liberating. 'I've had this big, unknown thing that I've had to keep a secret for so long, and not only doesn't it have to be a secret now, but it shouldn't be.' However, he was now getting fewer job interviews. 'Now I have a diagnosis and I'm being honest, like I'm getting less job interview offers, which is a bit sad.'

Both Brad and Sophie used disclosure as a test of attitudes, Brad in the workplace and Sophie in a variety of contexts. 'With jobs ... as soon as possible really. Because it's a good sort of litmus test. If they're the kind of people who don't even want to have me in the building for an interview because of it, then that's the kind of place I don't want to work, so the sooner the better really.' Sophie disclosed as disabled more frequently than as autistic. 'I tend to use the label 'disabled' with a lot of people, but I use the word 'autistic' less often. ... it's, kind of ...like, this is the first test of, can you deal with people being disabled around you, because if the answer is no, I don't want to give you anything that is more specific that you could try and use against me.'

Disclosure was generally a pre-condition of receiving reasonable adjustments, rather than the full strategy for obtaining them. Anne had received support at work as a result of disclosure to two managers but was unsure whether her employer had any relevant policies. 'None that I am aware of, they did not mention any to me when I disclosed my ASD. I'm not entirely sure they actually know that ASD is classed as a disability.' However, disclosure did not necessarily lead to support, as Leon found when volunteering. 'I've not been protected in any way.' He had still not determined the best approach to disclosure. On the one hand he generally considered 'honesty ... the best policy' and had been advised to 'always disclose' by a charity. On the other he was concerned 'if something goes...' and that 'some people, you know, maybe do harbour that little bit of prejudice'.

The strategy used by participants and discussed here was managed disclosure rather than disclosure in all cases. This allowed them to weigh up the potential risks and benefits and make a decision in each individual case. However, reactions to disclosure were not always positive. For instance, Bill 'wanted to tell my friends I'd got this diagnosis', but 'experienced some really negative experience coming out to friends'.

#### **4.7 Strengths and Interests**

Participants used their strengths and interests in a variety of ways, including in employment, leisure and social activities and relaxation and de-stressing. For instance, Phil used music, one of his main interests and strengths, in all these ways. He worked as a freelance musician, providing one-hour music sessions, including in care homes. Music had increased his self-confidence and also given him the 'confidence to go out and meet people' and 'a lot of social tools that I didn't have before'. it also helped him relax and 'to bring back calm and control when I'm feeling a bit agitated and anxious'. Phil recommended looking for jobs which combined strengths with enjoyment. 'It's what do you enjoy and what are you good at, and it's really just thinking about those two things.' He seemed to have achieved this as a freelance musician.

Leon loved languages and travel. He had used his language interests and skills on a freelance basis translating websites and also for a while working for the local council interpreting service 'where I assisted asylum seekers at, you know, GP surgeries and dental practices. So I used my French there'. He had also started attending a Spanish conversation group 'cause I've got this interest in languages and it keeps the Spanish up'. His strong interest in languages helped him deal with meeting new people. 'Its quite daunting meeting new people ... because it's something I'm really passionate about, sometimes the anxiety can ease off.' He also felt that engaging in pleasurable activities could contribute to improving self-esteem and that doing nothing had the opposite effect. 'I'm going to Spain middle of this month. So seeing, ... nice places and...and ... doing things that you like doing. Sometimes a lot of time on my own, but I'm going with my father. So we'll have a really good time and...so doing things that you have...pleasure will increase your self-esteem. But if you do nothing and just vegetate, that's going to lower your self-esteem.'

Several participants used their interests to socialise and relax. George found his interests in buses and Dr Who were shared by other autistic people and that, for instance, he had 'been at Doctor Who meet ups that were more than 50 per cent on the spectrum'. Anne's choice of her current employment, a small information technology firm, was partially motivated by the fact that employees were allowed to bring their dogs into work. She visited 'one of the dogs on my floor when I do have some free spare time and this helps to relax me too'. She tried to make connections with people 'by showing an interest in their dog which is quite easy for me to do as I love animals'. Both Anna and Yumi found animals a good starting topic for conversation.

Betamax considered it important to be aware of both strengths and weaknesses when doing a professional degree. He had chosen learning disabilities nursing as he felt it used his strengths in terms of 'thinking on your feet and ... being creative' and 'dealing with the person and then getting their trust before you deal with the thing [medical condition]'. He hoped to use his 'life experience, including my efforts in accessing services for myself' in his future career.

#### **4.8 Managing energy and sensory issues**

These strategies can be very loosely divided into three groups of strategies with the following roles: minimising or otherwise managing exposure; managing and minimising their impact, including relaxation strategies; and distracting attention. Strategies for minimising or managing exposure included avoidance, exit and replacing them with more positive stimuli. Anne took breaks to get away from noise. 'I do this at work every now and then as my office is quite loud as we all take client calls so it is quite noisy.' Anne often combined these breaks with relaxation and de-stressing strategies. 'I usually take a break and make a cup of tea or go outside to get some air for a few minutes. .... I take breaks during the day ... where I just listen to music for a few minutes or paint.' Clare would briefly leave. 'Sometimes if things get too much I will say I'm just popping out for a minute, like during a debate or a conversation or something like that. ... Sometimes it helps for me to just be alone ... like go to the toilet, hide for a few seconds or minutes, and then come back out

whenever I feel a little calmer or ready to do that again.' Part of her strategy involved not telling people she was becoming 'overwhelmed' to avoid drawing attention to herself and people fussing, which she felt 'in some cases ... doesn't really help'.

Sophie brought in bottled water as she found the tap water tasted 'slimy', wore comfortable clothes at home, and had stopped attending noisy events, though this could restrict her social activities. 'A lot of places that I would ... hang out with friends or play games ... tend to be pubs. ... and they're very noisy and they're very crowded but then... it's, like, Friday evening. It's incredibly loud. And that means that I'm physically in pain being there. So, then I had to say, oh I can't actually go to any of these things. Oh, I need to, like, take a step back and avoid this. And that's very difficult to deal with.'

Izzy was only able to manage sensory overload in a previous job through working at quiet times. 'I could only do that by effectively working every evening and every weekend because distraction issues in the workplace, being required to work in open plan offices with no accommodations, ... just made it impossible for me to work efficiently.' This resulted in becoming 'too exhausted or disillusioned ... to continue.' Strategies for managing and minimising energy drain included deciding what activities to prioritise and doing little outside them other than resting. In order to manage working in London three days a week, Izzy needed to spend most of the weekend resting. 'If I work full-time and commute to London part of the week, I cannot do a lot of stuff outside work. And I really mean cannot ... On the Sunday, I didn't actually get out of my nightwear all day because ... the only way of having sufficient energy get back down to London after the week I had last week was to do virtually nothing.' As part of this strategy Izzy had recognised the importance of resting in order to be able to do things and the differences between 'resting' and 'doing nothing'. 'I've got a new mantra ... resting isn't doing nothing. Because I would tell myself off for doing nothing ... I am resting, and resting is an active coping strategy.'

Sam also managed energy by resting and avoiding too many commitments. 'If it's possible establish a way of, if I'm feeling that it's getting too much, that I can get away and I try to make sure I don't have too many social commitments too close together. ... If I have to have a long day where I'm out all day I try to make sure that I have at least ... the day before and at least one, preferably more than one, day afterwards when ... I don't have a great deal to do and I don't have to go far from home. It's a matter of pacing myself really with regard to the fatigue.' Similarly Izzy avoided 'back-to-back meetings ... noisy fans or noisy apparatus or having rooms ... too hot because I get quite agitated when I'm too hot.' She also tried to ensure 'decompression time ... breaks within meetings ... information in advance of meetings'.

Participants had a variety of relaxation and de-stressing strategies. These included exercises, contact with animals, stimming, music, therapy and medication. Bill used exercise both to relax and to stop thinking. Izzy had 'always' used exercise to manage anxiety. Leon used exercise to 'de-stress' and 'let off steam'. Phil did a lot of swimming and running 'because that helps me when I'm frustrated with things ... just to try and stay positive.'

Several participants used or had previously used therapy. There were different views on the most appropriate therapy. Bill had found talk therapy 'really helpful and both he, Clare and Leon did not want cognitive behaviour therapy (CBT). Leon had tried CBT and found it made him 'more anxious'. He had discussed it with other autistics and found agreement that it worsened rather than improved things. 'It's not a thing that works for us. ... You come out and ...you beat yourself up rather than trying to challenge.' Phil was finding CBT very useful (after one session). However, his reasons for finding it useful are the same reasons that Leon and some of the other participants found it problematical. 'I'm actually having therapy to try and change the way I perceive things ... So I can try and see things from a more objective side ... I've not got many problems at all. ... But any problem that I have, stems from taking things the wrong way. And the therapy that I'm taking ... it's all about changing the way I process things, my thoughts and feelings to change my behaviour. That's something that's going to make a big difference.'

Several participants had required strategies to access (appropriate) therapy. For instance, Jim had seen a number of therapists without his doctor's recommendations and obtained his doctor's signature to see his current counsellor without an appointment, which would have been difficult to get due to long waiting times. 'I was able to negotiate something whereby I didn't actually need to see him. I'd just gone in to sign a piece of paper on the agreement that I would come back to talk to him at some point.'

Some participants used distraction strategies based on engaging in another activity to distract their attention from, for instance, noise or troublesome thoughts. As indicated in section 4.1, Alice found that having someone to talk to in the doctor's waiting room acted as a 'filter' and reduced her stress from the surrounding conversations and other noise. Anne 'usually took something with me like a book or my headphones to listen to music ... as I usually would get myself quite nervous in the waiting room just before appointments, so the distraction helped.' Chris and Sam used activities as distraction from thoughts about unpleasant or traumatic situations. Chris: 'Sometimes when I'm quiet at home in the evenings I'll just start thinking about it [benefit assessment] and so I try and keep podcasts playing and things like that so when I have those down moments when nothing's happening my mind doesn't go back to it.' Sam: 'If it gets too bad [reliving situations] I try to distract myself by reading or watching something I'm interested in.'

#### **4.9 Communication and social interaction strategies**

Participants had a variety of different social interaction strategies in addition to online socialising and using strengths and interests discussed in sections 4.4 and 4.7. As well as the online interactions with other autistic people already discussed, there were face-to-face strategies. Leon had made a few autistic friends since his diagnosis and had a coffee club and engaged in various activities with them. Diva spent time with the autistic community and Sam had got to know some autistic people and made one close friend through a local autism initiative. The participants were overwhelmingly positive about their interactions with other autistics with Leon the only one with both positive and negative experiences. His positive comments were typical of those of other participants, for instance that it was 'easier to engage

with autistic people', that they had a 'good rapport' and could they could 'share our experiences'. On the other hand, he felt that some of them were 'kind of bullies', 'very domineering' and 'rude'.

A few participants had strategies for remaining in control of their social interactions, including being able to leave when they wanted. George sometimes preferred to go to friends' houses rather than them visiting him to enable him to leave when he wanted. Sometimes he created 'an excuse for not staying too long', for instance visiting on the way back from the shops with food that needed to be put into the freezer. Jas had developed what they considered 'some really unhealthy coping mechanisms' to prevent 'getting too close to people' in response to being 'persecuted' and 'humiliated' as a child and being 'scared of, if I was nice to them ... that I was presenting them with complete vulnerability ... then they could hurt me.' This included being 'not very nice' to a friend they 'wanted to kind of get close to', playing 'mind games all the time' and 'test[ing]' him. Jas would 'crumble quite quickly' and become 'extremely sweet'. They considered the interaction 'very hot and cold' and 'very unappealing'.

Jim had a circle of close friends who he had known for over ten years. He found interaction 'easy' with them, as they did not 'have to build up to something via small talk. We can easily be silent with each other and it's not a problem.' He preferred not to interact with larger groups or when someone not part of this group got involved. For instance, he 'gave myself permission to cancel' participation in a group trip when one of his friends invited 'someone I didn't really know'. He was also 'cautious' about social interactions with colleagues as part of 'keeping a separation of work and social life. ... I want to be able to have a break from it [work] when I go home'. Jas was trying to do more 'activist stuff' against their 'better judgement and was entering new groups. They quite enjoyed 'watching other people interact ... getting whatever training we're doing and 'the process of seeing other people's ideas' in a meeting and saying 'maybe one or two things'.

Max mainly socialised in the pub. However, he expressed a degree of ambivalence about this as a strategy. On occasion it could be very successful. For instance, 'last night at the pub was probably the easiest night I've had in the pub in a long time in that I had managed to have normal conversations with some of my friends and it felt like it used to be ten years ago.' However, he was also questioning the role of the pub in his social life, whether he should try and 'rekindle his pub friendships' and the role of heavy drinking in this. 'I was a bit of a party animal – no drugs, just alcohol, and maybe I should become that person again but I can't because I can't afford to do it. ... it's not really what I want to do. But maybe I should spend more time in the pub and rekindle these friendships that think they exist'. While other participants mentioned going to the pub or avoiding pubs at busy times, socialising in the pub did not seem to be a strategy for any of the other participants.

Several of the participants were involved in long-term relationships. However, other than Izzy (see section 4.5), they did not seem to have had any particular strategies for forming relationships. Alice used rules to determine how she should treat her wife when she was upset. 'My instinct is to talk to her and to discuss what is happening, but that doesn't work at all. ... So I go by the rule, yeah, shut your mouth, either leave the room if you can't stand it, or try to help her on an emotional level ...

like bring her coffee, bring her a blanket, bring her the dog ...we have a little dog, and just put it on her lap and just put her hands on the dog so she can start cuddling the dog. And we know that brings her out of her distress.' Clare endeavoured to maintain clarity about boundaries in her relationship with her partner and 'I always try and be as clear as I possibly can with my partner in terms of where we both stand on certain things, on certain boundaries'. Her strategies for doing this in general and not just in relationships included putting in brackets 'I was being sarcastic or just sarcasm' or 'joking' to clarify how she intended to be interpreted.

Jas (who was assigned female at birth) experienced 'trouble with just meeting people' but that there was 'something in between meeting people and getting into a relationship' that was 'less difficult'. They had been in situations where they had relied on their male partner and was currently doing this, though not living with him. Jas considered this reliance on a male partner 'a big thing with working class women' and 'a really dangerous and precarious situation to be in'.

Several participants used explanation-based strategies and/or strategies to allow them to exit or avoid certain types of conversation. However, exit and avoidance strategies seemed to have been more successful than explanation-based ones. Jas was trying to be 'upfront about what's going on my head so that people can kind of contextualise what I say a bit more'. They were also trying to stop over-explaining. 'I'm kind of trying to combat that, because ... it's like regardless of my better judgement, I'm kind of vomiting out these justifications without much control'. They had realised recently that 'over-questioning and over-justifying and seeing things that aren't here, like all the time' could be symptoms of panic attacks. Bill had tried to explain to his son that some of their communication difficulties were due to his limited working memory, which he had evaluated as 'about three'. 'Recently I have tried to explain to him. I have to list them back to him as concepts. He is gradually understanding I cannot hold all those concepts at once.'

Alice had tried explanations with colleagues, but this was generally unsuccessful. 'I had quite a lot of one-to-one talks either with my trainer or with a certain colleague who had reprimanded or somehow mistreated me ... I always tried to explain why I did what I did. And I tried to find out what their problem was ... I just got answers like, yeah, well, you're strange; ... you talk too much'. George tried to communicate with psychiatrists 'as clearly as possible when he was distressed 'with words, because words is the way I communicate'. However, he found that 'they were really requiring me to act distressed' and considered that 'people who are paying attention to my body language aren't paying enough attention to what I'm saying'.

Max felt that he sometimes would 'end up in the conversation and then strategise how to get out of it'. For instance, when he did not want to speak to a work colleague 'I would just engineer the conversation to come to a very rapid conclusion and then jump in my truck and drive away so I didn't have to put up with him'. In her previous employments when clients on the phone were being 'chatty' and Sam 'didn't feel up to it', she 'would maybe say ...the boss is around, I have to keep this to business. And, they were, all right fair enough; understand kind of thing.' If he wanted to 'get away ... because of the noises' Lola would 'just say yes, no, yes, no, yes, no, bye-bye, I'm off'. Sophie would avoid talking for long periods of time when

she was 'really struggling with my mental health' and 'structure' her day so she did not need to talk.

Another strategy was asking other people for explanations. If he felt that people 'were getting frustrated' with him Phil 'would explain to them, look, you know, I haven't understood what you've said to me, and I haven't appreciated the way that you've been frustrated at me. If anything, it's your job to explain things clearly and to make sure that I understand fully what I'm doing'. Lola and Sam both used listening strategies, Lola particularly with people he did not know. 'I don't say a thing and I listen to what they're saying and work my way around from there'.

Yumi sometimes initiated conversations by talking about an 'innocuous topic ... such as cats, because usually people aren't upset when you ask them if they like cats.' He found this worked at least to some extent 'because I get to the point where I sometimes talk about stuff.' This is a variant of small talk, but based on a topic of interest to him.

Several participants had portable low-tech communication aids. Dinah had an 'I am autistic' card but had only used it twice in five years. The second time involved a difficult situation and humiliating treatment in a vision clinic. 'And I was just weeping, so I showed him the card, and I said, I think I'd better just go, and he said, "no, no, this is your eyes."' Izzy carried 'little note cards on a lanyard so I can actually write notes to people. I used that at the Bob Dylan concert. And...it was far too noisy to speak'. Sophie had 'the little badges that are like, oh green, please come and talk to me. Or, like, red, do not talk to me at all'. She thought that they might make her feel 'more comfortable and confident'. However she would only wear them in places where she knew it was 'safe for me to do that'. She was concerned about doing this in general public places and felt the need to be unobtrusive, 'I'm not sure I would do it in a public space because in a lot of ways I end up being safer when I don't draw attention to myself as an autistic person'.

#### **4.10 Employment strategies**

Strategies based on research and preparation and using strengths and interests have already been discussed in sections 4.3 and 4.7. Other strategies will now be discussed, including factors that affect choice of employer, freelancing, self-employment, using an apprenticeship, obtaining qualifications, moving around and changing industries.

Anne had chosen her employer rather than purely being chosen by them. She had also started applying early and persisted until she got a job she liked. 'It took me almost a year of applying to get my current job but now that I have it I love the company I'm in and it's the perfect fit for me.' Both Jim and Anne had considered non-work factors in choosing their employer. Jim liked being able to walk to work and had previously changed jobs to reduce travel time. Anne liked the fact that employees could bring their dogs into work and the sleeping pods for breaks.

Several participants had worked on a freelance or self-employed basis at some point or intended to do so in the future. Bill currently worked freelance as an architectural model maker, though he had not had a lot of work recently. Previously he had

worked as a freelance technician hanging paintings in galleries. Leon had been self-employed as a website translator. Clare hoped to become a self-employed travel agent and Yumi to start his own business making YouTube videos and writing short books. Clare considered that the benefits included not being 'at the mercy of an employer who might not be very accommodating, who might not understand autism ... workplace politics'. It would also allow her to work from home. This was important to her as high anxiety levels could make it difficult to go out, but she was still able to work. 'Even on my worst days when I'm struggling I can still do work, I can still carry out a lot of those things from a computer.' A related issue was raised by Sophie who was able to work out and obtain a degree when her mental health was very poor. 'They assume, oh you're getting a degree, you must be fine. And it was like, no, really not fine.' Being able to work from home, but not to go out or interact with other people is probably an issue for many autistic people. The self-employment model was one of the strategies participants proposed to resolve this. Bill considered the benefits of freelance work to be control of his own time, space and the project.

Phil had recognised the need for a strategy to develop his client base. 'Because it was self-employed, I went out and spoke to a lot of people ... to just introduce myself and do a half-price trial ... just to get my foot in the door. ... you go back to those places again, you get to build a rapport with people. So, I had to visit a lot of places first to meet them and just say ... this is what I offer, would you be interested in me coming to do a trial, and then bit by bit you get to know them and you go back every now and then. Then you start to build a regular portfolio of people that you go and see, and then they pass you onto other people ... a home that, you know, you connected with.' He had developed this career while still working as a teaching assistant, presumably to maintain his income while developing his client base.

However, Bill had not initially understood what was involved in working for himself and found it difficult to promote himself. 'I thought you just had to make the art. I didn't realise I would be promoting myself as a personality ... running a small business. ... I thought someone would look after me ... I was really uncomfortable with pitching my work ... I could not promote myself.' The need for self-promotion could be a particular issue for autistic people, but this requires further investigation. As will be discussed in the next few paragraphs, several participants were willing to accept reduced salaries, travel long distances, change industries or move around in order to obtain employment. This indicates its importance to them, in line with the literature on the value of value of employment to autistic people (Baldwin et al., 2014). Sophie had used an apprenticeship to change careers and Alice to get into employment. Both Sophie and Dinah had accepted employment which they were significantly overqualified for. In Dinah's case this had involved under-representing her qualifications by not mentioning her PhD when applying for a support worker post. 'And that was a really good thing. And when they discovered ... that I had a PhD ... it really quite freaked them out.'

Max had moved round the UK to obtain civil engineering employment and subsequently worked in a number of other countries as a commercial skipper. Izzy, who lives in the north east of England, had recently obtained a job in London. Fortunately her employers allowed her to work three days a week at home, so she only needed to commute once a week and stay two days a week to London. Several

participants had changed industries in order to get employment. When Max decided to stop working as a commercial skipper he had put his experience and skills into a search engine to obtain suggestions for a new industry and it had come up with 'film locations'. Max and Sophie both started at the bottom on a much lower salary than they had had previously in order to try to get established in a new career.

Brad had been contacted by a cyber security firm which was setting up a programme to train autistic people. He was intending to propose remote working in order to avoid a stressful commute to London. "Cause it's IT and it's 2019, there's no real reason why you have to be face to face, you can work remotely, I've done that and it works very well.'

Several participants had obtained jobs through contacts and recommendations. For instance, Dinah: 'The pottery and the art were ... with people I already knew, and that's how I got the jobs, so I didn't have to worry about getting the jobs. ... And the Birmingham job, I got because they'd heard me giving a talk at a conference.'

Several participants used the strategy of obtaining (additional) qualifications. Brad obtained a computer repair certificate to enable him 'to move up the ladder and get an office job'. Betamax decided to go to university and get a degree, as he realised that 'the only way I was going to jump up from lowest rung of the ladder up, say, three levels was through a degree. So that's what persuaded me to go to university, it was a very calculated plan.'

Several participants used a strategy of impressing potential or actual employers by enthusiasm, volunteering for additional tasks and showing how good they were. In her interview Sophie said 'I can fix your website for you. ... I can help out with all of these areas because I have three university degrees. I just want experience in this thing. So, I think that helped a lot with the, oh yes, we want to hire this person who's wildly overqualified and also seems to be willing to work for an apprenticeship, like, salary.' Once employed 'as soon as they put me on something I'd be like, oh here's all the work you asked me to do. ... okay, here's some more work. ... And I'd be like, oh I did this too ... And then I started, kind of, taking over other parts as well where I now have more responsibilities than I had before that they even expected the apprentice to have at all.' While this may not have been a problem for Sophie with her considerable experience and expertise, this type of strategy requires care to avoid exhaustion and burnout.

Several participants had obtained reasonable adjustments. Information about some of the technology-based adjustments has been provided in section 4.4. Details of other adjustments will be presented in section 8.19 and 8.20 of the recommendations. The main strategies involved in obtaining them were identifying needs, making requests and discussion with employers. For instance Anne made requests of her manager. Izzy had discussions with her employer. 'And so the discussion then took place about how it would be managed for me to live in [north east England] and work in London and that's when we came up with a plan that I would be able to travel down and just spend two days a week in London and work from home the rest of the time.'

Jas and Sophie had both used studying for a degree as a source of income at difficult times in their lives. Sophie 'had enough funding to this that I could balance things out. ... I literally did this because I was suicidal and I couldn't work but I could

do a degree, because that was dependent on me, like, reading text and writing things.' Jas used university admission to obtain a student loan so they could pay their rent and not be homeless. 'It came down to survival, I had to get the student loan ... because it was completely unviable for me to do working ...enough to afford my entire rent and bills and food and everything, if I was doing like a nine to five at a 6th form, I couldn't do that.' They had to use a combination of strategies to get accepted, including calling 'the local university ... on clearing day, and sort of made a case'.

Lorenz and colleagues (2016) provided a categorisation of the 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 in section 4.1, they provide too little detail to compare their strategies to those identified here.

#### **4.11 Learning from autistic people and other strategies**

In addition to using technology to obtain advice from other autistics (see section 4.4) a small number of participants learnt strategies from other autistics. Anne found it very useful to learn the 'coping strategies' used by other autistic people at university. 'Listening to other people's stories on how they cope with weekly struggles has been useful to me.' Bill looked forward to meeting his autistic friends, as it helped him to 'recognise my own sort of behaviours'.

Other strategies used by small numbers of participants include persistence, learning, trying things, a decision making strategy and self-acceptance and related strategies. Several participants used persistence as a strategy. Jas had 'three tries to my GP to get referred to thoracic medicine and then when I did my sleep study, it came back that yes, I have sleep apnoea.' Betamax and his needs assessor 'both constantly kept on at Student Finance until they relented' and he received the support he required.

Bill resolved his problem of choosing what to wear by having 'all the same clothes, 10 of the same shirts ...'. Phil believed in trying things, 'getting stuck in and giving it a go ... and if it doesn't work, then at least you know'. Falcon overcame the barrier of negative expectations that he would not get to university by 'not listening to those people' and 'trying to overcome that barrier' This was 'a very big, positive thing' for him even though he did not get into his first choice university.

A few participants had self-acceptance strategies. For instance, Jim was starting to move past the 'wants and shoulds' which he felt were the source of a lot of his low self-esteem and becoming 'more accepting of what actually is there' and 'that there are things about me that are just me and aren't going to change'. Leon was 'accepting who I am and just trying...switch that inner voice off' and reduce 'unhelpful talking' about 'things like failures'. Bill had 'let myself off the hook recently' and was trying 'not to have endless things to do'. Jas had changed the name they used (though not legally) as part of their strategy of moving on through a 'new identity and forgetting who I used to be'. They were also in the process of 'unlearning ... unhealthy coping mechanisms' to try and prevent 'getting too close to people' such as 'being mean to people that I like'. Bill had a routine he tried to 'stick to' involving

exercise and 'a little bit of socialising'. George was trying to increase his 'tolerance for things being less than ideal' by 'deliberately doing things outside my comfort zone sometimes'.

## **5. 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. The main barriers experienced by participants related to communication, social interaction, lack of appropriate support and resources, stereotypes and misunderstandings of autistic people, sensory issues and energy and internal barriers. These barriers generally covered all activities, including employment and job search, interaction with service providers and social interaction. Barriers specific to particular areas included those related to benefits and job search and employment. Barriers experienced by smaller numbers of participants included those related to diagnosis and disclosure and relationships with family.

### **5.1 Communication Barriers**

Communication barriers included not being listened to and taken seriously, the use of ambiguous and imprecise language, being misunderstood and misunderstanding others. Anne was not listened to and taken seriously by doctors and counsellors. For instance a counsellor implied she was "putting on" her symptoms, as she was more nervous with her than in the waiting room and did not understand that Anne 'would be more nervous speaking to her than sitting, not talking to someone in the waiting room'. Similarly a doctor tried to 'belittle' what she was saying with comments such as "but everybody feels nervous talking to others". Doctors dismissed what Brad said though he had done the research to back it up. Instead he was told it was just a 'cold' and to "stop wasting my time". Barriers to communicating with medical professionals are in line with other studies which show poor communication between autistic professionals and health care professionals (Nicolaidis et al., 2013).

Max was not listened to by a civil servant when he tried to resolve tax problems and was threatened with security being called to evict him. 'Every time I opened my mouth to say something he'd [tax civil servant] say if you speak to me like that I'll get security.' When the situation was finally resolved 'in actual fact they owed me money'. Sam was frequently not listened to, particularly when she gave longer explanations. She was not taken seriously, including by professionals, when she mentioned difficulties. Instead she was told 'that's difficult for everybody'. Or, 'it's all in your head ... you're creating barriers' when she was 'describing legitimate autistic difficulties' and her 'reality'.

Sophie was also not listened to or taken seriously, leading to her doctor not referring her for diagnosis and a friend not accepting her experiences, for instance, of her

mother trying to obtain access to her bank account. George found that more attention was paid to his body language than his words and his distress was not taken seriously as he was not 'performing' it. Instead comments were made about how 'articulate' he was and how well he was communicating.

Several participants mentioned experiencing difficulties with small talk or social chit chat. Chris had not returned to a gym where he had attended an induction session due to feeling he would need to engage in small talk. 'The thought of having to go back and say good morning to her [person who did introduction] on the way in to the gym just puts me off going. ... I think it's because of how taxing I find these interactions, and the sense that afterwards I always get them wrong.' Izzy experienced difficulties when role playing situations as part of police training. This included making 'small talk with the motorist who I was pretending to have stopped', but she realised that other students were not having similar difficulties. 'And it suddenly dawned on me that the other students could just make this kind of chitchat stuff. And I just hadn't got a clue what to say ... I was looking awkward thinking, what the hell am I supposed to talk to this random stranger about?' Anne was concerned that she sometimes forgot 'to make small talk at work' and that the other person might think she was 'rude' or 'selfish' for just talking about work. Bill felt that he did small talk, but 'really badly'.

Several participants experienced misunderstandings, either being misunderstood themselves or misunderstanding others. Izzy felt that her 'intense interest in people or subjects' was often 'misconstrued' and it was assumed that she had another 'agenda' that she was 'completely unaware of'. Falcon experienced a number of misunderstandings with other people. 'People don't understand me a lot of the time ... sometimes I [mis]understand other people.' Some of this may have been related to the fact that some people found he had a 'weird voice'. Jas's mother had difficulty in understanding them. 'I think that the different ways that I communicated... did not make sense to her at all'. Bill experienced misunderstandings, including with his family, as he focused on the 'original experience' whereas the other person 'changed it into the meaning'.

Body language could be difficult to interpret. For instance, George did not know when talking to someone at a party who was 'jigging about' whether that meant he was boring them or they needed the toilet. He felt that 'we're probably neurotic enough without imagining that we're boring them, when they just need the toilet ... But we're told that a healthier response to their jigging was to imagine that we were boring them'.

Autistic people are sometimes accused of not being able to take turns. However, George's experience was that 'everyone else managed to butt in and have their say fine, but I'd end up getting told off for butting in'. Izzy found meetings, particularly conference calls difficult, due to the 'difficulty of judging when I can be heard'.

As discussed in the strategies section 4.3, several participants used written notes as a strategy in various contexts. However, Jas was now worried about using notes due to objections by a specialist. 'He didn't like the fact that I had written the things down ... Like the way that I compiled my notes for my own reference was wrong, and so that kind of gave me a complex about looking at my notes and using them to

help'. However, they found that speaking without notes did not work very well. 'And so I end up speaking kind of freely, and then this really doesn't match up well, especially with a non-autistic person's way of processing information. Because I'll go on like tangents or I'll just speak in a weird way or something'.

Lola generally provided minimal information to doctors and required them to ask follow-up questions as otherwise he would say 'yeah, I'm fine, bye' in order to 'to get out of the place'. He also did not inform his doctor when his tablets stopped working as he was worried about 'a confrontation'. Sometimes autistic people were ignored, particularly when accompanied by another person. 'He spoke to my mum the entire time. ... And it really hurt how ... it was all directed at my mum ...it was kind of like I wasn't in the room' [Clare]. A related barrier was autism policy discussions not involving autistic people, including when they were present. For instance, Izzy found that 'when you work on autism policy and you're in meetings, you are part of a group of people being discussed, and that can be deeply uncomfortable. ... I think part of the difficulty is that people forget we're in the room.' Sam required more thinking time and wanted a structure which allowed people 'to take a pause in what they are saying, to think and put their words together without someone else immediately jumping in to fill that silence'.

As in the questionnaire, several participants experienced difficulties with benefits questions that were not designed for autistic people. For instance Chris found 'the questions don't seem to be even designed to capture the kind of problems I have with mental health and autism. And it seems almost like it's been designed ... to miss me, and that that doesn't necessarily mean that I'm not struggling to the degree that it should capture me'.

A few participants experienced difficulties with phone use. When he was younger, Falcon 'refused to use the phone to talk to anyone, especially if it was in relation to getting a problem...phoning the bank or whatever, getting a problem fixed' Phil considered that phone calls and text messages could be 'really misunderstood and ... that's the route of a lot of the things that I struggle with.' He therefore preferred personal interaction.

Several participants experienced difficulties with workplace and job application communications. Bill and Max found networking difficult. For instance Max 'went to a conference last week ... it was all networking...and I absolutely detest it. I've always been useless at networking'.

Anne experienced difficulties with abstract interview questions. She found them 'vague and subjective' and needed them to be 'more direct'. She found it 'hard to know where to start' with questions such as 'Tell me about yourself'. Yumi considered the personality tests in online job applications to be 'about some vague abstract notion'. Jim found it difficult to work are what job applications really wanted. 'I found it really hard to kind of think laterally and think, what are they actually asking here?' These comments show that some of the structural barriers experienced by autistic people in obtaining employment (Rosqvist and Keisu, 2012) relate to unclear and ambiguous communication.

Several participants felt that the workplace had unclear rules and expectations. Dinah expressed this as 'you get dumped into a system which has arbitrary rules'. Anne sometimes 'struggle[d] with unclear expectations'. For instance, if someone asked her to meet them from another department but did not specify a time she was unsure whether just to turn up or wait for them to specify the time. She found it 'harder to contribute my ideas in a meeting than 1-1'. She also felt that she could tell colleagues, but not clients when she did not understand something, as this would be considered 'unprofessional'. These unclear rules and expectations also covered career development. For instance Jim felt 'there was probably a ton of stuff I could be doing to either improve my skills or develop my networks or something, but I just couldn't get beyond what I was actually doing day to day. Because no one had told me that certain opportunities were available or I could be doing x, y and z to improve my career prospects.' Dinah did not know what she was supposed to do when she saw someone not knowing their job properly.

Where training was provided it was not necessarily communicated clearly. For instance, Alice experienced difficulties during her apprenticeship. 'She [trainer] rarely really explained things in full detail and in a logical order. It was just do that, do this, go there, get that finished. And I was ... you told me to finish it but you don't tell me how to start it.' She required the theory not just information on how to do things. 'And she never gave me a concise theory, she never gave me a plan and a logical explanation on how and why things were done in a certain way.'

## **5.2 Social Interaction Barriers**

Overall, participants' experience of social interaction was not particularly positive and they experienced a number of barriers. Several participants experienced barriers to workplace social interaction which in some cases had an impact on getting jobs. Anne had difficulties with 'banter' at work. 'I think people think I'm weird for not participating in it. I don't really get sarcasm a lot of the time too so I think when I don't react as expected to sarcasm people think I'm offended or reserved.' Brad felt that not being able to 'do the social thing' was a barrier to getting employment. Izzy worried when accepting her current job that a lot of the other workers were 'very social' and had 'regular excursions'. She felt the options when she was available were 'joining in and getting overwhelmed and having to leave' and 'not joining in, feeling like a bit of a social pariah'. She also experienced difficulties with the intranet which had a social role and could end up not knowing what was going on. 'I have to almost force myself to go on to the intranet and be social ... that does absolutely nothing for me. ... So, I tend to forget about the intranet for long periods of time and then ...something's being talked about I know nothing about.' Leon had had 'a very checkered work history' and 'struggled ... in the work environment'.

Several participants had experienced bullying, exclusion or being made to feel bad about the way they interacted with others in line with the literature on the very negative social interaction experiences of autistic students (Hastwell et al., 2017), though our sample was more diverse and did not just consist of students. Dinah felt that there were often in- and out-crowds. 'Autistic people are very rarely to be found in the in-crowd. And they don't always mind being in the out-crowd ... but ... there's a lot of suffering out there from people trying to fit in, in a workplace, and being

regarded as alien beings.' Jas had experienced a lot of bullying and this had strengthened their view of being 'different' and 'socially outcasted'. They were very concerned to avoid further bullying and consequently had become 'very cautious and ... would rather turn inwards and away from people to avoid risking, repeating and triggering more of that sort of thing.' Leon had been targeted for bullying due to being 'a bit quiet and not as sociable as others and they can make fun and...yeah, I've had that '.

Betamax sometimes felt isolated and misunderstood. 'I don't think that people really understand where I'm coming from enough to involve me socially.' Sam was sometimes isolated at events and felt 'absolutely mortified' when this happened. 'It's just been impossible to get myself into ... a one-to-one or a little group to be in a conversation with and just constantly seeming to be hovering around the edge.' She was sometimes hassled by 'one or two' generally older men. 'Oh, you're on your own blah, blah, blah. Where are your friends?' Sophie had been made to 'feel bad' about her use of language and tone of voice and she found this 'triggering'. This had made her feel unsafe in a context in which she had carried out a particular hobby. 'It's a big deal to me because it was one of the main places where I would find friends and now ... I don't feel safe there.'

Several participants were concerned about things they were doing wrong and other people's reactions. Leon was 'so self-conscious of ... sweating ... at the slightest bit of exertion' and this was 'inhibiting' him from social interaction. Yumi felt that he annoyed other people without knowing why, though this could be due to 'not getting their subtleties and jokes'. He worried about saying 'something offensive' and saying 'the right thing' and about not being liked and being 'unwanted'. Brad felt that he was making repeated 'social faux pas' and sometimes 'the same mistake over and over again'. Sam worried about 'bad timing' when she contacted people.

Exhaustion could affect social interaction. After seeing friends for 'two or three hours' Brad felt 'like falling asleep in my chair regardless of how much sleep I've got recently.' Betamax felt that he sometimes declined social invitations as he needed to sleep to cope with his heavy schedule. 'I've been on ... three long days, I've got two nights coming up, I need this entire 48 hours to sleep, because otherwise I won't be able to function.' However, other people sometimes misinterpreted this as not wanting to have any contact with them.

Jim found it difficult to participate in activities where someone he did not know was involved and, for instance, withdrew from a trip when a new person was invited. 'That kind of one new person ... just put me off entirely and I actually didn't go in the end, and I'd kind of paid up my money and everything.' Sophie felt there was no-one who would give her a supportive reaction if she tried to talk about her difficulties. 'It's kind of like, I'm your entertainment, or, I need to deal with you now seeing me differently because of things that happened to me. Or, you get angry at me because I'm not helping you lie to yourself about who and what I am.' Most of the barriers occurred in interactions with non-autistic people. However, Leon had also found some autistics 'very domineering', 'very rude' to him or 'judgemental'.

### **5.3 Lack of (Appropriate) Support and Resources**

Few of the participants had experienced having their needs fully met and in an appropriate way. Both lack of resources and misunderstandings of their needs contributed to this. Many of the participants received no support post-diagnosis in line with the literature on high levels of dissatisfaction with post-diagnostic support (Jones et al., 2014). Anne would have liked but did not receive 'a follow up appointment' after diagnosis to talk about help and support available locally and that she had 'a lot less support and less people I can talk to about these sort of things' since she had left university.

Where support was available it was frequently insufficient and/or unsuitable. Bill felt that his post-diagnosis support group was more about supporting others than receiving support. This was 'very stressful, particularly when other participants talked about possible suicide: 'so and so is going to kill himself, can your support him'. He did not want to occupy the group's limited 'valuable time' with his 'trivial problems ... which weren't trivial'. Leon ended up in a support group pre-diagnosis where he was 'the only guy that was there' and the health professionals facilitating it were 'just so rude'. Lola was offered a person to support them in attending clubs or social activities. However, the only time was mid-week afternoon when groups of interest to him did not meet.

Several participants were offered therapy, particularly if they also had mental health issues. However, they were concerned about the limited choice of therapies available and the limited number of sessions free of charge. The only therapy offered to most participants was cognitive behavioural therapy (CBT). Other than Phil, who was very positive about it after one session, participants considered it inappropriate and even potentially damaging. For instance, the approach based on looking at things from 'this perspective' made Clare 'almost feel alienated' by implying 'the way that I think, the way that I process things is invalid or is not correct.' She felt that she ended up 'going through this vicious cycle of having a crisis moment' followed by inappropriate support.

Izzy was refused mental health treatment by Improving Access to Psychological Therapies (IAPT). 'As a logical autistic person' she had said she would not tell anyone if she seriously intended to harm herself and that prevented them drawing up a 'safety plan' and IAPT was only able to provide eight sessions. 'Why on earth would I alert somebody to that fact who would try and stop me?' Only a limited numbers of hours (generally 12 sometimes extended to 16) of therapy were available from the National Health Service (NHS). However Bill required '12 sessions to stop being suspicious of [therapist]' and considered that he needed 'about 50 hours' of therapy.

Several participants experienced problems with long waiting lists, which also made it difficult to always see the same doctor. For instance, Brad 'never [saw] the same doctor really'. In combination with the variable quality of doctors at his surgery – 'one or two good doctors at my surgery, and a lot of bad ones really' this had made him 'reluctant to go to the doctors'. Jim found that he could not get to see his doctor, as 'he's booked up so far that the next appointment literally isn't on their system' and did not really 'want to explain to another doctor, yeah, I have a history of mental health'. He had therefore, as discussed in the strategy section, had to devise ways of accessing diagnosis and therapy without seeing a doctor. Several participants

found that when they did get to see a doctor the available time was much too short. For instance, Chris had a list of '13 points' for a '10-minute interview'.

A few participants felt under pressure to show that they did not require any (mental health) support. For instance George felt 'they wanted just to establish a paper trail which evidenced that I didn't need any help really'. Lola gave up going to a community psychiatry nurse after being put under pressure by him repeatedly saying: "don't you think you should go back to work". Chris felt that he was only allowed a certain number of visits to his doctor. 'So the GP ... more or less said "some things we need to catch early but not this" ... And then she said, "so I'll hopefully see you in a couple of months", ... I feel like I haven't had the permission to go for a couple of months.'

Jim had asked for mentoring from a local autism organisation to provide a bit of support in decision-making and help him 'see opportunities ... see the bigger picture of things'. However, about 18 months after applying he got an email saying 'do you still want a mentor? We can put you onto a six-month waiting list'. He felt this was due to 'lack of resource ... not that people don't care'.

#### **5.4 Stereotypes and Lack of Knowledge**

Most of the participants mentioned stereotypes. Many of them were based on perceptions of autistic people as totally incapable. This had two main impacts on participants: assumptions including by doctors and diagnosis professionals that they could not be autistic if they were able to do anything and assumptions if already diagnosed of low capabilities.

The stereotype of not being autistic will be discussed first. For instance when she informed him of her diagnosis Izzy's doctor reacted "'but you run your own household, you're not a ward of court", as if you could only be autistic if you had profound difficulties in your own life'. Anne's teachers and other adults assumed she was ok as was doing well at school. Sophie's 'coping mechanisms' were used against her on the 'assumption that, oh you are functioning adequately clearly you could not be autistic'. This stereotype also led to assumptions that support was not necessary. For instance, Betamax did not receive a promised 'guide' at university as he was considered 'able'.

There were also very negative stereotypes of the behaviour of autistic people. Some of these stereotypes were encouraged by irresponsible media reporting. For instance Jim commented 'Or like people that have been convicted of terror offences, and so and so, who has been diagnosed with Asperger's syndrome, it's absolutely irrelevant.' A related stereotype is the association of being autistic with anti-social behaviour. For instance, Sophie noted 'whenever there's a man who's, like, acting like an arsehole, people go, oh he must be autistic. And it's because people just assume that being autistic means being an arsehole.'

One of the factors that contributed to autistic people being stereotyped was a lack of knowledge amongst many professionals as well as in the general population. A combination of lack of knowledge and stereotypes was still contributing to autism not

always being recognised in women and girls. For instance, Anne considered it 'specifically hard to pick up on symptoms for girls too, so a greater awareness from doctors would be useful'. Sophie found it 'incredibly frustrating' that 'it doesn't matter how many examples I give you ... that autistic trait can never apply to autistic women, because autistic women don't exist. We all know this.'

Misunderstandings of the diversity of autistic people had also led to participants rejecting autism as a possibility for themselves. For instance, Sam's knowledge of autism was 'the stereotype of the silent, usually male, child sitting facing the wall and lining up toy cars', which clearly did not fit her. Lack of knowledge and understanding of autistic people led to pressure on participants such as Brad to be 'normal'. Behavioural expectations could also be influenced by factors such as gender and culture. For instance Jas, who was assigned female at birth, was made to feel they had failed their mother's gendered expectations of cleaning and cooking 'a good meal'.

Chris found that the information in his psychology degree was 'medical model deficit based; anything to do with abnormal psychology, it was like that' and that employment coaches lack 'autism awareness'. Betamax's experience on a nursing degree was 'teaching about autism and ... very lacking in knowledge of autism' and 'It goes right up the regulatory body this lack of understanding and accommodation, I think.' It is therefore unfortunately unsurprising that participants are experiencing both lack of knowledge and stereotypes from medical professionals.

However, lack of knowledge did not always lead to stereotypes. For instance, Sophie found that her employer was 'willing to support but I don't think they had really much knowledge at all about what that means'.

## **5.5 Noise and Other Sensory Issues and Energy Drain**

Problems with noise were the main, but by no means the sole sensory issue experienced by participants. Bill was unable to 'turn ... off' sounds. Brad and Alice had experienced problems with noisy crowded waiting rooms. Brad found 'The waiting rooms are really loud, that's actually a huge problem for me. You're just a lot of people crammed together.' While participants found this distressing, unlike in the literature (Muskat et al., 2015; Nikolaidis et al., 2015) and the questionnaire responses this does not seem to have affected healthcare use.

Izzy, Jim and Leon had had difficulties with unsuitable, noisy accommodation, Izzy in a hostel dormitory where she stayed when working in London and Leon while looking for something better. Due to the noise Leon 'was just like a zombie, not sleeping'. Izzy also found the lack of privacy difficult. Noise was a barrier to Sophie going to the pub at busy times and the 'really crowded loud place' where she would find friends. However, she no longer wanted to subject herself to 'physical pain' to meet people and engage in hobbies, so this restricted her social activities.

Anne, Falcon, Alice and Sophie experienced sensory issues with textures and/or clothes. Anne sometimes found clothes uncomfortable due to their texture, but which clothes were uncomfortable varied from day to day. She experienced particular problems with 'smart clothing for work'. Falcon found 'interview clothes'

uncomfortable and was concerned about giving a 'bad impression' if he attended an interview in clothes he found comfortable. Sophie found it difficult to find suitable clothes to wear for work, as well as warm clothes for the winter, as she found jackets 'claustrophobic'.

Food smells from the kitchen in the open plan office could be a 'big problem' for Izzy. Sophie was sometimes unable to eat food she had prepared the previous day without feeling sick. Alice was 'hypersensitive' to bright lights and certain colours. Brad was unable to look at the 'diagonally aligned bricks' on the pedestrianised high street and found it 'painful'. Crowds were a problem for several participants. Lola would get off a crowded bus and wait for the next one. Jim also experienced problems with crowds and Sophie avoided certain events if they were likely to be loud and crowded.

Several participants experienced energy drain and exhaustion from work, social interaction or other activities. Bill found that he had less capacity as he had got older and Sam that fatigue had become worse. She 'needed every bit of energy I had' for work and self-care and had 'nothing left over' to try and look for a new job to get out of an unsuitable one. Diva ran out of energy quickly and this was exacerbated by noise and lights. George had limited energy and found that it ran out faster when he was already 'partly drained' or things lasted 'too long'. He therefore did not want to waste energy on 'unnecessary things' as then 'everything else will start draining me' and he would have insufficient energy for things he found important. Dinah took a long time to recover when she had been 'flattened' by external circumstances. Several participants, including Bill, found interaction tiring.

## **5.6 Internal Barriers**

Participants had a number of internal barriers, with low self-esteem and anxiety probably the most common. Several participants compared themselves unfavourably to others and/or were very hard in their judgements about themselves. For instance, Sam felt that 'most people didn't like me because I wasn't a likeable person' and 'so ugly that I've even got an ugly voice'. She seemed to see herself as 'the one who holds the queue up fumbling to get hold of coins or giggling inately when someone is picking on me as the foil for them ramming their personality down my throat because I can't think of anything witty to say in reply'. Bill was 'aware' he was not a 'nice attractive person' though he tried 'hard to be nice'. He tried not to consider 'selfish' his 'drive to pursue my own interests'.

Yumi felt that he was 'a bit of a boring loser' and Chris used to call himself 'a shit person' as his 'mental self-identification'. Phil considered that he had 'low self-esteem and misinterpreted things'. Chris also had 'low self-esteem' and felt this was largely due to the pressure he put on himself through 'wants and the shoulds' and that the way to improve it was to be 'more accepting of what actually is there'. Jas had gained a significant amount of weight in a short period of time as a result of illness. This had affected their 'body image' and already not very good self-image, as they found that people treated them differently: 'really just the reaction people give you, like people really do treat fat people awfully'.

Sophie was 'always' anxious as her 'default'. She felt that what she was anxious about was 'being too much myself' as a result of negativity from other people, 'just because I've been told so much that who I am isn't right or good enough'. Anxiety was a 'huge problem' for Chris. He also found it easier to focus on the negative than the positive. 'It's very easy to think that things will go badly and then when they do go badly those experiences are remembered very clearly, whereas when a day goes reasonably well it doesn't seem that the mind remembers it.'

Anxiety and poor self-esteem could lead to participants leaving jobs or other opportunities. For instance, Leon had left 'good opportunities' after a week, as his 'anxiety levels have just been so high'. Phil had missed opportunities 'he would really like to do' due to 'lacking confidence' and possibly also the associated issue of 'fear of failing'.

Some participants experienced pressures to be 'normal' or felt 'different', without necessarily understanding why, and this sometimes had physical effects. For instance, Brad 'was getting constant, really painful headaches, where it was affecting my vision'. He has now realised that 'it's from stress of just forcing myself to be normal. I was breaking down psychologically, and it was manifesting physically'. Max had experienced a lot of negativity and sometimes felt totally alien. 'It's caused a lot of darkness in my life by not understanding ... why I can sometimes see things that other people can't see. ... the separation that I have introduced myself to my social circle, but it's also ... separation from humanity to a certain extent ... I really don't feel like I belong, and it's a horrible feeling.'

Change was difficult for some participants. For instance Bill had difficulties with 'sudden surprises'. Chris would like to make changes in his life but did not know what changes he wanted. Anne found 'any sort of change' difficult and had 'struggled' with the change to university and from there to work. She planned out her time and changes to her plans, such as a cancelled training session at work, often made her 'more nervous and stressed' and 'sensory overload ... more apparent'. Brad had left a job as he 'couldn't handle it' when he was 'sent to a different town to deliver pizza for one night', as it was 'different'.

This discussion of the internal barriers of a general autistic population rather than university student group shows both similarities and differences from the literature on the negative experiences of autistic students (Hastwell et al., 2017). In particular anxiety and self-esteem rather than anxiety and depression seemed to be the main issues and external factors included pressures to be 'normal'.

## **5.7 Diagnosis and Disclosure**

Several participants experienced barriers related to diagnosis. Anne lacked information about what was involved and received limited information subsequently. Diva had to get a private diagnosis, as his doctor considered he was not autistic and the three year delay led to him considering suicide. Max had not yet received a diagnosis as he 'got lost in the system for two years'.

Dinah self-diagnosed but avoided formal diagnosis at least in part due to not wanting to have her identity determined by 'arrogant professionals'. She felt that the way diagnosis was delivered by 'these very powerful people' could have lifelong impacts.

Bill found negative reactions to disclosure very distressing and would have liked some preparation for disclosure. Sam was compared to a 15-year old relative which she considered inappropriate and insulting for both of them.

## **5.8 Job Related Barriers**

Participants experienced a variety of job-related barriers. Yumi had submitted numerous unsuccessful job applications, having 'stopped counting after the first few hundred'. He had only received feedback in two cases, making it difficult to improve subsequent applications. Some of the applications involved on-line personality tests and in some cases he was informed he had failed them. The use of personality tests has been criticised as discriminatory by autistic individuals and organisations. However, research would be required to confirm this. The only job Dinah managed to get from interviews was one as a support worker, for which she was overqualified. Brad was getting fewer job interviews since he was diagnosed. Max experienced difficulties with the 'cup of coffee' interviews in the film industry and differences in its criteria from those in engineering where he had previously worked.

Betamax was frustrated at not being given opportunities for training and promotion, unlike co-workers on the same grade and being given 'fob-off answers' when he questioned this. Jim lost his enthusiasm for career development due to senior management questioning why he had been hired. Leon felt that there was a lack of jobs autistic people could 'excel in'. Chris lacked knowledge about how to get jobs and was unsure what type of job he wanted.

Several participants had bad workplace experiences. Max became stressed when the delivery note he required to do his job properly was not available, he was asked for things that were 'bizarre' and colleagues and managers did not understand problems that were obvious to him. He also lost a job for which he was overqualified. Alice was given 'very menial tasks that had nothing to do with what I had to learn' during the training that formed part of her apprenticeship as a bookmaker. She also experienced problems with colleagues due to being more successful at selling children's books from talking to the children rather than their parents. Leon 'struggled ... in the work environment'. Sam experienced sensory overload in a large open plan office and Izzy was not given a smaller office when she asked, though there was one available. Her manager responded in a totally uncaring and bullying way by declining her request to come into work later when her beloved dog was dying. Leon experienced what he called 'indirect bullying' involving being given 'more work' as he was 'not assertive enough'. It resulted in 'burnout' and him leaving.

## **5.9 Family problems**

Several participants had experienced major difficulties with their families. Diva was estranged from his family and Anne had no contact with her parents. Alice had broken off contact with her family as a result of abuse. Sam experienced unreasonable and damaging expectations as a child, largely as a result of being born when her parents had almost given up having a biological child and were looking to

adopt. It was 'hammered' into her parents who passed it onto her that she was something special, 'a golden girl, she'll go far'. She may have projected this feeling at school, leading to bullying. This was setting her up to fail and probably had a major role in her current feelings of inadequacy and need to handle every situation 'perfectly'. Max was told by his step-mother that he could not have Asperger's, as she worked with autistic children. Betamax's mother did not accept his autism and other adult diagnoses.

Jas was the only participant to talk at length about family problems, in this case with their mother, and to have this as a major theme. They felt betrayed by their mother who was getting married to ... someone who was the best friend of someone who sexually abused me as a child, and she knows this ... and I think that in marrying him, she's kind of already made her decision to separate herself out from me. 'Jas also felt that their mother was 'very characteristically one of these people who really does pick the partner over her child'. They experienced a lot of negativity from their mother, who did not understand their communication and other needs and blamed them for everything. Jas was made to feel inadequate, unable to meet cultural and gender expectations and 'broken', though their mother apologised after being sent information about their diagnosis. However, a lack of common interests and their mother's total lack of interest and understanding of their achievements at university made Jas feel 'we can't relate to each other'.

## **6. Good Practice**

Our interviewees highlighted several examples of good practice. The main theme identified was person-centred acceptance. This was identified as being very important to participants and is a clear counter to the experiences of stereotyping, not being listened to and being misinterpreted in the barriers sections. Particular types of good practice included giving consideration to sensory needs, modifying communication, supporting the development of skills, being able to apply support proactively rather than it needing to be sought out, providing a sense of acceptance and treating an autistic person as a person not a diagnosis.

We also felt that some of our participants found it easier to describe good practice by focusing on forms of bad practice they had experienced or that support should not take, including feeling ignored, ambiguous communication and feeling forced to fit in. Reports of our participants featuring good practise were mainly focused around being seen as a complete individual, with strengths and weaknesses. This person-centred approach was a feature of good practice that ran across several contexts, education, work, diagnosis, and helped underpin several practical strategies identified by participants. The core themes identified by this approach were; acceptance, being proactive, a sense of trust and clear, unambiguous communication. For good practice these themes came through to provide a sense that the person receiving support was seen and treated as a person rather than a diagnosis. Needs could be considered and met in a manner that did not leave an autistic person feeling stigmatised or identified as different.

Having a feeling of being accepted was a permeating factor in engaging with support as early as possible. This was reported as key for a number of front line services.

For instance GP's being non-judgemental and understanding was highlighted by Anne: 'My GP was very good, she was understanding and did not judge me'. Betamax had received excellent support from his union. 'These guys actually take it seriously, you are a member once you are a member.' Feeling listened to and trusting a group to have your best interests at heart, is suggested to be what is enabling support to be accessed.

The provision of clear explanations in a therapeutic context supported access, which could be maintained for a period of time, rather than a one-off appointment as might be provided by a GP. As Phil responded: 'And he asked me what's changed, and they really explained really well how things that have happened in the last couple of weeks personally have started to actually have a positive impact, taking away stresses and pressures.'

Service providers could support access to their services by showing acceptance, particularly through difficult times. This type of good practice was reported as being useful in multiple contexts and tended to provide support as general access or if someone begins to struggle. For instance, in educational settings it was reported, by Falcon, that this 'just generally made me feel more comfortable, try to make me feel better in lessons, but also when I didn't go to lessons helped'.

Acceptance seemed to generally help our participants feel more connected to the world around them. For instance, when asked about the importance of acceptance it was reported by Phil 'it just allows people to support others and to understand where they're coming from.' Acceptance here is not just a function enabling access, it is promoting understanding rather than dismissal.

Having this sense of support and acceptance from the beginning is likely to give the best chance of long-term support and achieving the best outcomes, which was recognised. 'So, I think it's a massive benefit to find out as early as possible, [to get diagnosed], to get the support you need and to meet people like yourselves to understand that you're not on your own'. This quote by Phil suggests early acceptance can reduce the impact of being isolated and that a quick, effective diagnosis pathway can indirectly support this, particularly when there are opportunities to meet others undergoing the same experiences.

Our participants have identified acceptance being a core feature of any good practice, however several were only able to do so by highlighting their experiences of not being accepted. This may be due to it being easier sometimes to identify what does not work in order to be supported to identify what does. There was a general view that not being accepted or feeling forced to hide was a difficult situation that could impact on themselves or others. 'It allows people to be themselves without having to hide, and that [hiding] can be really damaging'.

Falcon expressed his need for acceptance and being listened to as good practice by recognising what was not supportive for him. 'I think I have a tendency when people stamp down and try to enforce things on me, to feel mistreated and react negatively.' Several of our participants struggled with identifying specific good practice experiences as opposed to identifying what needs to change to become good practice.

A 'known and trusted person' was a key identified element that was frequently reported as helpful. This form of support allowed the person using it to structure an interaction and access support: 'You got a ticket with a time on it, you got union representation, so you've got someone to speak to. You got human resources. There were rules'. Providing the underlying structure seemed to give a sense of comfort to our interviewees, preventing social misunderstandings and reducing stress.

Interviewees also reported the sense of acceptance they got from key trusted individuals, often family members, in this case Falcon's father, allowed them to trust that the supporter could step in when they started to feel overwhelmed. 'I kind of know when my mind is shutting down, it kind of is at the moment, and it becomes really hard to talk. And he's there, and he knows how. He knows when to speak up for me, and how to.....he's the only one who really tries to understand me'. It is the acceptance and the knowledge that comes from this acceptance that allows a supporter to correctly identify, anticipate and then give effective support.

However, it was also recognised that the role of trusted person could be draining for someone to take, and this may have an impact on the sense of self-efficacy and lead to guilt. 'They're just more used to putting up with me ... I think other people get tired of me, don't really understand me all the time, whereas other people will most of the time.' Falcon also identified potential weakness with this practice i.e. that though a known and trusted person is an example of good practice they may have unintentional side effects on the person receiving support. This impact is something that requires further study around known and trusted individuals being considered as recommended good practice.

There were fewer incidents of professionals being identified as known and trusted individuals, but scope to become one was highlighted. This may be due to the time investment needed to build up acceptance and a reciprocal relationship: 'My GP was very good, she was understanding and did not judge me and when it was taking a long time to get a diagnosis appointment she chased up with the hospital and requested that they expedite me as I would be leaving university soon and would have to start the process all over again at a new GP.' Once the acceptance and recognition of Anne's need was established her supporting professional was able to recognise the need for proactive support, that Anne herself could not ask for.

Our interviewees also suggested that 'skill building' was valued and was frequently linked to known and trusted individuals. In short acceptance and sense of safety allowed someone to develop their skill set and empower themselves. 'Well, they offered to put things in place to...not put me in places that would make me uncomfortable. But I said the point is that I want to do things that put me out of my comfort zone'. Here Falcon recognises that not having support in place would be difficult for him. However, he felt that it was more important to overcome how he felt and that enabling him to do so was support that would benefit him going forward rather than simply make things easier for himself. Good practice here is allowing Falcon to experience something he, and his supervisor in a work setting recognises as uncomfortable and supporting Falcon to do this as a means of personal growth.

Skill-building support had been used to provide phone training for Anne in an employment role: 'This way I could address the particular concerns I had about speaking to clients on the phone. The woman who ran this session was good at understanding why I was nervous about taking calls...' There was also a social component to this support, modelling and providing a window into a social world: 'She was really skilled with the way she spoke. She'd expose her own personal. You are supposed to talk a little bit about your personal stuff. You are supposed to give a little bit about yourself in the rapport building. She would give a bit about herself ... She was just really helpful'.

What seemed to be key for skill building to be considered good practice is that it was sought out, rather than enforced. All our participants who had mentioned this as good practice had either offered and accepted this kind of support or sought it out. The general inference is that enforcing confidence or social skill building was likely to have a detrimental impact. Good practice around skill building would be to ensure it can be sought out. In view of the importance that our participants placed on services being proactive it may be good practice to develop effective signposting to skill building support.

The timing of acceptance and person-centred support was evidently felt to be important. Being accepted with proactive modified communication was highlighted as effective practice, with recognition that this proactive support was rare, as Brad commented on for an employment training session. 'They'd really made an effort to communicate in such an autistic friendly way that I wasn't used to it, you know? It was mildly shocking. Yeah, but it's great, I really appreciate what they're doing, I'll be sure to thank them for that when we're actually in communication'.

Anne also noted the effort made by medical professionals to change how they communicated. Rather than using a style that required interpretation on behalf of the autistic person, the focus was on being clear and unambiguous. 'The doctor who diagnosed me was also pretty good, the questions he asked were worded nicely and were less subjective.' Anne also highlighted the problems she encountered when this good practice was not in place. 'There were unfortunately a few occasions of doctors I met who did not show good practice and did not seem to really listen to what I was saying. These ones tended to not know what to do with me so threw me back to my GP and I was referred to quite a few different doctors.' This difficulty with unambiguous communication seemed to be particularly significant in the diagnosis and medical sectors. For instance, Bill further highlighted common problems he had encountered and the recommendation of good practice as clear, direct and unambiguous communications. 'She's clear with her vocabulary. Other doctors have much more clipped ambiguous sentences.'

There was a recognition that without this being put into place proactively, the result could be an autistic person leaving medical or diagnostic settings without accessing the support they need, as escaping from an uncomfortable situation became more highly valued than receiving support. As Lola stated 'just ask another question, don't just leave it as yes or no... because otherwise, I would just lie, yeah, I'm fine, bye...To get out of the place.' This is obviously concerning if potential support is being missed, when proactive understanding of the needs of an autistic person would mitigate this.

The need for extra processing and structure in support come through as a feature highlighted as particularly important. 'She is pretty good at actually listening. She would sum up afterwards. After we had a dialogue she would sum up at the end.' We got a sense of how acceptance and proactive changes could make a positive impact on how an autistic person could view a medical or therapeutic appointment. For instance, Bill 'would say beforehand I have 10 questions, so she would say, shall we make it a double appointment over the lunch hour. She basically accommodated for all my cluttering. ... She definitely intuitively knew.'

Having easily recognisable and accessible service to access reasonable adjustments was also seen in (some) educational settings, as Betamax highlighted. 'there is a list of reasonable adjustments within university that are also listed. They've been brilliant. When I'm on campus, they're brilliant'. What seemed to be crucial is that services and approaches could be put into place proactively rather than having to be sought out.

Positive attitudes are the first stage in receiving support. Anne highlighted the positive response of her employer to disclosure. 'I disclosed to my current employer in my first couple of weeks at work and they were nice about it.' However, acceptance is a first stage and knowledge of the needs of autistic people is also required in order to provide adequate support. Anne further noted 'I still feel that they do not understand the condition but they try their best to look out for me and let me take breaks when I need to and move me away from bright lights etc.' Best intentions may be important in helping someone feel accepted but it needs to develop into evidence based informed good practice.

This may be achieved by actively involving the autistic person in the process, as in Izzy's case: 'When I was recruited to my current job, I was invited to suggest accommodations that would assist me during the recruitment process.' We did find that some proactive support for employment settings was available, but that it tended to be focused on interview rather than the workplace. This is again raised by Izzy. 'My employer did provide a lot of information in the form of photographs and detailed information about the journey to the office, how to enter the office, who would be in the office, those kind of bits of information. And the interview was set up whereby I was given the questions in advance. I was able to prepare my answers. And that was an accommodation provided for all candidates, not just autistic candidates.'

It should be noted that many of our participants seemed to have difficulty identifying what was supportive, rather than what was problematic. As such, involving the person in discussions of support needs to follow the proactive, accepting and informed communication good practice model mentioned earlier.

The support for sensory differences and social difficulties was accepted by some employers, but also a recognition that perhaps adjustments in work settings were the most difficult to ask for due to feeling unsure of the impact this could have. As in Anne's experience 'I told them that I get nervous talking on the phone and to new people and that bright lights can affect me. I didn't go too much into detail, as I wasn't sure how they would react. My manager was nice about this and said to let me know if I ever need anything'. The good practice here could be improved by the

employer being more aware of the likely problems Anne would encounter and to be accepting of this when planning her support package.

## **7. Conclusions**

### **7.1 Overview**

The results presented here were obtained from interviews with autistic people carried out by the autistic led An Auternative project to investigate the barriers and strategies which affect participation by autistic people. The results are based on analysis of 21 interviews with autistic people. Participants are very diverse, but

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.

Existing research on the strategies used and barriers experienced by autistic people is still rather sparse. 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. The literature on barriers experienced by autistic people has generally considered particular domains such as the health service (Muskat et al., 2015; Nikolaidis et al., 2015 and/or particular groups of autistic people, such as students (Beardon et al., 2008; Hastwell et al., 2017) rather than the full range of the autistic population and domains in which they might experience barriers. The project's earlier questionnaire-based research identified a wide range of strategies used by them and barriers experienced. While providing a number of advances over the previous state of the art it also led to further questions. The research presented here has answered some of them, including through provided more details about the ways in which different strategies are used and their advantages, disadvantages and costs.

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 barriers and strategies are context specific and which can be applied in a variety of contexts.
5. Obtaining detailed information about many of the strategies, including their advantages and disadvantages and the factors which affect their effectiveness.
6. Obtaining preliminary suggestions for developing a model of good practice.
7. Using the results to determine detailed recommendations.

### 7.3 Strategies

Participants used a number of different strategies. A number of employment and job search strategies were provided. Otherwise, the strategies could generally be used in a wide range of contexts including with different service providers, in job search and employment and social interaction. The most commonly used strategies were a trusted or support person, masking and imitation and research, preparation and planning.

The trusted person's roles included providing moral support, advocacy, speaking or phoning for the person when they felt unable to, intervening in difficult situations and providing expert advice and support and practical support. Other than when particular expertise was required, parents or other family members and partners were preferred where available. This strategy has clearly successfully supported increased and less stressful participation. However comments are more nuanced than those obtained from the questionnaires, where the only disadvantage mentioned was possible lack of availability of the trusted person. Other potential disadvantages included the possibility of becoming dependent, changing the nature of the relationship with the trusted person and making the autistic person less 'equal', the possibility of organisations not providing promised support, losing control of the situation and the ability to exit when you want and possible impacts on the trusted person. The most important factors in using this strategy successfully are an appropriate choice of trusted person and maintaining an appropriate balance between independence and support.

Participants considered masking to involve monitoring (and adjusting) behaviour, not using sensory objects and other adaptations, forcing yourself to make eye contact or putting on a persona or 'mask'. Two participants had successfully used masking in interviews, but found it was not sustainable in the long term in the workplace. Other participants found masking essential to avoid bullying and/or to work in placements as part of a nursing degree. A trans female participant engaged in both gender and autistic masking and as an autistic person found gendered cues difficult and had needed to research them. A few participants had stopped or reduced masking and wanted to be accepted as they were. Several participants were concerned about the costs of masking, particularly exhaustion, even when it was successful.

Research was used to support access to diagnosis, medical treatment and benefits as well as find out about firms they were applying for jobs at. It was possibly particularly useful in complex situations where the 'professionals' they were dealing with lacked information. For instance one participant used it to get medical treatment through a research trial and another had to research immigration law to determine her entitlement to benefits. Preparation included the use of notes, lists and scripts for doctor's visits, though this could be used more widely and with their employer's permission one participant used notes in a job interview. The main drawbacks are the time involved, though some participants enjoyed research, and possible negative reactions from professionals.

Other strategies included using technology, analysis and reflection, using diagnosis and managing disclosure, strengths and interests, managing energy and sensory issues, communication and social interaction strategies and employment strategies. Participants used and were positive about technology use in various different contexts. They most commonly used email, internet, SMS and social media. Several participants preferred technology-mediated written communication to phoning. It was less mentally challenging and tiring, required less concentration, provided time to think and decide how to word communications, avoided misinterpretation of passion as anger and kept hostility at a distance. These technologies were used to socialise, keep in contact with friends and a long distance relationship, contact services, shop and planning journeys. A few participants used noise cancelling headphones and there was also some use of planning tools and assistive technologies. One participant preferred larger keyboards and was using a portable Bluetooth keyboard with her phone when she was away.

Several participants used analysis and reflection and found them useful, including to avoid negative consequences. One participant had successfully used a 'spreadsheet' and 'job/person spec' to choose her husband. However, many participants had a tendency to 'overthink' or 'overanalyse'. This could avoid rush judgements and extreme thinking and one participant felt they needed overthinking to function. However, it but could increase upset and get in the way of taking action. Several participants used diagnosis to better understand themselves, their needs and interactions with other people. This often led to improved self-esteem. This increased understanding was also used to improve relationships with family and partners. However, there were a few potential problems. These were the deliberate exposure of deficits and weaknesses in the diagnosis process, countered by a strategy of focusing on strengths to counter this, lifelong negative impacts of diagnosis if communicated inappropriately, and possible changes in behaviour, such as becoming more cautious. Disclosure strategies were generally based on management, for instance on a need to know basis and/or to close friends. Two participants used disclosure as a 'litmus test' of other people's attitudes, including whether an employer had negative attitudes and should be avoided. Managed disclosure allowed participants to weigh up the potential risks and benefits to them to make a decision in each individual case, though they still encountered some negative reactions.

Participants managed energy, sensory issues and stress through distraction, relaxation and other strategies for reducing impact and avoidance. Distraction included other activities, such as listening to music or reading in waiting rooms and talking to a trusted person. Relaxation and de-stressing strategies included exercise, contact with animals, stimming, therapy and medication. Participants were critical of the limited varieties of therapy available and lack of information about them. Avoidance strategies included bringing in bottled water to avoid drinking unpleasant tasting tap water, getting off a busy crowded bus, withdrawing from activities if an unfamiliar person joined and not participating in activities in e.g. crowded noisy pubs. The non-participation and withdrawal strategies had the drawbacks of limiting social and other opportunities but were necessary for participants to avoid overload.

Social interaction strategies in addition to interests and strengths and socialising online, already discussed, included socialising with autistics, controlling interaction so they could leave when they wanted and having a small group of close friends. One participant mainly socialised in the pub but was critical of the heavy drinking involved. Other participants used the pub, when not too noisy and crowded, but this was not a strategy. Participants used explanation-based and exit and avoidance strategies, but the exit and avoidance strategies were more successful than explanation-based ones. In an interest-based variant of small talk, one participant used an innocuous topic, cats, to start conversations.

Participants had a variety of employment and job search strategies. This included researching firms they were applying to, actively choosing the prospective employer, including using non-work related criteria, apprenticeships and freelance work/self-employment. They considered that self-employment had the advantages of being able to work at home, which they could do even if unable to leave the house, avoiding employers who were not accommodating and did not understand autism and control of their own time and space and the project. Other strategies included using contacts and references, obtaining additional qualifications, impressing potential and actual employers by enthusiasm, volunteering for additional tasks and showing how good they were and asking to work at home to overcome difficult commutes. Participants had also moved around and changed industries to obtain employment. This range of strategies shows the commitment and creativity of participants in trying to obtain and maintain employment. Some of the strategies such as volunteering for additional tasks and frequent moves risk burn-out.

Other strategies included an informal name change, not listening to people with negative expectations and having multiple versions of the same clothes to avoid having to choose what to wear.

#### **7.4 Barriers**

All participants experienced at least a few barriers. However, this should not be taken out of context. Our second research question was about identifying barriers to increase understanding of the range of barriers autistic people experience and support us in providing recommendations to overcome them. Therefore, the existence of a large number of barriers does not automatically imply that autistic people generally have a poor quality of life. On the other hand, the nature of some of the barriers does imply that they are experiencing unnecessary and serious difficulties which threaten or have already reduced their quality of life and that it could be significantly improved by removing these barriers.

The main barriers were communication barriers and lack of support and resources. Other barriers included social interaction, stereotypes and lack of knowledge, noise and other sensory issues and energy drain, internal barriers, diagnosis and disclosure barriers, job related barriers and family problems.

Communication barriers included not being listened to and taken seriously, particularly by doctors and other professionals, but sometimes also by friends, and some doctors objecting to the use of notes, one of the preparation/communication

strategies. For instance difficulties were not taken seriously. Other barriers included the use of ambiguous and imprecise language, lack of clear communication about rules and expectations and lack of clear communication during training. Further communication barriers related to benefit forms not designed for autistic people and vague and abstract interview questions.

Social interaction barriers will be briefly discussed next as they are related to communication barriers. Several participants experienced barriers to workplace social interaction, which could affect their ability to get jobs. They included difficulties with banter, expectations about social interaction at work, social intranets and workplace excursions. Other barriers included bullying, exclusion and being made to feel bad about how they interacted with other people. Exhaustion both limited social interaction and could result from it. Finally, there could be difficulties participating if an unfamiliar person was involved.

Few participants had their needs met and in an appropriate way, as a result of a combination of a lack of resources and misunderstandings of these needs. Most participants had received no support post-diagnosis and available support was frequently insufficient and/or unsuitable. Where participants were offered therapy, they were concerned about limited options and a limited number of free sessions. There were long waiting lists for doctors' appointments and a few participants were pressurised to show they did not require (mental health) support. Promised support from organisations was not always provided.

Most participants mentioned stereotypes, which were generally based on perceptions of very low or non-existent abilities of autistic people. This had led to assumptions, including by doctors and diagnosis professionals, that people cannot be autistic if they had some abilities and assumptions of low capabilities if already diagnosed. These stereotypes also sometimes resulted in support not being provided if an autistic person appeared 'able'. Further stereotypes related to the bad behaviour and criminality of autistic people, encouraged by irresponsible media reporting. Lack of knowledge by professionals as well as the general public contributed to stereotyping and resulted in autism frequently not being recognised in women and girls and some participants rejecting it as a possibility for themselves.

Noise, sometimes accompanied by crowds, was the main sensory barrier, including in waiting rooms. It could inhibit social activities due to the need to avoid noisy crowded places. Other sensory issues included food smells, bright lights, some colours and some patterns, including on pavements. Some participants experienced difficulties in finding clothes which were both comfortable and suitable for work or interviews due to issues with textures. There was also a gender issue related to perceptions of what clothes were suitable for women. Work, social interaction and other activities caused energy drain for several participants and in some cases this had increased with age. This could limit social activities and the ability to look for a more suitable job so as to leave an unsuitable one.

The most common internal barriers were low self-esteem and anxiety, which was the default state of some participants. Several participants were very judgemental of themselves or compared themselves unfavourably to others. Anxiety and low self-esteem could lead to participants leaving jobs or other opportunities. Some

participants felt 'different' or experienced pressure to be 'normal', sometimes with negative physical impacts. Change could also be a problem.

Barriers related to diagnosis included lacking information as to what was involved, having to get a private diagnosis due to a doctor not considering them autistic and delays due to paperwork being lost. Barriers related to disclosure included negative reactions, which the managed disclosure strategies used by participants were unfortunately not able to prevent.

Job related barriers included submitting very large numbers of applications without receiving any feedback, making it difficult to improve job application strategies, not being given the same opportunities for training and promotion as other workers on the same grade and being given 'fob-off' answers when this was questioned. Workplace barriers included senior management questioning why they had been hired, important documents not being available, being given menial inappropriate tasks and sensory overload.

While some participants, as discussed briefly in section 4.1, had good relationships with their families, others had had serious problems with them and had no or minimal contact with them. Specific problems included being made to feel inadequate and 'broken', and unrealistic and damaging expectations, leading to bullying and current feelings of inadequacy and the need for perfection.

## **7.5 Good Practice**

Participants provided several examples of good practice. However, it was relatively sparse. This is probably a combination of the limited availability of good practice and some participants finding it difficult to identify and discuss it. In some cases they found it easier to describe good practice through the types of bad practice or support they did not want, including feeling ignored, ambiguous communication and feeling forced to fit in. Good practice was based on seeing autistic people as complete individuals with strengths and weaknesses and as people rather than diagnoses. It included acceptance, clear explanations, meeting sensory needs and supporting skill development, with all support and adaptations provided without stigmatising the person or making them feel different. It frequently involved proactive approaches. However, the diversity of autistic people and their needs means that individualised approaches developed in consultation with the person are also required.

## **8. Recommendations**

Consideration of the empirical survey data and the discussion in the conclusion section leads to the following recommendations. 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 General**

1. Scottish, UK and local government to be proactive about consulting autistic people rather than charities and giving them a major role in drawing up and implementing policy.
2. Valuing (autistic) people as they are rather than based on assumptions of they should be.
3. Supporting (autistic) people to achieve their maximum potential without assumptions about what they cannot do.
4. Holistic person-centred perspective which considers the whole person rather than just their 'conditions'.
5. Treating everyone with respect and not mocking or ridiculing people on account of differences or expecting them to function in a particular way.
6. Non-judgemental reactions to disclosure.
7. Moves from awareness to acceptance and valuing the contribution that autistic people can make to society as a result of their differences.

## **8.2 Communication**

1. Use of clear language and avoidance of ambiguous expressions, particularly by employers and public bodies.
2. All organisations should state their rules clearly and unambiguously and not have any unwritten rules.
3. Listening and taking seriously what (autistic) people say rather than dismissing it, downplaying it or reinterpreting it in terms of (lack of) emoting and body language. This includes accepting when an autistic person states they find something difficult or are in pain/distressed even if they do not act distressed.
4. Talking with people not about them and speaking to the autistic person not their companion(s), even if another person answers on their behalf
5. Talking respectfully about issues that affect autistic people and members of other minority groups, seeking their advice and opinions where appropriate and not ignoring them or assuming they are not present.
6. Allowing thinking time, not rushing to fill gaps in conversation and providing more structure.
7. Trying to avoid small talk/social noise type questions and only asking questions which require a real answer when talking to autistic people.

## **8.3 Overcoming stereotypes and misinformation**

1. Widely available provision of clear information about autism and other neurodivergent conditions, including neurological aspects.
2. Careful and responsible reporting of stories involving autistic people and not stating when the alleged perpetrator or person convicted of a (violent) crime is (assumed to be) on the autistic spectrum (or a member of another minority group), as this is not relevant and encourages prejudice and discrimination.

3. Ensuring that diagnosis does not lead to reduced expectations of autistic people, particularly children and young people, or any negative treatment

#### **8.4 Technology**

1. Development of apps to practice social skills and software to support understanding of ambiguity.
2. Support for setting up web sites, forums etc where autistic people can share strategies.
3. Development of apps to indicate how crowded and noisy particular public transport vehicles and routes are likely to be and to identify the vehicles and routes that are likely to be quietest and least crowded.

#### **8.5 Leisure activities**

1. Encouragement and support for exercise for autistic people
2. Involving autistic people in planning inclusive social events, as more likely to be aware of the barriers and think creatively about what would be inclusive and enjoyable.
3. Times when sports centres and leisure activities are open only to autistic people and have low sensory stimulation
4. Encouraging autistics to have fun

#### **8.6 All services**

1. Recognition of the value of the real lived experience of autistic and other clinical professionals and service providers
2. Drawing on real life lived experiences to improve health care and other services for autistic people, people with mental health issues etc.
3. Training for all services providers and other professionals on autistic equality by autistic people
4. More options for interactions with services providers including providing dedicated regularly monitored email address and phone number staffed by people with autistic equality training.

#### **8.7 Health services**

1. Active encouragement for autistic people, people with mental health issues etc to enter medical profession and removal of barriers to them doing so.
2. Closing the empathy gap between autistic people and the medical establishment
3. Provision of medical cannabis through the health service
4. More direct access to specialist health services without having to go through GP

#### **8.8 Mental health services**

1. Taking mental health needs as seriously as physical health ones

2. Implementing measures to reduce mental health problems by dealing with underlying causes, including isolation, lack of community, discrimination and workplace and other stress.
3. Improved access to mental health services, including through mental health specialists in general practices and options for self-referral
4. Provision of support and treatment for PTSD (post-traumatic stress disorder), with no time limits on when the stress occurred.
5. Providing of a much wider range of treatment options, including talking and other therapies, long-term and multi-disciplinary approaches, not just cognitive behaviour therapy, as well as clear information about the different options and their differences.

### **8.9 Benefits**

1. Changing the philosophy of the (disability) benefits system to ensuring that everyone gets their entitlements rather than trying to reduce the number of claimants.
2. Treatment of all claimants with respect and ensuring their dignity is maintained.
3. Higher rates of benefits
4. Removing the need for required benefits reassessments, as autistic people are going to remain autistic even if they develop new strategies.
5. Providing advance information about when any assessments will take place and what they will involve with
6. The option for home assessments and assessment without face to face meetings.
7. Assessments based on full understanding of the needs of autistic people and other people with hidden disabilities

### **8.10 Diagnosis**

1. Increasing the number of diagnosis facilities to make NHS diagnosis available in all areas and significantly reduce waiting times
2. Providing easier access to NHS diagnosis, including direct access without a doctor's recommendations and doctors responding positively to requests for referrals
3. Appropriate and clear information about how the diagnosis will be conducted, the professionals involved and the venue to be provided in advance.
4. Flexibility about who the person being diagnosed brings with them and no requirement to bring particular people e.g. parents.
5. Avoiding stereotypical assumptions about who is and is not autistic, including that women and girls, people who do not stim and people who seem 'able'/successful cannot be autistic.
6. The purpose of diagnosis should include identify support needs and enable support to be better targeted, not just to determine whether the person is autistic. This should include referring people who are not autistic elsewhere for support.
7. A standardised approach to diagnosis should be developed by a group including both autistic people and diagnosis professionals.

### **8.11 Support**

1. Availability of post-diagnosis information and follow-up meetings to discuss what diagnosis means in practice, reactions to it, disclosure and support.
2. Production of information and advice to support disclosure in different situations, including in the form of a card. This should include suggested responses to different reactions and responses for different cultures and contexts.
3. Significantly increasing the quantity and variety of support available to autistic people, both immediately post-diagnosis and subsequently.
4. The availability of support and self-help groups in all areas and clear information about what they do.
5. All support and advice should be confidential, non-judgemental, person-centred and take account of differences.

### **8.12 Therapy, counselling and health**

1. Entitlements to free NHS therapy to be based on need not artificial limits.
2. Increases in the numbers of autistic professionals able to provide support.
3. Availability of counselling by counsellors with an understanding of autistic people and their needs.
4. Opt-in schemes for monitoring the health and well-being and additional support needs of autistic (and other disabled) people
5. Widespread availability for free animal therapy of different types.

### **8.13 Support 'team'**

1. Additional resources should be provided by national and local government to organisations of appropriately trained professionals and volunteers to staff the support team system.
2. Autistic people should have a significant role in the running of these organisations.
3. Each autistic person who wants it should be entitled to a small support team and an agreed number of hours of support with all support provided free of charge.
4. If desired, the autistic person should be introduced to the team and let get to know them/build up trust in over a period of time. - typo, correct
5. The support provided should be tailored to the autistic person and take account of their interests and needs.
6. Support provision should take place at appropriate times to enable the person to engage in activities of interest.
7. Support provision could include general mentoring/explanation of expectations in different situations; support in organising and being accompanied to appointments and social and other activities; acting as an intermediary in various circumstances; support in carrying out household and daily living activities; and non-expert support in completing tax returns and other financial activities.

### **8.14 Education and support for students**

1. Sufficient support of all types to students, including specialist mentoring and study skills support, with a simple assessment process
2. Provision of up-to-date rather than older model laptops and desktop computers and the removal of the requirement to contribute £200
3. Staff teaching about autism and autistic people should have up-to-date and accurate knowledge, including autism equality training by autistic people and the most recent research literature .
4. More flexible requirements by regulatory bodies including with regards to hours e.g. reduced requirements or meeting them over a longer period, with funding to do so.
5. Facilitating learning in the most appropriate way.
6. Person centred education which encourages all learners to develop strengths and minimise weaknesses and, as much as possible draws on interests, including to motivate learners
7. Autism (and other disability) equality training by autistic (and other disabled) people in schools for both students and staff from primary school on.

### **8.15 Preparation for entering employment and post-school education**

1. More information, support and guidance on transition from education to employment and from school to post-school education.
2. More publicly available information about what it is really like for autistics on a variety of courses at different universities and at a variety of workplaces etc..
3. Availability of information about and free short courses on independent living skills
4. More information, including specially targeted at autistic people, on starting and developing a career, both through employment and as a freelance/self-employed.
5. More apprenticeships specially targeted at autistic people
6. Support and training for autistics in promoting and 'selling' themselves
7. Continuation of support for those who have had it at school.
8. Modification to equality legislation to permit employment brokers to only support autistic people (or other named marginalised groups).

### **8.16 Employment**

1. The availability of confidential mentoring for all workers.
2. Additional support to identify and prevent or mitigate (potential) workplace problems, particularly those involving autistic people, at an early stage before they become serious.
3. Buddy schemes.
4. Legal requirement for employers (other than very small ones) to provide and publicise part time and job share options
5. Allowing cats and dogs in the workplace, unless there is a good reason not to do so.
6. Greater flexibility in working hours for all workers
7. Providing quiet, calm places for breaks e.g. soundproofed pods with comfy sofas and quiet rooms for working in for employees without personal offices.
8. Workplace social events which are both inclusive and genuinely voluntary, with no pressure to participate and the option to leave at any time.

9. Unions to be more proactive about recruiting and supporting autistic and other disabled workers, developing and publicising good practice, using good practice where it already exists and putting pressure on employers about reasonable adjustments

### **8.17 Workplace information and communication**

1. Clear information in a variety of formats about expectations, rules, hierarchies and job roles to be easily available and provided to all new workers, whatever their employment status.
2. Ensuring that there are no unwritten rules, hidden expectations or similar. Providing clear explanations about opportunities that may not be obvious and the requirements for success
3. Encouragement to ask questions, clear information about who to direct questions to and a guaranteed response in a short time period.
4. Praise and recognition for all workers who do their job well rather than cultures of blame

### **8.18 Interviews**

1. Interview questions and information about the venue and interviewers should be sent to all candidates in advance unless there are good reasons not to.
2. Care in formulating interview questions, keeping them on topic and avoiding social chitchat.
3. Judging interview performance by answers to questions rather than dress or social interaction.

### **8.19 Reasonable adjustments - general**

1. Strengthening legal requirements to reasonable adjustments in all domains, including for all workers, regardless of employment status, length of contract etc.
2. Provision of additional resources by the state to make all reasonable adjustments cost neutral and overcome delays in their implementation
3. Proactive approaches, including consultation with autistic (and other disabled) students and workers and asking all individuals their requirements when starting a new job or educational institution
4. Requiring professional regulatory bodies to apply reasonable adjustments to their accreditation requirements so they can be met in different ways.
5. Applying reasonable adjustments sensitively and without outing the person as disabled or different.
6. Recognising that autistic workers may have additional impairments that affect their needs for reasonable adjustments
7. Support in determining needs for reasonable adjustments
8. Recognising that different autistic people need different reasonable adjustments, so that not all of those suggested below will be required by all autistic workers.

### **8.20 Suggested workplace reasonable adjustments related to time and place**

1. Option to work at home for part or all of the week.
2. The option to work in a small quiet room on their own or with only a few people, noting that some autistic people are not able to share workspace
3. Quiet spaces autistic people can retreat to for breaks or to work it when necessary if they do not have quiet individual offices
4. The option to work in a small group or on your own with some contact with other workers.
5. Flexible working schedules agreed together with the worker. This could include flexible working hour, longer and/or more frequent breaks, avoiding consecutive meetings without a break or alternatively blocking activities.

### **8.21 Suggested interview reasonable adjustments**

1. Being able to wear casual comfortable clothes to interviews without any negative effects on the chances of getting the job.
2. More flexible approaches to interviews, including one to one interviews and a choice of interview style
3. Quiet locations with appropriate lighting and removal of e.g. clocks and mirrors.
4. Additional time and breaks, if necessary
5. Follow-up questions if there are misunderstandings or the initial answer does not fully answer the question
6. The option of alternatives to an interview, such as a few-day trial in the workplace.

### **8.22 Other suggested workplace reasonable adjustments**

1. Assignment in consultation with the worker of appropriate work tasks, which minimise the need for multi-tasking and immediate responses and do not involve a lot of short duration tasks.
2. Except in the case of real workplace emergencies, not changing tasks once they have been assigned unless the worker asks for this.
3. Options to avoid certain tasks carried out by other workers e.g. those involving phone use.
4. Determining and using autistic workers preferred communication methods, for instance email rather than phone or to email first before phoning.
5. Providing documents in accessible formats
6. Personal assistance and support, including support workers, specialist mentors and job coaches
7. Regular confidential meetings with specialist mentors with trained by autistic people and experience of working with autistics for autistic employees. Specialist mentors should be able to support workers in a variety of ways, including speaking to managers, colleagues and clients, explaining expectations and managing sensory issues
8. The availability of training in alternative formats, including one to one training in the worker's workspace.

### **8.23 Research**

1. Transport needs of autistic people

2. Effective reasonable adjustments for autistic people in the workplace, education and services, including case studies of their use
3. Effective measures to eliminate bullying
4. Stereotyping and how best eliminate it.
5. Apps and other software to practice social skills and support understanding of ambiguity.
6. Apps and other software to provide information about noise and other sensory issues in particular locations, internal and external.
7. How gender and other personal characteristics affect the use of masking and imitation.

## 8.24 Other

1. Building council and other low cost accommodation in quiet areas and with good sound insulation and taking account of noise issues when offering accommodation to autistic people.
2. Recognition that issues can be traumatic or triggering and not asking others to recount their traumas without good reason and in an appropriate context.
3. Recognition of the diversity of autistic people and that all autistic people have strengths as well as weaknesses (just like non-autistic people)
4. Autistic-friendly public transport, including which takes account of sensory issues and allows the avoidance of crowds
5. Support and encouragement for autistic people to use their interests to make connections with others and obtain employment
6. Organisation(s) run by autistic people to give them a voice.
7. Not telling children and young people that they are 'bad'.

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