An Auternative Research Project: Strategies, Barriers, Good Practice and Recommendations – Final Overview Report

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

Summary: The An Auternative Research Project is an autistic led project with a majority autistic team supported by an Advisory Board of autistic people. The project investigated the strategies used by autistic people and the barriers experienced. Project research activities included a literature survey, a questionnaire, a diary exercise, interviews and an impact survey, all with autistic people. We obtained 223 completed questionnaires, eight diaries, 21 interviews and 21 completed impact surveys. This report provides an overview of the results we obtained, including some of the strategies and barriers, a brief overview of the good practice and a selection of recommendations, from the questionnaire, interviews and impact survey. The volume of data we obtained meant that we were unable to analyse the diaries within the project, but intend to do so subsequently.

Keywords: autistic, strategies, barriers, good practice, recommendations

1. Introduction

The research project idea came out of a Scottish Autism Research Group seminar in 2016. Several autistic participants were concerned about the approaches presented, which focused on 'interventions' and the limited, if any, understanding of real autistic lived experiences in these interventions. 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. Zyggy Banks supports autistic students at the University of Leicester. Callum Watson is an assistant psychologist who has formerly supported autistic students. Michael, David, Panda, Callum and Zyggy are all employed as research assistants by the University of Glasgow.

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

We will use the terms autistic people and autistics for everyone on the autistic spectrum, as the terms preferred by the autistic community (Kenny et al., 2016), but will use the terms used by participants in quotations. Our approach to autistic people is based on the social model of disability (Johnstone, 2012; Swain et al., 2003) and the compatible neurodiversity model. Thus, we have an understanding of autistic people experiencing social, attitudinal and infrastructural barriers and frequently also social exclusion (social model of disability) as 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 commonly used deficit based medical definitions and approaches. The focus on deficits has unfortunately affected research. It also continues to affect attitudes to autistic people and lead to very negative perceptions.

The report is organised as follows. Section 1.1 presents the research questions and research activities and section 1.2 and overview of the participants. Summaries of the strategies, barriers, good practice and recommendations we obtained are presented in sections 2, 3, 4 and 5 and conclusions given in section 6.

1.1 Research Questions and Activities

The research project investigated 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 experienced by autistic people in causing most of their problems. 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 are including some of our main recommendations for doing this in this report.

We carried out a number of research activities to investigate these questions. They included a literature review (Mery et al., 2018), a questionnaire for autistic people (Hersh et al., 2020ab), a diary exercise and interviews with autistics (Hersh et al., , 2020c), as well as a short questionnaire on the impacts of the research on the project team members, members of the

Advisory Board and the research participants (Hersh et al., 2020d).   This research presents a summary of the results we obtained.

1.2 Overview of Research Participants

We obtained 223 useable questionnaire responses, 21 interviews and 21 responses to the impact questionnaire. The gender distributions were 58% female, 33% male, 6% non-binary and 4% other for the questionnaire and 33% female, 62% male and 5% non-binary for the interviews. The gender representation of the questionnaire in particular is not typical of that reported for the autistic population. However, another recent study had an even high percentage of female participants (Livingston et al., 2019) and the previous low representation of autistic women in research makes this higher representation very welcome.

Both the questionnaire and interview had a good age distribution, but no participants over 74. For the questionnaire 89% were white, 8% black or mixed race and 3% other. For the interviews the figures were 90% and 10%. 37% were working class, 47% middle class, a few upper class and 14% other for the questionnaire. 43% were working class, 29% middle class, 5% other and 23% unspecified for the interviews. 97% of questionnaire participants used speech most of the time and 19% used another form of communication at least some of the time either with speech on its own, with a system on a mobile device or PC used by 12%. All interview participants used speech most of the time, but 62% used another from of communication at least some of the time. Five impact participants were project team members, two members of the Advisory Board who had participated in the research and 16 research participants. They were not asked for personal data to avoid identities being guessed.

2. 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 disadvantages and/or costs. The drawbacks and costs of strategies provided by participants are also 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.

2.1 A trusted or support person: This was a common strategy used by most participants and the second most commonly used social interaction strategy in the questionnaire responses. It was used to support access and effective use of all services and in job search and the workplace. Individuals

who provided support included parents and other family members, partners, friends, support workers, employment advisors, specialist mentors and consultants. Organisations included trade unions and citizens' advice. Interview participants seemed to prefer family and used friends less often and professionals when specialist expertise was required or other people were not available. The trusted person's roles included providing moral support, advocacy, accompanying the person to meetings, speaking or phoning for them, including to book appointments, and providing (expert) advice and practical support. Other roles included intervening in difficult situations, explaining and helping them complete benefits and job application forms and acting as an intermediary with work colleagues. Although participants were very positive about this strategy, several potential drawbacks were mentioned. They included limited availability, the possibility of dependence, losing control of the situation, imbalances in relationships and possible impacts on the trusted person.

2.2 Masking and imitation: Masking was used by a significant majority of participants and was the most frequently social interaction strategy for questionnaire participants. It 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. Masking was used as a workplace strategy to manage and maintain relations, but at the cost of exhaustion and burnout. Imitation included adopting the appearance and/or behaviour of an admired person and finding a person with similar colouring and body type and copying what looked good on them. Comments were varied. Many participants found masking essential. Several participants noted the costs, including exhaustion, emotional distress and not knowing how you feel. Masking could also make it more difficult to get a diagnosis. There were differences between the responses of the questionnaire and interview participants. In general the questionnaire participants were more positive, whereas several of the interview participants had stopped or were trying to reduce or eliminate the use of masking and their use of masking was frequently in response to bullying.

2.3 Research, preparation and planning: The related strategies of research and preparation were used by most participants. However, planning was less popular. They were used to improve access to diagnosis and other services and the chances of obtaining employment, as well as in social interaction. Preparation including keeping a diary of difficult experiences, preparing notes, lists and scripts for doctors' visits, preparing social scripts and small talk for different situations and remembering something important to the person. Preparation for interviews included asking for and preparing questions in advance and reading body language books. Preparation could also make it easier for participants to use the phone. Research included obtaining evidence and preparing the case to support obtaining a referral, diagnosis or medical treatment investigating groups before joining them and firms before applying for jobs. Planning included day to day planning of

work/studies. Participants generally found these strategies very useful, but they had some disadvantages. Prepared scripts could reduce anxiety, but only if the other person followed them and any deviations could cause panic. They could also make participants appear robotic and they could forget the script or not have access to it. Research and preparation could be time-consuming, though some participants enjoyed them.

2.4 Technology: Participants used a number of different technologies, particularly commonly used technologies such as email, text, Internet, online chat, Whatsapp, Skype and Facebook. These technologies were used to contact services, online ordering, socialising and keeping in touch with a long-distance partner. Several participants preferred email or other written communication to phoning as it was less mentally challenging and tiring and allowed thinking time. Technology, including online games provided popular alternatives to face-to-face socialising, including with other autistic people. Specialised software included planning tools e.g. Trello, Claroread (to tint the screen and provide speech output for text) and mindmapping software for structuring ideas. Specialised hardware included a wheelchair, Irlen lenses, noise cancelling headphones and a Livescribe pen to link notes to recordings. A few participants used (alternative and augmentative) communication systems (AACs) to support face to face communication. This included a phone text-to-speech programme and phone notes.

2.5 Analysis and reflection: Several participants engaged in analysis and reflection and a few explicitly used logic. Analysis and reasoning were used to understand both what was happening in a situation and emotions. Questionnaire participants used this strategy more frequently than learnt strategies to understand emotions. One participant had successfully used a spreadsheet to identify their current partner. The overall view was that this approach could be useful in some circumstances, including helping participants understand what they should and should not do. However, many participants had a tendency to overthink and overanalyse. This could be useful in some circumstances, but also exhausting. There were again differences between the experiences of questionnaire and interview participants with the interview participants more positive and the questionnaire participants more concerned about overanalysis leading to incorrect conclusions. There is also the issue of whether analysis as a useful strategy can be separated from overanalysis.

2.6 Using diagnosis and managing disclosure: In addition to research and preparation already discussed, strategies to obtain a diagnosis included self-referral, identifying a not for profit firm that did diagnosis and saving up for a private diagnosis. Many participants used diagnosis to understand themselves and their issues better, to improve their self-esteem and to challenge negative narratives. It was also used to improve understanding and/or relationships with significant people. An interview participant had become more cautious about going out since diagnosis, but was ambivalent

about whether this was a good or bad thing. Other concerns related to the power of diagnosis professionals and the damage that inappropriate communication of the diagnosis could do, and the need for a more rounded approach to diagnosis to avoid the autistic person being made to feel that they only have weaknesses and not strengths as well. One participant used a strategy of focussing on their strengths to counter this. Disclosure strategies were generally based on managing disclosure, frequently on a need to know basis, including to managers and close friends. A few participants disclosed widely. Some questionnaire participants used disclosure as a workplace strategy and one interview participant used it to determine whether the organisation was sufficiently welcoming to autistic people for them to want to work there. Disclosure was also necessary to get reasonable adjustments, with asking for them another workplace strategy. However, there were potential risks of misunderstandings and negative reactions. A related strategy, which could possibly also be used in other contexts, was asking what doctors knew about autism.

2.7 Strengths and interests: Participants used their strengths and interests in a variety of ways, including in employment, leisure and social activities and relaxation and destressing. One participant considered that the most suitable jobs combined interests and strengths. Not unsurprisingly using interests worked best with other people with shared interests. Otherwise, problems could occur. However, participants did not mention looking for groups with common interests e.g. on the internet.

2.8 Managing energy and sensory issues: These strategies can be loosely divided into three groups. The first group of strategies for minimising exposure included taking breaks in quiet areas and using them for relaxation, asking for a quiet room for interviews, avoiding networking and talking to people in the workplace, avoiding social activities in noisy crowded pubs and getting off crowded buses. This had the disadvantages of restricting social activities and a possibly extended wait for the next bus. Energy drain minimisation strategies included prioritising activities. The second group of relaxation and destressing strategies included exercise, contact with animals, stimming (sometimes unobtrusively), meditation, music, therapy and medication**.** Several participants had required strategies to access (appropriate) therapy, including self-referral and obtaining a doctor's signature without seeing the doctor. The third group of distraction strategies involved reading, listening to music, talking to a trusted person or other activities to distract their attention from, for instance, noise or troublesome thoughts.

2.9 Communication and social interaction strategies: Social interaction strategies not already discussed included a small circle of close friends, maintaining control of interactions e.g. by excuses to leave early or having their own transport to leave when they wanted.   Communication strategies included asking doctors to repeat things and write them down and this could be used in other contexts. Several interview participants used explanation-

based strategies and/or exit and avoidance strategies, with the latter more successful. Starting conversations by talking about innocuous topic such as cats worked to some extent. This could be considered small talk about a topic of interest to the autistic person. Several participants used low tech communication aids, including an 'I am autistic card', note cards to write on and a traffic light system to indicate whether you want others to initiate conversation or not talk to you.

2.10 Employment strategies: Strategies not already discussed included considering non-work factors in choosing an employer, freelance work/self-employment and moving around and switching industries to find jobs. Self-employment was considered to have advantages to autistic people in terms of control of when and where they worked and avoiding workplace difficulties. It was sometimes combined with strategies for developing the business e.g. doing half-price trials. Other strategies included obtaining additional qualifications, using contacts and references and impressing potential or actual employers by doing more than asked for. Further strategies included volunteering and autistic-friendly employment. While volunteering was sometimes successful, it could lead exploitation as cheap labour and not lead to employment. Several participants obtained reasonable adjustments, but did not have particular strategies for doing this. Small numbers of participants had mentors, possibly due to low availability. Autistic-friendly work-places were considered to include support work, menial work (as less expectations), working with animals to 'destress' using special interests having an 'excellent manager' and 'home-working'. Some participants used contacts, recommendations or networking to obtain jobs, though others found networking difficult.

2.11 Other strategies: Humour was used by most of the questionnaire participants and their personalities by a significant minority. However, they were not mentioned by interview participants as strategies and were not major themes in questionnaire comments. They were often effective, but possibly most suitable for reasonably confident people with good self-esteem. This is unfortunately not the case for many autistic people. Other strategies included persistence, trying things and self-acceptance and related strategies.

3. Barriers

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

3.1 Communication barriers: Most participants experienced communication barriers. They included not being listened to or taken seriously, the use of

ambiguous and imprecise language and being misunderstood, including as a result of inappropriate expectations about body language and tone of voice. Distress could be ignored if not also shown in body language. Difficulties were often played down. Communication with receptionists was sometimes experienced as hostile, intrusive and requiring unnecessary personal information and could impede access to appropriate health care advice and treatment. Benefits forms were complicated, unclear and seemed intended for physically disabled rather than autistic people. Job application forms also had vague and unclear questions. Communication barriers in interviews included not understanding expectations, bluntness and difficulties with social awareness and interaction. Other barriers included difficulties with small talk/chit chat, sometimes experiencing objections to the use of written notes as a communication aid, difficulties in entering group discussions and rules and expectations not being communicated clearly.

3.2 Social interaction barriers: Several participants experienced barriers to social interaction at work. This could make if more difficult to get jobs and lead to marginalisation or being considered 'weird'. Other barriers involved bullying, exclusion or being made to feel bad about the way they interacted with others. Other barriers involved tiredness impeding or following social activities, difficulties with unfamiliar people and concerns about doing things wrong and other people's reactions.

3.3 Expectations of phone use and lack of alternatives: Most questionnaire participants and several interview participants experienced some difficulties with phone use and preferred email or other written communication. Some reasons for this are given in section 2.4. The need to phone a doctor to make an appointment could act as a barrier to referral and consequently diagnosis. The need to phone also acted as a barrier to obtaining benefits. Email and online booking systems were not always available.

3.4 Lack of (appropriate) support and resources: Few of the participants had their needs fully and appropriately met. Barriers included lack of resources and misunderstandings of their needs. Available support was frequently insufficient and/or unsuitable e.g. limited hours of therapy and lack of options. There were long waiting lists for doctors, diagnosis and mentoring and sometimes much delayed responses to requests. Some participants were put under pressure to show they did not require mental health support.

3.4 Stereotypes and lack of knowledge: Most participants mentioned stereotypes, frequently based on perceptions of autistic people as totally incapable. This led to assumptions, including by doctors and diagnosis and other professionals, that they could not be autistic if they were able to do anything and that they had limited capabilities if already diagnosed. A lack of knowledge amongst many professionals and the general population

contributed to stereotyping. A combination of lack of knowledge and stereotypes was still contributing to autism not always being recognised in women and girls, participants not being referred by doctors for diagnosis if they did not 'flap enough' or seemed 'well adjusted' and some participants initially rejecting the idea they could be autistic. Participants who did not 'look autistic' could experience difficulties in getting benefits. Employers 'fear and misunderstanding' sometimes led to a lack of even basic courtesy. Another stereotype, unfortunately encouraged by irresponsible media reporting, was that violent crime and anti-social behaviour were linked to autism.

3.5 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. Noisy crowded waiting rooms and other areas were a particular problem. They affected access to the health service and the ability to communicate effectively with medical professionals. Noise levels in job and assessment centres and the lack of private rooms affected access to benefits. Noise and crowds could inhibit social activities.   Other sensory issues included textures and clothes, food smells, including from kitchens in open plan offices, bright lights, certain colours and patterns, including on pavements. Several participants experienced energy drain and exhaustion from work, social interaction and other activities. This limited their ability to e.g. try to change unsuitable jobs and engage in social activities.

3.6 Internal barriers: Participants had a number of internal barriers, with low self-esteem and anxiety the most common for interview participants. Several participants were very hard in their self-judgements and compared themselves unfavourably to others. Anxiety was the 'default' state of some participants. Other barriers included difficulties in adapting to change, pressures to be 'normal'**,** feeling different, poor executive functioning, burn-out, stress and exhaustion. While these issues can be seen as internal, participants also described a variety of negative experiences and negative external circumstances which could have had a role. However, participants tended to blame themselves and consider themselves inadequate rather than considering the role of lack of understanding, support and other barriers in their external situations.

3.7 Diagnosis and disclosure: Barriers related to diagnosis included a lack of information about what was involved, difficulties in obtaining doctors' referrals, including due to stereotypical assumptions about autistic people, long waiting lists and even 'getting lost in the system'. NHS diagnosis was not always available or only available to people with additional conditions. There were also concerns about lifelong impacts of inappropriate communication of the diagnosis. Participants were rarely if ever given information on how best to disclose and some participants had experienced negative reactions which they had found distressing.

3.8 Barriers to obtaining benefits: Barriers to obtaining benefits included being discouraged by personnel, poor quality advice and badly designed forms. Further barriers included the need to sign on in person, exacerbated by the need to queue, poor sensory environments, the lack of privacy 'disrespectful' staff and a feeling of 'being judged.   The need for phone use, including form completion by phone, was another barrier. Benefits could be turned on and off repeatedly without reason, leading to insecurity.

3.9 Job related barriers: Barriers to obtaining a job not already discussed included not obtaining feedback on unsuccessful job applications and the use of on-line personality tests which have been criticised as discriminatory by autistic individuals. Barriers in employment included excessively demanding, menial or otherwise unsuitable tasks, not being given the documents or other tools to do the job properly, and sensory overload, particularly in large open plan offices. Barriers to obtaining reasonable adjustments included lack of space to negotiate them, not being diagnosed or identifying as autistic when they started work and concerns about disclosure. Participants also expressed concerns about not obtaining promotion and not being given the same training and promotion opportunities as colleagues.

3.10 Family problems: Several participants had experienced major difficulties with their families. This included being estranged from part or all of the family as the result of abuse or other bad experiences. Further negative issues which caused barriers included unreasonable and damaging expectations and being made to feel inadequate, including for not being 'normal' or meeting gendered and cultural expectations.

4. 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.   Person-centred acceptance was identified as an important compenent of good practice for participants and is a clear counter to the experiences of stereotyping, not being listened to and being misinterpreted in the barriers sections. Good practice was based on seeing autistic people as complete individuals with strengths and weaknesses and as people rather than diagnoses. 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. Good practice 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.

5. Impacts on Project Team, Advisory Board and Research Participants

In general participants' experiences of the project were positive and they learnt various things from it. They had a greater understanding of the strategies they used and more confidence in using them, as well as an interest in trying new strategies, though a few participants were still unsure as to what strategies were.   Participants had generally enjoyed being interviewed by another autistic person, though one participant found having to consider past experiences difficult. They found the diary exercise useful in understanding their experiences. Participants had become aware of strategies they used unconsciously as well as the great diversity of strategies. Several participants increased their self-acceptance and improved their self-esteem. Members of the project team had enjoyed the experience, particularly the interaction with other team members and learnt a lot of lessons to carry into future projects.

6. Recommendations

The project obtained a very large number of recommendations and we will be looking at the best means to disseminate them and encourage their implementation. Some of the main recommendations are presented below. Additional recommendations and the details of the research on which they are based can be found at Hersh et al., (2020abcd).

6.1 General

1. Scottish, UK and local government to be proactive about consulting autistic people directly and giving them a major role in drawing up and implementing policy.
2. Treating all autistic people with respect, empathy and acceptance, avoiding assumptions and providing support to enable them to achieve their maximum potential
3. Listening to what the autistic person is saying and not reinterpreting it in the light of their body language, your assumptions or other factors
4. All communication by service providers and other organisations should be clearly expressed rather than ambiguous and (organisational) roles and expectations should be clearly stated.
5. Talking with people, not about them, speaking to the autistic person not their companion(s), even if another person answers on their behalf, and allowing for thinking time in responses.
6. Careful and responsible reporting of stories involving autistic people, for example not stating when the alleged perpetrator of a crime is (assumed to be) on the autistic spectrum (or a member of another minority group).

7. The Scottish and UK governments to set up working groups of autistic and other neurodivergent people to produce clear information about autistic and other neurodivergent people and distribute this widely.
8. Autism equality training by autistic people for all service providers and organs of national and local government and financial and other support from government or local authorities for training autistic people as trainers to do this.
9. Proactive approaches to reasonable adjustments including consultation with autistic (and other disabled) students and workers and asking all individuals their requirements in educational institutions, employment and services.
10. Research about autistic people should involve autistic researchers and community members in significant positions in the research.
11. Funders of autism research should engage more directly with autistic researchers and significantly increase the proportion and amount of funding for non-medical research.

6.2 Research questions to be investigated

1. The causes of the low self-esteem, high self-blame and high levels of anxiety of many autistic people and the strategies and other approaches that can be used to overcome this.
2. The effectiveness of the different strategies used by autistic people and the individual, circumstantial and other factors that affect this.
3. Developing a range of communication, social interaction, travel and support apps for autistic people.
4. The use of reasonable adjustments to improve access to employment and services.
5. The role and value of a strong positive autistic identity and the factors that contribute to the identities of autistic people.
6. What are the transport needs of autistic people.
7. Using technology to support/promote communication by non-verbal people.
8. What are the motivations for masking and imitation, how they impact on mental health and exhaustion and the role of stigma in the motivation for masking.

6.3 Support

1. Significantly increasing the quantity and variety of support available to autistic people, both immediately post-diagnosis and subsequently.
2. All support and advice should be confidential, non-judgemental, person-centred and take account of differences.
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 and tailored to them.
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.

5. Foundations that currently support autistic charities are strongly encouraged to deal directly with autistic individuals and organisations.

6.4 Suggested interview reasonable adjustments

1. The option of alternatives to an interview, such as a work trial in the workplace.
2. More flexible approaches to interviews, such as one to one interviews and interviews focused on what you can do.
3. Provision of questions in advance, where feasible
4. Being able to wear appropriate clothes which do not trigger sensory issues, cause distraction or are influenced by gendered stereotypes to interviews and in employment without any negative affects on the chances of getting the job.
5. Quiet locations with appropriate lighting, removal of e.g. clocks and mirrors and additional time and breaks, if necessary

6.5 Suggestions for workplace reasonable adjustments

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,
3. Quiet spaces people can retreat to for breaks or to work it when necessary if they do not have quiet individual offices
4. 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.
5. 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.
6. Options to avoid certain tasks carried out by other workers e.g. those involving phone use.
7. Determining and using autistic workers preferred communication methods, for instance email rather than phone or to email first before phoning.
8. Providing documents in accessible formats
9. Confidential personal assistance and support, including support workers, specialist mentors and job coaches, provided by external agencies.
10. The provision of training in alternative formats, including one to one training in the worker's workspace and involving external agencies if necessary.

7. Conclusions

This report summarises the results of an innovative autistic-led research project. 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 devoping a model of good practice.
7. Using the results to determine detailed recommendations.

The results include strategies used by autistic people, barriers encountered, the rather sparse good practice and recommendations for making real change to the lives of autistic people. Although sparse the good practice contained elements of a model for good practice which could be further developed. The results were obtained from questionnaires, interviews and a diary exercise involving autistic people and an impact questionnaire involving everyone with impact to the research. The research was based on co-production and ethics. The lived experiences of autistic people, obtained from research participants, the Advisory Board and autistic team members, were central to all aspects of it.

One of the main stereotypes identified by the research was that autistic people are totally incapable. The presentation of a number of strategies used by autistics is therefore important in showing that autistics are able to show agency and take control over their own lives. We both recommend the strategies to autistic people and those who support them as a resource and advise that no strategy is appropriate to all autistic people and in all circumstances. It is important that autistics choose strategies to take account of the strengths, interests and other characteristics and the particular situation in which they are being applied.

The recommendations presented here cover some of the main areas where we consider change necessary. A full list of recommendations will be available from our website https://anauternative.uk/. Project team members are also available to give advice on their implementation.

References

Hersh, M. , Elley, S., Banks, Z., Mery, P., Dawson, M., Cowan, D. and Watson, C. (2020a) Accessing services and social interaction: strategies used by autistic people. In: Milton, D., Murray, D., Ridout, S., Martin, N. and Mills, R. (eds.) The Neurodiversity Reader. Pavilion. ISBN 978191275539 (In Press).

Hersh, M., Elley, S., Banks, Z., Mery, P., Dawson, M., Cowan, D. and Watson, C. (2020b). An Auternative Research Project: Strategies, Barriers, Good Practice and Recommendations – Results from Questionnaire. https://anauternative.uk/an-auternative-questionnaire-report.pdf.

Hersh, M. , Elley, S., Watson, C., Mery, P., Dawson, M., Cowan, D. and Banks' Z. (2020c). An Auternative Research Project: Strategies, Barriers, Good Practice and Recommendations – Results from Interviews. https://anauternative.uk/an-auternative-interview-report.pdf

Hersh, M. , Elley, S., Watson, C., Mery, P., Dawson, M., Cowan, D. and Banks' Z. (2020d). An Auternative Research Project: Results from Survey of Impacts on Project Team, Advisory Board and Research Participants. https://anauternative.uk/an-auternative-impact-report.pdf

Johnstone, D. (2012). An introduction to disability studies. Routledge.

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

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

Mery, P., Watson, C., Banks, Z., Cowan, D., Hersh, M., Elley, S. & Dawson, M.(2018). An Auternative critical literature review. Available at https://anauternative.uk/documents/2018/11/an-auternative-critical-literature-review.pdf

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

Acknowledgements