

**Co-production with Autistic Adults:**  
**Reflections from the Authentistic Research Collective**

Eloise Stark<sup>1,2,3\*</sup>, Dorota Ali<sup>1,4</sup>, Annalise Ayre<sup>1</sup>, Naomi Schneider<sup>1</sup>, Sophia Parveen<sup>1</sup>, Keith Marais<sup>1</sup>, Nick Holmes<sup>1</sup>, and Richard Pender<sup>1</sup>

<sup>1</sup> Authentistic Research Collective, University College London, London, UK

<sup>2</sup> Department of Psychiatry, University of Oxford, Oxford, UK

<sup>3</sup> Oxford Health NHS Foundation Trust, Warneford Hospital, Oxford, UK

<sup>4</sup> Institute of Psychiatry, Psychology & Neuroscience, King's College London, London, UK

**Author email addresses**

Eloise Stark, [eloise.stark@psych.ox.ac.uk](mailto:eloise.stark@psych.ox.ac.uk); Dorota Ali, [dorota.ali@kcl.ac.uk](mailto:dorota.ali@kcl.ac.uk); Annalise Ayre, [annaliseayre@gmail.com](mailto:annaliseayre@gmail.com); Naomi Schneider, [naomiarty@googlemail.com](mailto:naomiarty@googlemail.com); Sophia Parveen, [sophia.parveen@googlemail.com](mailto:sophia.parveen@googlemail.com); Keith Marais, [maraiskeith@gmail.com](mailto:maraiskeith@gmail.com); Nick Holmes, [nick\\_holmes76@hotmail.com](mailto:nick_holmes76@hotmail.com); Richard Pender, [richard.pender.14@alumni.ucl.ac.uk](mailto:richard.pender.14@alumni.ucl.ac.uk).

**Author note**

We have no known conflict of interest to disclose.

\* Correspondence concerning this article should be addressed to Eloise Stark, Department of Psychiatry, University of Oxford, Warneford Hospital, Oxford, OX3 7JX. Email: [eloise.stark@psych.ox.ac.uk](mailto:eloise.stark@psych.ox.ac.uk)

**Keywords:** Autistic insights, participatory research, human and disability rights, qualitative research, co-production.

**Abstract:** 134 words

**Main text:** 5,027 words

**Lay summary:** 198 words

**Authorship Confirmation Statement**

E.S. and D.A. led on writing the article, while all co-authors contributed ideas and iterations to the manuscript. All co-authors have reviewed and approved of the manuscript prior to submission. The manuscript has been submitted solely to Autism in Adulthood and is not published, in press, or submitted elsewhere.

**Author Disclosure Statements**

None of the authors have competing financial interests to declare.

### **Abstract**

This paper explores co-production in relation to autistic people. We reflect on the co-production process with autistic adults from the Authentistic Research Collective at University College London. We aimed to support the autistic population's mental health needs by co-producing a document on adapting psychological therapy, and by developing a set of reflective guidelines to guide and encourage future co-production initiatives between autistic and non-autistic team members. We reflect upon six elements that are of potential importance for future co-production projects with autistic adults: (1) the meaning of co-production, (2) ground rules and a traffic light system; (3) environmental adaptations; (4) digital communication tools; (5) encouraging authenticity; and (6) supporting autistic strengths. We conclude by discussing future research avenues into optimising co-production with autistic people, and how such research may influence both practice and policy.

### Main text

Research into Autism Spectrum Conditions (henceforth ‘autism’) has seen remarkable progress since it was first described by Psychiatrist Leo Kanner in the 1940s<sup>1</sup>. Since then, research recruiting autistic people has become increasingly participatory, driven by such a framework’s potential to produce knowledge, relevant and meaningful to autistic people and their families’ lives <sup>2</sup>.

Autism, a neurodevelopmental condition, brings both strengths and challenges to the autistic person. Some strengths include passion for specific interests <sup>3</sup>; great attention to detail <sup>4</sup>; extraordinary talent in art, music, maths, calendar calculation or memory <sup>5</sup>; and strong sense of justice <sup>6</sup>. Key challenges autistic people may face include hyper- or hypo-reactivity to sensory stimuli; social communicative and interaction differences across multiple contexts; and preference for sameness and predictability <sup>7</sup>. In addition, autistic people are at far greater risk of mental health challenges, with a high proportion of autistic adults experiencing severe mental health difficulties<sup>8</sup>.

### Our process

In the summer of 2019, our project was granted funding from the UCL Centre for Co-production in Health Research to set up a co-production research collective, comprising seven autistic adults and one non-autistic adult (the eight authors of this paper). See Table 1 for our demographic information. This paper arose from our reflections on the co-production process as a group through open discussions over Zoom and on Slack, and individually through a questionnaire filled out by group members asking open questions concerning our experiences of the co-production process. Two group members (E.S. and D.A.) then independently assimilated the common themes from all sources to form the key reflections within this paper. Feedback was collected at multiple timepoints, with the questionnaire collected near to the end of the project. The six elements were finalised with a group consensus that they reflect our key learning points from the process, and all group members had the chance to make edits to the final manuscript.

Demographic	All group members (n=8)
Age (range)	27-45 years (3 declined to comment)
Autistic vs. Non-autistic team members	7:1
Age of autism diagnosis (range)	25-45 years

	(2 declined to comment)
Gender (%)	
<i>Male</i>	12.5%
<i>Female</i>	37.5%
<i>Non-binary</i>	12.5%
<i>Declined to comment</i>	37.5%
Ethnicity (%)	
<i>White</i>	62.5%
<i>Declined to comment</i>	37.5%
Sexual Orientation	
<i>Heterosexual</i>	12.5%
<i>Homosexual</i>	12.5%
<i>Pansexual</i>	12.5%
<i>Undecided</i>	12.5%
<i>Declined to comment</i>	50.0%
Highest educational level attained	
<i>Foundation degree</i>	12.5%
<i>Postgraduate degree</i>	50.0%
<i>Declined to comment</i>	37.5%

**Table 1.** Demographic information from the Authentistic Research Collective.

Our goals were twofold: first, to co-produce a document on how psychological therapies could be adapted for autistic adults, given that the number one research priority for autistic adults and their families is understanding which interventions improve autistic people's mental health, and how these could best be adapted <sup>9</sup>. The second goal was to co-produce reflections on empowering autistic team members and supporting future co-production projects. The reflections included here were arrived at, during, and in-between meetings, and we chose to anonymise our reflections to maintain privacy.

Initially, we met twice a month. Meetings were held in a room at University College London (UCL), but we could also join remotely if we wished to. Later, the format of our meetings often incorporated an option to be involved using only written communication,

using Slack as a platform. The meetings lasted from one to three hours including breaks. During the initial meetings, we co-produced a set of “group rules”, which were revised as the project evolved (see Table 2). The ground rules involved risk management, key to which included not sharing detailed distressing personal information, as well as including trigger warnings before any potentially upsetting shared material.

It is important in any project for researchers to think carefully how their own views and values impact upon the research process and their goals <sup>10</sup>. Our team consisted of autistic and non-autistic members. We all shared the belief that, although autistic people can have very debilitating difficulties and co-occurring conditions, autistic people are highly valuable members of society and adaptations should be made to help autistic people flourish. We shared values of curiosity, respect, open-mindedness and, above all, authenticity. This had an effect on how we worked together in general and, specifically, how we thought about our co-production goals.

We also reflected that autistic individuals form a large spectrum. It is therefore important to include a greater diversity of autistic people in future projects and to carry out many different projects with different groups of autistic people. For example, autistic people with learning disabilities or those who are completely non-verbal might require different adaptations than the ones we discuss here. Indeed, diversity was a big part of the discussions within our group, and also within the guide that we co-produced concerning therapists making adaptations when working with autistic adults where we refer readers to the topic of intersectionality and the ‘social GRRACCEESS’ (A heuristic to remind practitioners of common social differences, with the letters corresponding to different aspects: Gender, Race, Religion, Age, Ability, Class, Culture, Ethnicity, Education, Sexuality, Spirituality) <sup>11</sup>. Furthermore, we feel that it is vitally important to recognise that we are not representative of the full spectrum and diversity of autistic adults. For example, there was a notable lack of diversity in terms of age of autism diagnosis, BAME representation, and level of educational attainment which are factors crucial for the experience of disability. We did, however, have a diverse range of sexualities and gender within our group. Future projects would greatly benefit from ensuring a wide range of diverse autistic perspectives within co-production groups, and could perhaps reflect upon diversity and intersectionality

Lastly, risk assessment and management in co-production is a complex process, although one that, in our view, should be met with curiosity and exploration. For instance, we reflected that expectations for co-researchers to have an adequate external support network is exclusionary, as not everyone is able to access the same level of support. One proposed

way to address this would be to use funding to provide external support to any member of the co-production process that would find such support helpful.

### Reflection One: Co-production

Co-production has no precise dictionary definition – therefore, we reflect on its different conceptualisations. In terms of participant involvement, research can be seen as a spectrum (see Figure 1), ranging from consultation (minimum level) to co-production (greatest level). According to the *Social Care Institute for Excellence*, co-production operates via several key values, including: people from a specific group are assets with skills that should be built upon; breaking down barriers and power imbalance between professionals and people who use services; reciprocity (both parties get rewarded for doing something to benefit others); mutuality; and facilitating services by helping organisations become agents for change <sup>12</sup>.

[Insert Figure 1 here]

In healthcare, co-production can take several diverse forms, including the co-design, co-evaluation, and/or co-implementation of services or their improvements <sup>13,14</sup>. These can be led by patients, carers, clinicians, and/or managers, and may or may not comprise a research component. As Filipe, Renedo, Marston <sup>15</sup> highlight, there are two common denominators among the different approaches to co-production. First, there is the core relationship between those personally affected by the research and service provision, and professionals (although there may of course be significant overlap). Second, there are the new forms of knowledge, values, and social relations emerging from the process.

Co-production is not straightforward and entails some major challenges and potential limitations. There is little consensus about how to co-produce research; it can be a time-consuming and stressful process, and may involve conflicts of interest <sup>16</sup>. Our group aspired to take an exploratory and critically reflective stance towards co-production.

Individuals from our team defined what co-production means to them:

*“Co-production means joining up with others to produce something. In the context of our project I feel that it means clinicians and psychologists listening to the autistic voices that have said ‘nothing about us, without us’.”* – Group member 1

*“Full equality, rather than just tokenistic participation. Being fully involved and working co-operatively in partnership with others in all parts of the project/research and having an equal say in all decisions. All contributions being heard and valued*



*equally, regardless of background/research experience/academic prowess.” – Group member 2*

*“Co-production is an approach, a philosophy and an aspiration. It means challenging the status quo by upsetting a traditional power balance. Specifically, it means working as genuine equals from start to finish. At times, in practice we may drift from these ideals and so constant reflection and curiosity is needed.” – Group member 5*

Co-production has potential applications in multiple areas of research and healthcare, and our group considered co-production especially valuable to autism research due to the ‘double empathy problem’<sup>17</sup>. The theory proposes when individuals who see the world differently interact with one another, empathising will be difficult for both parties. This may be relevant to neurotypical researchers explaining neurodivergent phenomena, as one group member explains:

*“Autistic people have long been excluded from research and it is possible this has seriously skewed the direction of studies and understanding about autism. Due to researchers being non-autistic, this meant pre-project assumptions, research questions and interpretations did not necessarily reflect the reality of an autistic life/struggles. This can perhaps be applied to research more generally, where important groups are not involved or silenced.” – Group member 4*

Indeed, a report from the UK named *A Future Made Together* asked autistic people, their families, researchers and practitioners, about their experiences of research participation<sup>18</sup>. A crucial finding was that UK research funding and output was not aligned with autistic people’s views regarding their own needs and priorities. Moreover, whereas researchers have suggested they are fully engaged with the autism community during research discussion and dissemination, autistic people and their families have not always supported this view<sup>19</sup>.

Co-production with autistic people has potential to overcome such translation barriers, ensuring studies produce relevant benefits<sup>20</sup>. The above suggests strategic action is needed. The Authentistic Research Collective aspired to contribute to the emerging programme of change, co-producing guidance for future co-production between autistic and non-autistic individuals, and calling for systemic change in research culture, in which co-production would be valued.

To date, there is little co-produced research with autistic people. Calls for emancipatory studies – studies seeking knowledge production beneficial to disadvantaged groups – have been co-produced with autistic individuals <sup>21</sup>, investigating both advantages and disadvantages of such collaboration. One project co-produced a series of seminars between autistic and non-autistic people, and explored the development of a collaborative framework for autism research <sup>2</sup>. In this project, five essential topics were identified: respect, authenticity, assumptions, infrastructure and empathy. Further, a co-produced research project on healthcare improvements was run with people with learning disabilities and/or autism (and their carers) <sup>22</sup>. Finally, the Academic Autism Spectrum Partnership in Research and Education (AASPIRE) published a set of guidelines for autistic people’s inclusion as co-researchers or participants <sup>23</sup>. Their recommendations include autonomy maximisation, consent procedures accessibility, multiple modes of participation, adapting surveys, and creation of accessible interview guidelines.

### **Reflection Two: Group Rules and the Traffic Lights System**

In our first meeting we discussed “group rules” – to guide us and to provide a sense of safety. These included maintaining confidentiality; not putting people on the spot; and allowing people to freely leave meetings so as to accommodate sensory and emotional regulation. These ground rules were agreed upon as a team for the safety of each individual and were added to as the process evolved and challenges emerged, such as the question of how to fairly make decisions (see Table 2).

<b>Initial Group Rules</b>
1. Meetings will be held in an autism-friendly environment, and the use of sensory aids is encouraged (e.g. noise-cancelling headphones, fidget items).
2. All group members will value and treat each other with kindness, respect and consideration.
3. We will utilise a ‘traffic light system’, reflecting our communication and interaction preferences and abilities. Alternatives to means of communication other than speech (e.g. written) will be fully supported.
4. We will not put anyone on the spot by asking them to speak or through a direct question and reassure each other that it is fine to be quiet, that simply our presence is valued.
5. We understand that it is normal for groups to become side-tracked and encourage group members to request a return to the agenda.

6. We expect differences of opinion and will listen respectfully, even when we disagree.
7. We advise group members not to disclose personal experiences that may be distressing to others.
8. We will facilitate contributions to discussions after meetings are concluded (via digital communication) to allow for additional processing time and to respect thoughts that develop following the meetings.
<b>Additional Group Rules</b>
1. <i>Professionalism</i> : Group members should be mindful to adopt a professional style: to use polite, respectful language; to acknowledge, thank and praise other group members for their contributions; and, during disagreement, build on ideas or offer alternatives, rather than simply criticising an idea.
2. <i>Time out</i> : If group members feel anxious or overwhelmed, they are asked to take time before responding. When responding, we advise group members to be professional; to not use critical, blaming or personal language; to acknowledge one's own uncertainty and employ assertive curiosity when asking for clarification; and to keep responses brief to allow others time to process and respond.
3. <i>Decision-making mechanism</i> : We will vote on key decisions in the group. A proposer will word a question, shape options to be voted on, and set a deadline for the vote. Group members can share their views around a vote in a calm, neutral and factual manner. We will specify a quorum (minimum vote) for a vote to be valid, and group members will need to accept and support the agreed decision. In the event of a tie, the proposer will have a chance to re-shape the options and to re-propose and re-submit the vote.
4. <i>Delegation</i> : The Authentistic group will delegate key tasks to group members, via an opt-in process. Group members will offer constructive feedback and trust each other to manage and lead individual tasks.
5. <i>Discussing potentially distressing personal information</i> : We clarified this original group rule (number 7) following feedback that group members felt that some potentially distressing personal experiences were important for discussing adaptations to psychological therapy, and asked individuals to provide trigger warnings before such disclosures so that other group members could choose not to listen to or read such contributions.

**Table 2.** Ground rules were co-produced by the team during the first meeting and evolved over time due to the needs of the group. The additional group rules were primarily devised following group conflict surrounding decisions, and largely resolved all conflicts with equanimity.

We also used a ‘traffic lights’ system to indicate our preferences and abilities for interaction. To date, traffic light systems have been used at various conferences and other group-based environments, to make such spaces safer and more accessible for those for whom flexible communication is a need. At each meeting’s beginning, we “checked-in” with each member to ascertain their communication preference, initially using a physical sticker worn by the individual to reflect this. We started out with three colours: green, yellow, and red. However, it became apparent three colours were not sufficient for the full range of our team’s communicative preferences and abilities. We therefore added white, blue and pink to address this (see Figure 2).

[Insert Figure 2 here]

In addition to in-person meetings, one of our working spaces was an app called Slack, an instant messaging platform where communication is organised into topic-specific “channels”. As some group members preferred communication via technology (see ‘Digital Communication’ below), we conducted our meetings with one of the channels opened. Members who wished to write rather than speak, could be part of the interaction in real time. We all indicated our traffic lights on this app. Thus, on one hand, the system was useful in respecting different communication abilities but, on the other hand, it was not always flexible in capturing changing preferences/abilities, as well as becoming less visual:

*“It perhaps got a bit less ‘visual’ as we moved to part-computer based interaction, and I think we could have done some more work on structuring the sessions to a) recap over the colours, and b) choose colours, with greater consistency and understanding of each other’s needs. I wonder whether a “check-in” might have been a good idea – to get a bit more context about people’s current state”*  
– Group member 3

*“I thought it was a very good idea but having a visual reminder guide that could be shown of the different colours and their meanings would have been helpful. It would also have been useful for each individual to have a lanyard/sticker indicating their choice to remind other members. I also felt that it was forgotten as meetings progressed and that we maybe should have had ‘traffic light check ins’ more frequently during meetings? And perhaps coloured stickers that people could change at will, as their comfort level/consequent communication preference may change in reaction to group content/discussion?”* – Group member 2

In light of these reflections, our first recommendation is the use of a check-in system, allowing members to indicate their interaction and communication preferences/abilities. This

may make co-production more accessible, put members at ease and facilitate engagement. The traffic light system is a good starting point, but members of any given working group may think flexibly on what works best for them. Having less formal and more frequent check-ins, especially when groups are small, may be a good idea, as well as having a clear visual reminder of the system.

### **Reflection Three: The Environment**

Environmental adaptations were a crucial part of our process. Sensory differences are reported by many autistic people<sup>7</sup>, including hypo- and hyper-responsivity to sight, sound, touch and taste<sup>24</sup>. These differences may be key barriers to autistic people's engagement in education, employment and other social contexts<sup>25</sup>. Group contexts present obstacles, such as fluorescent lighting and open-plan spaces. Further, non-autistic people may show intolerance or judgement of self-regulating strategies, such as sunglasses worn indoors (to reduce visual glare)<sup>26</sup>. Creating a sensory-friendly environment, as well as a culture of acceptance in regard to self-expression, stimming and various aids (e.g. wearing sunglasses and noise-cancelling headphones), was a key priority.

A key first step was booking the same meeting room to reduce uncertainty – although this proved practically difficult (the room was used for teaching). We checked whether we were comfortable with the sensory properties of the space i.e. light, temperature and noise. In relation to minimising sensory difficulties, attending via Skype or Zoom also proved beneficial for some (see 'Digital Communication'). On some occasions, a compromise had to be made between factors, such as staying in a room with uncomfortable lighting or moving to an unfamiliar space. Though it was sometimes complicated to achieve everyone's highest degree of comfort, by taking sensory experiences seriously and giving real consideration to minimising distress, we validated and respected the autistic experience.

Secondly, we made space for our members to 'stim'. Stimming refers to self-stimulating behaviours many autistic people engage in<sup>27</sup>. Many of these behaviours are harmless, including hand flapping, rocking, spinning and verbal repetitions<sup>27</sup>. In addition to being harmless, these behaviours are thought to be beneficial. Autistic people report stimming provides consistent and controlled motion/sound that aids coping with sensory and social worlds' uncertainty; and by helping with emotion regulation<sup>27</sup>. Our autistic members highlighted stimming's value from their own lives but, as many autistic people, also felt shamed by others when stimming, leading to camouflaging, and suppression of these behaviours<sup>28</sup>. We encouraged each member to be their authentic self. In order to encourage stimming, we brought in fidget toys and other equipment (such as weighted lap blankets) and reassured each other stimming was a valid self-regulating strategy.

*“Waiting rooms can be stressful. I much prefer going straight to where I need to be and not being somewhere public to wait. I liked the environment from the first meeting the best, as there was a breakaway area with sofas and it felt easily navigable (and there were fascinating academic posters on the walls to read in breaks!) I liked the fidget toys being available, and the weighted lap blankets.” –*

Group member 3

*“I attended the first few meeting in person. I found that quite challenging as, by the time I got there, I already felt exhausted due to the sensory onslaught of the journey (traffic, loud bus, interacting with people at the reception etc). Also, the location is in a very busy part of London i.e. lots of people and noise. Doing meetings via Skype/Zoom was the answer, as I’m not sure I would have managed the whole project attending in person.” –* Group member 4

Maintaining a distress-free and comfortable space was not a challenge-free endeavour. We were based in central London and, as such, most of our members had experienced (dis)stress getting there. However, we still strove to think about our situation flexibly and creatively (for example, later on in the project, more members connected via Skype/Zoom - see ‘Digital Communication’).

In light of our experiences, our second recommendation is for future co-production groups to think carefully about the physical environment, how members might experience it and what can be done to reach a level of comfort workable for everyone. ‘Stimming’ should be explicitly welcomed, and sensory aids or materials provided. Having a curious attitude towards individual differences, and working towards meeting both shared and different needs is likely to lead to best outcomes for everyone.

### **Reflection Four: Digital Communication**

From early on, we realised the importance of digital communication. Firstly, one of our members was not based in London and their involvement always depended on digital communication. Secondly, as many of us required processing time and/or could not participate in real time, adding contributions after a meeting, it became clear we needed a digital working space. This initially came in the form of e-mails, after which we relocated to an app called *Slack*. Slack is an instant messaging platform, allowing organisation of our work into separate ‘channels’. Transitioning to Slack was not without its challenges. As most of us were unfamiliar with the app, it took time to get used to and understand it:

*“Initially I did not participate via Slack, as it was a new medium for myself, and, as an autistic person, I find unknown things very daunting. I feel Slack needed to be introduced more gradually, and for group members to be given more training on how to access/use Slack. However, when I finally figured out how to join and communicate via Slack, it provided a great means of maintaining connection with other group members in between meetings, and I found it immensely valuable in accessing shared information/articles/resources.” – Group member 2*

Other encountered difficulties with Slack included the large volume of shared content perceived as overwhelming, and an uncertainty about communication rules. The latter arguably contributed to increased miscommunications and misunderstandings, since written text was perceived as more ambiguous, and clarification was not always immediate:

*“The dynamics of Slack in particular were contrasting, as, at times, I truly enjoyed the interactions and connection and benefitted a huge amount from suggested resources. It did prove tricky on occasion however, as interaction can easily be misconstrued/misunderstood/misinterpreted, and at times this triggered distress, resulting in the need for repair of group relationships.” – Group member 2*

Nevertheless, for some, Slack became an essential communication tool both outside of and in real-time sessions. Some of us found it easier to communicate via writing and, therefore, we kept one of the channels opened (and sometimes projected on a wall during a meeting). Others would read out the contributions. A group member explains:

*“Because I find speaking very difficult, being able to write has been the main reason why I was able to stay involved with the project. Writing in physical meetings, as well as digital environments, and allowing others to read things out, has made the project accessible for me. One thing that could be improved, in order to put all forms of communication on the same level, is to invest in making clearer guidelines for respectful/efficient written communication.” – Group member 4*

We also used Skype and Zoom, two video-calling platforms. These were increasingly employed, providing better control over our environment and to fit our work amongst our other commitments.

*“At times, contributing via virtual means (Skype) was challenging, as initially I did not appear to be welcomed by other group members, and I felt excluded as a result. This issue was addressed by everyone contributing to a meeting via Skype (then Zoom), which I feel helped to make this a far more acceptable means of*

*accessing the group meetings (and actually developed to become the preferred means of access for many group members!).” – Group member 2*

*“Technology has both helped and hindered in different respects. On one hand, it enabled us to span a wider geographical area, and has also allowed participants to work from home and to regulate their degree of interaction (e.g. switching off the camera). On the other hand, it has possibly created points of exclusion, e.g. assumes people have easy access to internet.” - Group member 5*

One of the caveats of technology were technical issues:

*“During meetings we found that some of the equipment and video calling sound quality was difficult for me too, and we made adaptations to solve those issues very quickly through experience.” – Group member 1*

In light of these experiences, we make the following recommendations in relation to digital communication. Firstly, it is important to provide training to any new app or technology, as this can be a barrier to many. Secondly, accepting digital communication as a meaningful and equal communication form is essential. Thirdly, meetings run via video-calling platforms can overcome some sensory difficulties and accessing challenging and unknown environments. Nevertheless, clear guidelines and ground rules on how to resolve conflict stemming from digital communication should be discussed.

### **Reflection Five: Authenticity**

*He recognizes that it rests within himself to choose; that the only question which matters is, “Am I living in a way that is deeply satisfying to me, and which truly expresses me?”*

- Carl Rogers, On Becoming a Person, 1961

Authenticity is viewed as a healthy attribute in contemporary psychology and society<sup>29</sup>. Schlegel, Hicks<sup>30</sup> demonstrate the strong relationship between self-reported expression of the true self (i.e. authenticity) and well-being. In accordance with this idea, several members suggested being authentic should be both accepted and encouraged within the Authentic group. Indeed, we based our group name around the concept of being “authentically autistic” – *Authentic*.

Authenticity can be defined as acting in accordance with core aspects of the self, such as one’s values, emotions, and/or attitudes. Self-determination theory (SDT) suggests the “true self” is any aspect of the self that feels autonomous, internally caused, personally



meaningful, and self-determined. Authenticity as a positive attribute has been central to models such as Maslow's hierarchy of needs, in reaching self-actualisation <sup>31</sup>, and Carl Rogers' fully functioning person <sup>32</sup>.

It is unknown why authenticity is especially pertinent to autistic individuals, but we suggest it may relate to the autistic tendency to "camouflage." Camouflaging masks autistic traits and/or behaviours, and prevents others from perceiving inherent challenges <sup>28</sup>. Extensive camouflaging may make autistic people feel inauthentic, as how autistic people act on a day-to-day basis may chronically clash with how they feel internally, as well as eventually losing sight of who they really are.

*"I took authentic to mean acting in accordance with my values. I therefore tried to be open about how I was feeling and thinking throughout the process, as I value honesty and openness. I tried to behave with kindness and compassion for others, and to do my utmost to do a good job on the projects." – Group member 3*

*"I tried to be myself; adding honest experiences combined with intellectual curiosity. I tried to be as clear as possible about my limits. – Group member 4*

*"Dropping aspects of my usual professional identity – challenging myself to be less "expert", less in-role, more present and more egalitarian." – Group member 5*

Our subsequent recommendation is to explicitly encourage autistic and non-autistic members to develop a culture and acceptance of authenticity. This may be assisted by some teaching and discussion of camouflaging, and finding creative ways to "drop the mask", including actively encouraging stimming. Team members may be reassured there is no requirement to make eye-contact or contribute through speech – they could contribute via writing, drawing, or using technology.

### **Reflection Six: Autistic Strengths**

*"A strong sense of justice plays into the co-production dynamic of being equals, and for the common goal of doing something to benefit others. Attention to detail is a great skill. Kindness and empathy. The willingness to work through difficult times, which many of us have shown multiple times in our histories, is a huge strength in co-production." – Group member 4*

*"If you are empowering autistic people and autistic community to be directing the research, then that research is inherently grounded in a strengths-based approach, even when you are researching challenges. If autistic people are*

*empowered to be leading or coproducing that research, then you are implicitly assuming and recognizing that autistic people have strengths and skills.” – Dr Jacqueline den Houting (An Expert Discussion on Strengths-Based Approaches in Autism, 2019)*

Autistic people are a diverse group, possessing both challenges and strengths. Much of autism literature has focused on autistic people’s ‘deficits’ and difficulties, often interpreting strengths in the light of limitations e.g. detail-focused perception. On the other hand, arguably harmful stereotypes of the ‘autistic savant’ and significant talent being an inevitable part of every autistic person’s life, may reinforce the idea disabled people need to balance their difficulties with strengths in order to be considered worthy of respect and support. Keeping both these aspects in mind, we wanted to work from a strengths-based perspective, while addressing inevitable challenges. Focusing on autistic people’s special interests, whatever they are, may be a way of tapping into their strengths, creating social connections and even increasing employment opportunities <sup>33</sup>.

Strength-based approaches focus on what people can do, rather than what they cannot do <sup>34</sup>. We recognised and respected the challenges and difficulties of working in a group. Nevertheless, it is also important to focus on strengths and interests. This dual focus and support has been the best way to engage and enable autistic group members: supporting and accommodating challenges, while encouraging and nurturing strengths. Some strengths may arguably be specific to the autistic cognitive style, as well as being borne from the experiences autistic people are more likely to experience. Working groups should be sensitive to how a project disables or enables an individual <sup>34</sup>. For example, a detail-focused cognitive style can be an incredible strength. Allowing enough time for a project to be completed allows autistic members to more authentically exert their abilities. In a tight time-controlled setting, where strict deadlines have to be met, this strength can indeed be hidden or even seem like a ‘deficit’.

*“Just as one of our reflections as a group was that therapy might require “more sessions and more time”, I think that co-production might require more time. We needed to invest time in building our capacity to work together, and then there was a very difficult pivot point when we needed to become more target-driven and start producing. I think that because the team has a strength for detail-focused thinking, it would have helped to allow more time for this.” – Group member 5*

These are some of the strengths we think autistic people bring to a working group:

*“The willingness to work through difficult times, which many of us have shown multiple times in our histories, is a huge strength for the co-production process.” –*

Group member 3

*“Firstly, lived experience. Secondly, autistic people possess myriad strengths when they are enabled by supportive environments. Many people may be extremely passionate and very analytical, an arguably important skill when producing something.” –*

Group member 4

*“Innate honesty. Tremendous empathy for other’s wellbeing and other’s experiences. A tendency for deep thought and consideration. Attention to detail. Able to see unanticipated connections. Able to produce creative ideas/solutions (born from having to constantly ‘figure out’ life!). Perseverance and tenacity.” –*

Group member 2

Our next recommendation is therefore to have a strengths-based perspective, recognising and addressing how strengths can be enabled e.g. more time for the co-production process.

## Conclusions

This paper describes the Authentistic Research Collective’s experiences during co-production of an accessible guide to therapeutic adaptations for autistic individuals. The experience was, for most members, inspiring and often transformative. It involved gaining knowledge, building confidence, experiencing safety and recognition of our own experiences in others’, and finding self-acceptance and belonging.

*“Being part of the project has made me feel that I am contributing to something greater than I could do so alone, that through the process of co-production, I am part of a project that will offer an opportunity for lasting change.” –*

Group member 2

*“This was the first time I was in a group of mostly autistic people. It has been a great experience as, for the first time, I felt understood without effort.” –*

Group member 4

We hope future research will work to incorporate co-production as standard in elements of research design and implementation. In order to achieve this, we need other groups and collectives to reflect on our recommendations and add to the ongoing discussion about how best to use and adapt co-production with autistic adults, adolescents and children. Ultimately, research can meet autistic people’s needs better, if autistic voices are

part of the process. The goal is to both benefit the individuals who participate, empowering them within the process, and also to benefit the many, through rigorous and thoughtful scientific practice. Together, we hope co-production offers a better future for autistic individuals who collaborate and for the autistic and disability community as a whole.

### **Notes**

1. Identity-first language is the preferred language of many people on the autism spectrum (i.e. autistic individual rather than individual with autism; see Kenny, Hattersley, Molins, Buckley, Povey, Pellicano <sup>35</sup>). This was also the preferred language of the members of this co-production project, and we therefore use identity-first terminology in this article.

### **Acknowledgements**

We would like to express our gratitude to our funder, the UCL Centre for Co-production in Health Research. In particular we would like to thank Niccola Hutchinson-Pascal, Lizzie Cain, Susan Anderson, Rachel Matthews, Will Mandy, Anna Lawrence-Jones, Ethney Anderson and the Asperger London Area Group (ALAG) for their guidance, encouragement and support.

### **Funding**

This study was funded by Phase 2 Pilot Project funding from UCL Centre for Co-production in Health Research.

### References

1. Kanner L. Autistic disturbance of affective contact. *Nervous Child*. 1943;2:217-250.
2. Fletcher-Watson S, Adams J, Brook K, et al. Making the future together: Shaping autism research through meaningful participation. *Autism*. 2019;23(4):943-953.
3. Jordan CJ, Caldwell-Harris CL. Understanding Differences in Neurotypical and Autism Spectrum Special Interests Through Internet Forums. *Intellectual and Developmental Disabilities*. 2012;50(5):391-402.
4. Shah A, Frith U. An islet of ability in autistic children: A research note. *Journal of Child Psychology and Psychiatry*. 1983;24:613-620.
5. Happé F, Frith U. The beautiful otherness of the autistic mind. In: The Royal Society London; 2009.
6. Milner V, McIntosh H, Colvert E, Happé F. A Qualitative Exploration of the Female Experience of Autism Spectrum Disorder (ASD). *Journal of Autism and Developmental Disorders*. 2019;49(6):2389-2402.
7. APA. *Diagnostic and statistical manual of mental disorders (DSM-5®)*. Arlington, VA: American Psychiatric Association; 2013.
8. Hofvander B, Delorme R, Chaste P, et al. Psychiatric and psychosocial problems in adults with normal-intelligence autism spectrum disorders. *BMC psychiatry*. 2009;9(1):35.
9. Cusack J, Sterry R. Your questions: shaping future autism research. *London: Autistica*. 2016.
10. Berger R. Now I see it, now I don't: Researcher's position and reflexivity in qualitative research. *Qualitative research*. 2015;15(2):219-234.
11. Burnham J. Developments in the social GRRRAAACCEEESSS: Visible-invisible and voiced-unvoiced In Krause I. *Culture and Reflexivity in Systemic Psychotherapy Mutual Perspectives (139–160)* London: Karnac[Google Scholar]. 2012.

12. SCIE. Co-production in social care: What it is and how to do it. SCIE Guide 51 Web site. <https://www.scie.org.uk/publications/guides/guide51/>. Published 2015. Accessed 18th January 2020, 2020.
13. Batalden M, Batalden P, Margolis P, et al. Coproduction of healthcare service. *BMJ Qual Saf.* 2016;25(7):509-517.
14. Dunston R, Lee A, Boud D, Brodie P, Chiarella M. Co-production and health system reform—from re-imagining to re-making. *Australian Journal of Public Administration.* 2009;68(1):39-52.
15. Filipe A, Renedo A, Marston C. The co-production of what? Knowledge, values, and social relations in health care. *PLoS Biology.* 2017;15(5):e2001403.
16. Oliver K, Kothari A, Mays N. The dark side of coproduction: do the costs outweigh the benefits for health research? *Health Research Policy and Systems.* 2019;17(1):33.
17. Milton DEM. On the ontological status of autism: the ‘double empathy problem’. *Disability & Society.* 2012;27(6):883-887.
18. Pellicano L, Dinsmore A, Charman T. A Future Made Together: Shaping autism research in the UK. 2013.
19. Pellicano E, Dinsmore A, Charman T. What should autism research focus upon? Community views and priorities from the United Kingdom. *Autism.* 2014;18(7):756-770.
20. Long J, Panese J, Ferguson J, Hamill MA, Miller J. Enabling voice and participation in autism services: using practitioner research to develop inclusive practice. *Good Autism Practice (GAP).* 2017;18(2):6-14.
21. Bertilsdotter Rosqvist H, Kourti M, Jackson-Perry D, et al. Doing it differently: emancipatory autism studies within a neurodiverse academic space. *Disability & Society.* 2019;34(7-8):1082-1101.
22. Doherty AJ. Improving healthcare for people with learning disabilities, autism or both: A co-produced research project. *Community Living magazine.* 2020;33(2):24-25.

23. Nicolaidis C, Raymaker D, Kapp SK, et al. The AASPIRE practice-based guidelines for the inclusion of autistic adults in research as co-researchers and study participants. *Autism*. 2019;23(8):2007-2019.
24. Davidson J, Henderson VL. 'Travel in parallel with us for a while': sensory geographies of autism. *The Canadian Geographer/Le Geographe Canadien*. 2010;54(4):462-475.
25. Hendricks D. Employment and adults with autism spectrum disorders: Challenges and strategies for success. *Journal of Vocational Rehabilitation*. 2010;32(2):125-134.
26. Robertson SM, Ne'eman AD. Autistic acceptance, the college campus, and technology: Growth of neurodiversity in society and academia. *Disability Studies Quarterly*. 2008;28(4).
27. Kapp SK, Steward R, Crane L, et al. 'People should be allowed to do what they like': Autistic adults' views and experiences of stimming. *Autism*. 2019;23(7):1782-1792.
28. Hull L, Petrides KV, Allison C, et al. "Putting on My Best Normal": Social Camouflaging in Adults with Autism Spectrum Conditions. *Journal of Autism and Developmental Disorders*. 2017;47(8):2519-2534.
29. Smallenbroek O, Zelenski JM, Whelan DC. Authenticity as a eudaimonic construct: The relationships among authenticity, values, and valence. *The Journal of Positive Psychology*. 2017;12(2):197-209.
30. Schlegel RJ, Hicks JA. The true self and psychological health: Emerging evidence and future directions. *Social and Personality Psychology Compass*. 2011;5(12):989-1003.
31. Maslow AH. The farther reaches of human nature. 1971.
32. Rogers CR. *On Becoming a Person: A Therapist's Point of View of Psychotherapy*. Alemar; 1961.
33. Happé F. Why are savant skills and special talents associated with autism? *World Psychiatry*. 2018;17(3):280.

34. Urbanowicz A, Nicolaidis C, Houting Jd, et al. An expert discussion on strengths-based approaches in autism. *Autism in Adulthood*. 2019;1(2):82-89.
35. Kenny L, Hattersley C, Molins B, Buckley C, Povey C, Pellicano E. Which terms should be used to describe autism? Perspectives from the UK autism community. *Autism*. 2015;20(4):442-462.
36. Healey M, Flint A, Harrington K. Engagement through partnership: students as partners in learning and teaching in higher education. Higher Education Academy. <https://www.advance-he.ac.uk/knowledge-hub/engagement-through-partnership-students-partners-learning-and-teaching-higher>. Published 2014. Accessed.