

## **An Auternative Research Project: Results from Survey of Impacts on Project Team, Advisory Board and Research Participants**

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### **1. Introduction**

The research project idea came out of a seminar organised by the Scottish Autism Research Group seminar 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, 2020ab), a diary exercise (Hersh, 2020c) and interviews (Hersh, 2020d). This report presents the results of the final project activity, a questionnaire about the impacts of the project on the project team, members of the Advisory Board and research participants.

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) 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 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.

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 autistic people experience 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 at the end of the questionnaire and interview reports.

The remainder of the report is set out as follows. Section 1.1 presents the methodology. Results are presented in section 2 and conclusions in section 3.

## **1.1 Methodology**

A short questionnaire was drawn up by two autistic project team members, a researcher and a community member. It therefore involved coproduction, even though not all the team was involved. Due to shortness of time at the end of the project it was not piloted. The questionnaire was made available on line. The questionnaire was deliberately short. It comprised 9 questions. The initial closed question asked about the person's role in the project. The following six open questions investigated how they had found out about the project, what they had learnt from it, any changes they would be making in strategy use or their lives as a result of the project. The final two questions asked for suggestions for further research and further comments.

The target sample was people already involved in the project so advertising was not necessary. The link was sent to project team members via the project email. Individual invitations to participate in this survey as well as thanks for participation in the project were sent to Advisory Board members and research participants who had left contact details to be contacted for follow-up research or to be sent research results. However, the majority of participants could not be contacted, as they had not left contact details. A few days before the deadline Advisory Board members and research participants were sent a reminder plus further thanks. This was done via a group bcc email to maintain participant anonymity. Each question was analysed separately. Since there were only a limited number of responses a simple

approach to thematic analysis was applied based on theme identification rather than the more common approach involving coding.

## **2. Results**

### **2.1 Participant overview and how they found out about project**

The survey was answered by 21 people, five members of the project team, two members of the Advisory Board who had also participated in interviews and completed questionnaires, and 14 research participants who were not also Advisory Board members. These participants had completed various combinations of questionnaires, diary exercises and interviews.

The main means by which participants found out about the study were (personal) contacts, social media and searching for information online. Three participants found out through social media. Four participants found the information online and a further participant thought they may have done so. Two of these four were specifically looking for studies, one after diagnosis and the other 'because I wanted to be of use to the part of the scientific community that is interested in autism'. Seven participants found out through personal contacts. Two were contacted by one of the researchers and one by one of the Advisory Board members and four by friends. One found out through networking and another from a local autism initiative. Without specifying the source of the information one participant commented 'Informative and involved much careful consideration'. The remainder no longer remembered or had been involved from the start.

### **2.2 What participants learnt about strategies**

Just over 80% of participants had learnt something about strategies from the project. Themes included the value and diversity of strategies and participants learning more about their own strategies and how to use them. Comments on the diversity of strategies included 'there are many potential strategies that may suit different people' They also covered the importance of strategies being tailored to the individual, for instance 'it is understanding who each person is individually that allows us to provide the best strategies'. Comments on the value of strategies included: 'it is good to have some', the lack of 'universal strategies' and the limitations of strategies and the need for support from non-autistic people where they hold the power: 'Personal strategies only go so far. In situations where other (non autistic) people determine how things are organised their understanding and cooperation is vital in order to avoid harm and thrive as an autistic person.'

Learning about their own strategies and how they use them included learning that the strategies they use are also used by other autistic people: 'I learned that many of my strategies are fairly common in people with autism' and recognition of having strategies rather than a feeling of not coping: 'It has given me the opportunity to think more pragmatically and scientifically about my own strategies and realise that I do have them, as opposed to a general feeling of not coping in comparison to others'.

Further comments under this theme included mention of specific strategies, recognition of the validity of personal strategies, learning to communicate need and working on better strategies. One participant was working on reducing negativity about themselves and their strategies and developing better strategies. 'I feel that my unique mixture of automatic coping responses, strategies carefully worked out in my therapies and long suppressed needs for self-care, safety and comfort are all valid, much more than I thought them to be before. ... I'm inclined and learning to communicate why I need what, but I'm much less inclined to overtax myself because my strategies aren't accepted or understood. I also work hard on better strategies and on getting the old ideas (this isn't necessary / stop making a fuss / stop looking like an idiot / others don't do it, so it's wrong / you're being stupid, too weak, too sensitive...) out of my head so I can stop dragging myself down for my coping mechanisms and really use my strategies to my advantage.' One participant expressed the need to be more flexible in response to disappointment at not having been able to take part in an interview.

There were also participants who had not learnt anything or were still confused as to what strategies were. For instance, 'I still don't know what a strategy is really'. However, this participant also suggested that they had 'learned that my main one is avoidance I suppose'. There were also some misunderstandings. For instance, one participant considered that 'the project indicated that there are formalized strategies whereas I had mostly used ad hoc methods of working with people'. We would rather recognise that participants use a range of approaches and are aware of them to different extents. Some autistic people probably formalise their strategies more than others and this could use further research. One participant was 'surprised by the reliance on a trusted person as managing this process successfully seems very complex'. While this was a frequently used strategy and used in a variety of different ways, it was one of a number of strategies rather than the only strategy participants used.

An unexpected issue related to communication about the interviews. We had deliberately not contacted participants by phone about the interviews even when they had provided phone numbers, as we had received a very strong message from the questionnaires about participants not liking phone calls, particularly unexpected ones. However, some participants were expecting to be contacted by phone. 'Email wasn't the best way to get in touch. If the project mattered as much as I thought it did, I would have maybe received a phone call.' In future we should probably also send text messages where phone numbers are available.

### **2.3 What else participants learnt from the project**

About two thirds of participants had learnt something else from the project. The main themes were enjoying the research, things they could apply in their lives, things about autistic people and how to do this type of research better.

A few participants commented on enjoying the research. This included the value of talking to someone else on the spectrum in the interview as 'a reminder that you are not alone with your experience' and the 'nice routine' of the diary that allowed them

to see the (positive) changes in their life. 'Reading it back after a couple of months I barely recognise that person. Problems are transient.' Other comments related to enjoying participating in research: 'I'm a happy guinea pig!' and the benefits of keeping a journal every so often: 'I also realised that, hard though it might be for me to do it daily, I do benefit from writing a journal. And I'm planning on doing it intermittently, maybe every other month... Or a micro journal on my smartphone' Another participant was really 'gutted' and 'flattened' that they had not been able to do an interview due to the misunderstandings about communication modes discussed in section 2.2. They were 'looking forward to it' and felt 'they would have got the most out of it'. They also comment on sequencing and found it difficult 'to get out of sequence' by answering one part (impact) without having answered the previous one (interview). They had therefore considered not answering the impact questionnaire, but felt that would be 'throwing the baby out with the bathwater'.

A group of participants had learnt things they could apply. This included 'things I can apply in the workplace', 'really need[ing] a diagnosis' and the advantages of explaining rather than hiding being autistic. 'It may be easier if people understand why you may be a little different to how they expect rather than try to hide autistic tendencies.'

Comments on things related to autistic people more generally included how interesting autistic people are: 'some of the most interesting people I have had the pleasure to meet with' and the interconnection of the autistic community: 'a good reminder of how interconnected the autistic community can be, and that this can be a big support and help'. Other points learnt related to achieving change, with one participant considering that this required 'radical rather than incremental change' and believing in the need for 'autistic led initiatives' rather than the 'mainstream autism charity led agenda' with which they had become 'increasingly disillusioned'. Other participants had found that even their 'bad experiences' could be useful: 'I have learned that others could benefit from my bad experiences and ideas or strategies arising from them, so even when I fail it can still be used towards the greater good.'

Two of the project team had learnt about how to carry out coproduction research projects, including things to do differently. They agreed about the need for more planning of the project early on and the importance of accessible working and communication tools rather than a 'lowest common denominator option that everyone disliked but that we could all use'. One of them suggested the use of 'a round robin for document reviews', but some team members found it difficult to process all the comments on it. This further shows the importance of allowing sufficient time to determine appropriate tools which work for everyone in projects with a group of disabled team members with different accessibility requirements. Other suggestions included having at least two team members in each location, agreeing the sequence of group meetings in advance (when the project team is geographically separated) and reducing project scope to give more time for planning and learning from pilots before implementing them. A final comment was 'meeting the other team members and the support they offered during the project has been fantastic.'

## **2.4 Changes in participants' view of strategies as a result of the project**

Just over three quarters of participants had changed their view of strategies as a result of the project. Themes included greater information and understanding about strategies and their importance; and participants learning about how they use strategies and increased confidence in using them.

Comments on having more information and understanding about strategies and their importance included 'My view of strategies is more informed now' and 'It has further strengthened how important in my eyes how we all use strategies to deal with day to day challenges.' Further comments related to the wide potential applications of strategies and the fact that they were not restricted to particular groups of autistics or a particular type of strategy. They included 'I'm more generally aware of strategies, not just day to day strategies, but strategies for everything'; and 'It has helped me to realise that strategies are not exclusive to people who are doing well and they are not just about covering up disability to pass as functional.'

Comments about how participants used strategies included recognition of unconscious strategies, for instance 'My view has changed in as much as I believe that there are things that I do, but I can't identify them. For example, I can say that 'I used the strategy of putting on my headphones to block out the noise on the bus'. But I can't explain the strategies I've used to get myself out of bed, get ready, walk to the bus stop and get on the bus, even though there are a number of things about this process that would affect me.' Other comments included recognition of the impact of strategies on others, for instance 'yes now that I understand that I have them and use them I see that to the other party it will have influenced them heavily in their thoughts about me.'

Comments about increased confidence included greater confidence in using strategies that worked for them whatever other people thought. 'I'm more inclined to use strategies that others don't understand, are irritated, belittle or frown upon. It's about whether the strategy helps me! As long as I do no harm through any of my strategies, I'm the only one who has the right to decide whether they are working or necessary. If it helps me cope, it's good. Other people's acceptance or lack thereof does not make my needs or strategies invalid or unnecessary. And that's quite a new concept for me.' Another participant gained greater confidence in using existing strategies: 'if anything I may have gained more confidence in what was already working for me.'

A negative comment within this theme questioned the 'effectiveness of strategies'. 'I may help myself in that moment, but I often still come away from stressful situations feeling mentally drained, often with a very low mood. And I feel like I have no strategy to deal with that.' There may be other strategies they could learn to deal with stressful situations and participants have presented several relaxation and stress reduction strategies. However, there is also a need to be realistic about what strategies can and cannot achieve. They are a means for autistics to empower themselves by taking control of situations, managing some barriers and obtaining better outcomes. There is also a need for the removal of barriers by society and this could contribute to making some currently stressful situations less stressful for autistics.

One participant had learnt about the diversity of autistic people and one of the project team members commented on learning about strategies used in projects. General comments included 'possibly broadened?' and 'marginally that they are more important'.

## **2.5 Considering using new strategies or existing strategies differently**

Over 70% of participants were planning to do this, though the project cannot necessarily claim credit for all changes. In addition, one participant was 'always adjusting' and felt they could not credit the project with 'helping' and another might introduce changes after seeing the reports. The main theme was interactions with others.

Comments about interactions with others included 'considering preparing more for social situations and meetings', reducing contacts with others 'as I find it increasingly hard to understand them' and discussing problems rather than feeling ashamed: 'I feel more able to talk to others (using my discretion and judgement) about it when things go wrong rather than hide away ashamed.' This also included strategies for 'emotional management', though the participant was waiting to see how effective the modified strategies were. One participant was more aware of how they communicated and was successfully using a strategy based on explaining more and asking for help more often. 'Yes, I'm much more aware of how my autism impacts my communication with others and I try to ask for help more and more, especially from my autism therapist ... translating between me and the rest of my care network. I'm much more aware of being misunderstood and ... and try to explain stuff even when I consider it implicit or self-explanatory, and it helps. I feel more understood, seen and heard and thus less isolated. It's still a process, but it's promising!'

Two participants were looking at getting better support and reasonable adjustments, including in the workplace and in general, including with health professionals: 'I would like to get to a point where I can confidently use my formal diagnosis to insist on adjustments, and walk away if I am not being respected ... this also includes interactions with doctors/health staff - a new strategy for me to spell out that I am autistic at the beginning of the conversation, and see if I can use this to my advantage (either to leave early, or to avoid translation issues)'

One of the project team wanted to use 'the lessons learnt' in other projects and another participant to work with 'radical autism activists' using 'a human rights approach' rather than autism charities, as they were finding the 'whole concept of charity ... increasingly problematical ... as an autistic person'. A few participants were still 'assess[ing] and critique[ing]' strategies to 'find the best ones' for them. One participant was looking to improve their strategies for getting the right balance between accepting and rejecting opportunities. 'I believe I need to continue to refine the balance between: It's not going to be that bad so bite the bullet and do it / tackle it anyway. And No, I really need to miss this one.' This is something which is probably very important for all autistic people, though the right balance is different for each person. This participant was also looking at being more accepting of themselves and giving themselves less of a hard time, another important issue for

many autistic people. 'It's okay to be feeling like I do just now, so I won't beat myself up.'

## **2.6 Considering making changes in their lives as a result of the project**

Two thirds of participants were looking at making changes. However, the project was generally one of a number of factors contributing to this. Another participant who said 'no' then qualified this as 'it may have had a slight impact among other things on choice of where to live'. Themes included using greater self-understanding to improve their lives and sometimes also the lives of others, having a better balance of activities and control of their environment, changes in what participants felt about themselves and changes in what they were doing.

Comments on using greater self-understanding included continuing 'my already existing aim to keep trying to reach out and use my experiences to help others'. However, the formulation of the question encouraged participants to focus on themselves and the remaining comments under this theme related to how participants would use this in their own lives. Doing the diary exercise had helped one participant gain perspective and they hoped to maintain this. 'Doing the diary exercise and reading it back later helped me see that what feels like a big deal at the time is forgotten or fades pretty quickly so I try to keep that in mind.'

Comments on having a better balance of activities and greater control of their environment included better management of activities: 'I learned is to be more careful to manage what I do, over socializing is not good so cut back and make what I do more manageable' and a balance between stressful and restorative activities: 'My therapist ... suggest that I need to do things that are 'deposits' to balance out ... activities and experiences I find stressful. So the change I plan to make is to become more conscious of this and act upon it.' Another participant was trying to avoid being pushed into harmful behaviour. 'I want to really stop to allow people to push or coerce me into behaviour that is harmful or overwhelming to me, just because it's normal to others or because it would make things easier for them but harder for me'. This participant was also trying to create a better sensory environment: 'I also wish to try to refurbish my rooms so that my needs are better met. Like, soundproofing, building spaces where I feel protected and hidden (I bought myself a tent for that purpose, but I still need to make room for it)'.

Changes in what participants felt about themselves were generally based on having a more positive self-image, for instance 'just to be more proud of who I am and to believe in myself more' and 'I'm more self-assured, more aware of my autistic traits'. They also included improved clarity about what participants wanted to feel about themselves. 'It helped reinforce some of the ideas I already had going in about how I would like to feel about myself in the future.'

Changes in what they were doing included trying to find a new job, partly in response to the interview highlighting problems, 'what I heard myself saying while being interviewed'. Another participant was looking for a diagnosis, though it was not clear whether the project had impacted their views on the need for this. 'I just want a diagnosis to confirm/deny that I have Asperger's without that I don't really think I can

move further forward.’ Another participant was trying to make various changes to their life, but seemed to be lacking strategies to get support to do this. ‘I would love to make changes in my life but it’s all down to me. The first changes is to exercise more and eat a lot better and that would be a start.’ A comment which did not fit into any of these themes ‘read[ing] up and learn[ing] about the condition and what it means for me’.

## **2.7 Suggestions for further research**

Participants proposed a wide range of different suggestions, which can be grouped as follows (with the numbers not indicating priority):

1. Large scale evaluation of the identified recommendations and strategies to provide autistics a list of strategies that work or the circumstances and individuals they are appropriate to and service providers and policy making recommendations that work (if implemented properly). This could involve meetings with groups of autistic people.
2. Using technology to support/promote communication by those who do not use speech.
3. Better interactive communication and collaborative working tools that meet a variety of accessibility requirements.
4. Crowdsourcing to evaluate strategies and recommendations
5. Developing apps for managing strategies
6. Characteristics and physical differences of autistic people, including empathy, reasons for flexibility in some situations and rigidity in others, heart rate, joint connectivity and other physical differences, chronic bad timing and difficulties with key cards and touch screens.
7. Companion and therapy animals
8. Support and other strategies for overcoming avoidance.
9. Autistic people and employment, including the reasons employers tend to focus on the negative qualities of autistic people.
10. Intersectionality
11. Organisational and power dynamics in charities for autistic people.

## **2.8 Further comments**

The themes included experiences of participating in the project, the project’s potential role in achieving change for autistic people and the impacts on participants’ lives. Experiences of participating in the project were generally positive and participants enjoyed the experience. One participant thought that the fact that the interviewer was also autistic was what made it a good experience. ‘The interview ... was a very pleasant and surprising experience ... although it was much longer than I expected, it was not at all draining, something I attribute to compatibility with another autistic person.’ Other participants also enjoyed taking part and felt respected and taken seriously. ‘I really enjoyed taking part in this project! I felt validated, taken seriously, treated respectfully’ and ‘I really enjoyed taking part and had a great time with [researcher] who made me feel very comfortable and would love to take part in

future events.’ A member of the Advisory Board considered ‘it felt good to be consulted’.

However, another participant found the interview difficult. ‘I found the face to face interview a little challenging and was tired and a little emotional after it. I was beating myself up as I don’t like talking about myself and my past experiences.’ This raises questions for us as researchers about how we can provide more support for participants. Another participant ‘enjoyed participating’ and to see an ‘autistic led study’. However, they felt that the materials and interview lacked ‘specificity’ and consequently they ‘never really “got” this project or what you were looking for from me’. This affected the answers they were able to give. ‘It felt like I had to do mental gymnastics to connect your questions with your stated aims, and I couldn’t do that so I just gave you whatever mental navel-gazing trash popped up first.’

Comments on the project’s potential role in achieving change for autistic people included ‘It’s a small step towards equality for autistic people hopefully it can be built on.’; ‘It has been very interesting to join a project that may improve the lives of some Autistics. This has been my, and I believe that of the other team members, key motivation throughout.’ and ‘the need for more funding for projects of this type.’ In a related comment, one participant noted the emotional impact on them. ‘I bought into it very emotionally. I’d be surprised if quite a few other participants didn’t also do so. This impacts us in ways I hope I described elsewhere’.

Comments on the impacts on participants’ lives included ‘it has been a benefit to me in many ways’, though details were not provided. It had an almost transformative effect on one participant. ‘This project had a profound impact on me. Having an honest conversation with an autistic interviewer revealed uncomfortable truths which I had been trying to suppress. I felt empowered and emboldened by what I discovered about myself in the course of the interview.’ Unfortunately, it ‘pointed out how much frustration there is in my life’ to another participant, without providing solutions. ‘I just want to do a good job and get paid and I find it hard to understand how I always seem to be punished for this so obviously something needs to change but I don’t know what.’

### **3. Conclusions**

The results presented here are based on a short impact questionnaire completed online by 21 people with some involvement with the project: project team members, Advisory Board members and research participants, subsequently referred to as stakeholders. The term participant will be used here to refer to participants in this questionnaire. This is a reasonable percentage of the approximately 60 people we had contact details for to invite them to participate in the impact survey, it is only a small percentage of the stakeholders. Therefore, there is likely to be bias as a result of self-selection. However, the fact that the participants were not necessarily typical of all stakeholders does not negate the value of the positive impacts experienced by some stakeholders.

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 they 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. Several participants also expressed a strong emotional commitment to the project and its importance to them. The fact that the project was autistic led and that the interviewers were autistic seemed to be an important part of this.

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