

## The co-design and initial evaluation of a peer support program for autistic young adults

Davies, Jade; Redmayne, Ben; Allain, Leon; Portway, Lucy; Mandy, William; Cooper, Kate; Crane, Laura

*License:*

Other (please specify with Rights Statement)

*Document Version*

Peer reviewed version

*Citation for published version (Harvard):*

Davies, J, Redmayne, B, Allain, L, Portway, L, Mandy, W, Cooper, K & Crane, L 2024, 'The co-design and initial evaluation of a peer support program for autistic young adults', *Autism in Adulthood*.

[Link to publication on Research at Birmingham portal](#)

**Publisher Rights Statement:**

This is the accepted author manuscript of an article to be published in *Autism in Adulthood*; final published version will be available at <https://home.liebertpub.com/publications/autism-in-adulthood/646>

This original submission version of the article may be used for non-commercial purposes in accordance with the Mary Ann Liebert, Inc., publishers' self-archiving terms and conditions. "

**General rights**

Unless a licence is specified above, all rights (including copyright and moral rights) in this document are retained by the authors and/or the copyright holders. The express permission of the copyright holder must be obtained for any use of this material other than for purposes permitted by law.

- Users may freely distribute the URL that is used to identify this publication.
- Users may download and/or print one copy of the publication from the University of Birmingham research portal for the purpose of private study or non-commercial research.
- User may use extracts from the document in line with the concept of 'fair dealing' under the Copyright, Designs and Patents Act 1988 (?)
- Users may not further distribute the material nor use it for the purposes of commercial gain.

Where a licence is displayed above, please note the terms and conditions of the licence govern your use of this document.

When citing, please reference the published version.

**Take down policy**

While the University of Birmingham exercises care and attention in making items available there are rare occasions when an item has been uploaded in error or has been deemed to be commercially or otherwise sensitive.

If you believe that this is the case for this document, please contact [UBIRA@lists.bham.ac.uk](mailto:UBIRA@lists.bham.ac.uk) providing details and we will remove access to the work immediately and investigate.

# **The co-design and initial evaluation of a peer support program for autistic young adults**

**Jade Davies<sup>1</sup>, Ben Redmayne<sup>2</sup>, Leon Allain<sup>2</sup>, Lucy Portway<sup>2</sup>, Will Mandy<sup>3</sup>,  
Kate Cooper<sup>4\*</sup> and Laura Crane<sup>1,5\*</sup>**

<sup>1</sup> UCL Centre for Research in Autism and Education (CRAE), University College London, United Kingdom

<sup>2</sup> Ambitious about Autism, UK

<sup>3</sup> Research Department of Clinical, Educational, & Health Psychology, University College London, UK

<sup>4</sup> Centre for Applied Autism Research, Department of Psychology, University of Bath, UK

<sup>5</sup> Autism Centre for Education and Research, Department of Disability, Inclusion and Special Needs, School of Education, University of Birmingham, UK.

\* Joint senior authors

## **Correspondence to:**

Jade Davies, Centre for Research in Autism and Education (CRAE), IOE, UCL's Faculty of Education and Society, 55 – 59 Gordon Square, London, WC1H 0NU, UK.

Email: [j.davies@ucl.ac.uk](mailto:j.davies@ucl.ac.uk)

ORCID ID: 0000-0003-4782-6929

## **Community Brief**

### **Why was this program developed?**

It is important to design and test support groups that aim to improve the wellbeing of autistic young adults (ages 16-25) during the transition to adulthood.

If support groups are not co-designed, they are less likely to be considered acceptable by autistic people. By co-design, we mean different groups of people (e.g., autistic people, clinicians, researchers) working together to create something.

In this study, our team of autistic young adults, clinicians, researchers, and an autism charity representative, co-designed a program to support autistic young adults during the transition to adulthood. The program was developed because a UK charity - Ambitious about Autism - identified that there was a need for specific support for autistic young adults.

### **What does the program do?**

The program, called *Understanding You, Discovering You*, is designed to help autistic young adults embrace and understand their autistic identity. The program is designed to be delivered by two facilitators, one of whom is autistic, and includes up to ten autistic young people at a time. Autistic young adults decided the content of the program, and how it was organized.

### **How did the researchers evaluate the development of the new program?**

In this paper, we report our team's reflections about involving autistic young adults in the program's design, to guide the creation of similar projects in the future. We also gathered initial feedback about the program from program attendees to understand their experience and learn how to make the program better in future.

### **What were the early findings?**

We identified three main things that were important when involving autistic young adults in the co-design of our program: good preparation, effective and respectful communication, and making sure the collaboration is meaningful. Program attendees reported that they liked learning about autism, found value in the social connections

they made, and gained practical skills from the program. These findings tell us that co-designing programs with autistic people is a good way to make sure they are useful.

### **What were the weaknesses of this project?**

One weakness of this project was that only a small number of people filled out our post-program evaluation, which meant that we did not get as much feedback as we would have liked.

### **What are the next steps?**

Our next steps will involve adjusting the program based on participant feedback before doing a larger and more rigorous evaluation of the program.

### **How will this work help autistic adults now or in the future?**

This work provides a valuable example of how diverse teams (which include autistic young adults) can work collaboratively to co-design support programs for autistic people.

## Abstract

Post-diagnostic support can be useful for any autistic person, but it may be especially important for young adults (16 – 25 years) who may be negotiating their autistic identity while also navigating the transition to adulthood. Yet there is a lack of tailored support for this group. In this study, we document the process of co-designing a six-session online peer support program aiming to support young people to navigate their autistic identity in the transition to adulthood. Through documenting discussions within our research team, we provide three key reflections underpinning the success of our co-design process: (1) maximizing success through preparation; (2) facilitating effective, respectful communication, and (3) empowering meaningful collaboration. We also collected qualitative feedback from program attendees, which we analyzed using reflexive thematic analysis. This feedback highlighted how attendees appreciated the opportunity for self-discovery and to develop their understanding of autism. They also valued the social connections formed during the program. Finally, they said they benefited from the practical strategies they developed. Overall, these insights contribute to the growing body of knowledge on participatory autism research and highlight good practices when meaningfully involving autistic people in shaping the support programs that directly impact their lives. The peer support program, *Understanding You, Discovering You*, warrants further, more rigorous evaluation in future studies.

## **The co-design and initial evaluation of a peer support program for autistic young adults**

Accessing an autism diagnosis can be a lengthy, challenging, and complex process for autistic people and those who support them.<sup>1–5</sup> Certain groups of autistic people may be at particularly high risk of being missed or misdiagnosed. These groups include women and girls, those without intellectual disability, and those from minority ethnic groups.<sup>6–10</sup> Yet, even those who ‘fit’ with clinicians’ expectations of what an autistic person ‘looks like’ can face barriers, including the fear of not being believed; the financial cost associated with accessing a diagnosis; a lack of adequate clinician understanding of autism, and stigma.<sup>5,11</sup> Moreover, there is variability in the availability and accessibility of services across different geographical regions, resulting in an unequal provision of services.<sup>12,13</sup>

An autism diagnosis can provide validation, understanding and self-compassion<sup>14,15</sup> while also being a gateway to services and supports.<sup>2</sup> Yet the current landscape of post-diagnostic support falls short of meeting the needs of autistic people and their families.<sup>2,11,16–20</sup> Autistic people have called for increased availability of ongoing formal post-diagnostic support that provides practical guidance and education, connection to other autistic people, and a sense of self-understanding and empowerment.<sup>21–23</sup>

Post-diagnostic support may be especially pertinent for autistic young adults (aged 16 – 25 years). There are significant developments in one’s identity during this time of life, as individuals establish their values, beliefs, and aspirations; ultimately shaping their sense of self.<sup>24–26</sup> Societal norms and expectations often influence these values and beliefs, and it can be challenging to embed a stigmatized identity within one’s sense of self.<sup>27</sup> This complexity is reflected in research examining identity development in autistic young adults, with some autistic young adults being ‘proud’ of their diagnosis, some feeling ‘marked’ by their diagnosis, and others reporting a combination of both positive *and* negative emotions.<sup>28–30</sup> Difficulties in reconciling one’s autistic identity are associated with poor mental health outcomes.<sup>31</sup> Further, the transition to adulthood more broadly is considered a challenging time for autistic people, with many facing barriers to meaningful social connection, a reduction in support and services, and poor outcomes such as unemployment.<sup>32</sup> As such, there is a strong case for targeted support during this period.

Evaluation of support programs for autistic adults provides insights into potential opportunities. Crane and colleagues<sup>33,34</sup> evaluated an autistic-led peer support program for newly identified or diagnosed autistic adults using semi-structured interviews. Participants reported joining the program to learn more about themselves, gain a sense of empowerment, and develop practical strategies for navigating a predominantly non-autistic world. Initial evaluations of the program were promising. Participants made positive connections with others and felt better able to recognize their strengths and manage their challenges. Crompton and colleagues<sup>35</sup> reported similar findings via semi-structured interviews with 12 autistic adults about their perceptions of post-diagnostic support. Their findings highlighted the importance of connecting with like-minded autistic people, as well as the practical nature of support. Both studies<sup>33-35</sup> emphasized the need for long-term continued support post-diagnosis. While these preliminary studies highlight the potential opportunities of post-diagnostic support programs, from the perspectives of autistic people themselves, there remains a lack of tailored programs for autistic young adults.

Insights and perspectives from autistic people are essential in designing effective tailored support programs. Co-design is a participatory method that redresses power imbalances by including stakeholders as equal partners in the creation of a product, service, or intervention that they themselves would use.<sup>36,37</sup> The potential opportunities of co-design, for both individuals and design outcomes, are vast. For example, when used with other groups, the co-design of services and interventions has been shown to promote autonomy, self-advocacy, and empowerment for co-designers.<sup>38,39</sup> Further, by bridging the gap between researchers, practitioners, and service users, co-design results in more authentic and meaningful support.<sup>38,40</sup> Such participatory approaches have been widely called for within autism research and practice.<sup>41-44</sup>

Here, we document the co-design of a peer support program for autistic young adults. Given the growing need for “*improved reporting of inclusive practices and evidence of their effectiveness*”<sup>45(p94)</sup> we provide author reflections on the success of the co-design process<sup>46</sup>. We also provide initial qualitative feedback regarding the program, from the perspective of program attendees<sup>33,34</sup>, to provide an indication of whether the program warranted further, more rigorous evaluation<sup>47-49</sup>.

## **Emerging Practice**

The UK charity Ambitious about Autism identified a significant lack of post-diagnostic support for autistic young adults.<sup>50</sup> Aiming to reduce this gap in support, the charity developed a proposal to co-design a peer support program for autistic young adults. Feedback from autistic Youth Patrons at Ambitious about Autism was used to develop a proposal<sup>50</sup> and acquire philanthropic funding to undertake this work. The acquired funding was used to commission the current research and a diverse project team was assembled. The team was as follows. First, the team included representatives from Ambitious about Autism, including ten autistic young adults (including LA & LP) who co-designed the program, members of staff who facilitated the co-design sessions, and BR, who led the co-design process. Second, the team included four autism researchers who do not identify as autistic (JD, WM, KC & LC). Two of the researchers (KC & WM) are also practicing clinical psychologists who are experienced in working with autistic young adults in mental health settings. Several authors (BR, LA, LP, WM, KC, LC) have secured funding for and/or are involved in a further feasibility trial of the program outlined in this article.

Ten autistic young adults who were either involved in Ambitious about Autism's earlier post-diagnostic support work<sup>50</sup> or responded to an advertisement from the charity were selected to be part of the co-design panel. Members of the co-design panel received a £25 voucher for each co-design session they attended. The co-design process involved three 90-minute sessions, hosted virtually via Zoom, between November and December 2022. Sessions were attended by members of the co-design panel and were facilitated by three members of the Ambitious about Autism team. Panel members could choose whether they had their cameras on during the sessions. Panel members could also choose how they wanted to contribute to each activity (e.g., verbally, using the chat function, anonymously using Jamboard or Mentimeter), if at all. All members of staff from Ambitious about Autism had their cameras on for the duration of the sessions. Panel members were sent an agenda at least three days before each session (see Supplementary Materials A for an example), alongside a one-page profile of each member of staff from Ambitious about Autism that would be present at the session. The profiles contained the staff member's name, preferred pronouns, a photograph, and more information about them (e.g., their job role and interests outside of work). Each session used a variety of engagement tools, including Microsoft PowerPoint, Google Jamboard, Google Docs, and Mentimeter. While panel members were encouraged to attend each



session, average attendance was 73%, with approximately seven panel members attending each session. Where members did not attend a session, they received a summary worksheet and were able to input their feedback via email. Panel members were also sent optional tasks to complete following each session (e.g., to think of potential names for the program). Following the three co-design sessions, there was one 60-minute session in which two clinical academics (KC & WM) provided feedback on the co-designed program (which was titled '*Understanding You, Discovering You*' during the co-design sessions). Table 1 provides a summary of each co-design session, including the objectives, content covered, tasks completed, and outcomes achieved. Additional information can be found in Supplementary Materials B.

[Insert Table 1 about here]

Following the co-design and feedback sessions, BR created a draft course manual. The development of the course manual involved gathering existing training materials from Ambitious about Autism, researching specific topics (e.g., about setting goals) and working with KC and WM to generate bespoke content (e.g., about identifying social needs). BR, KC, and WM worked together to edit and refine the course manual. When the course manual was agreed upon, BR created all relevant material (e.g., PowerPoint slides, agendas, interactive activities). This material formed a 'beta' version of the program which was attended by nine autistic young adults (two of whom were part of the co-design panel). Using informal feedback from the attendees of the beta program, additional changes to the course structure and content were made before the public pilot program commenced. Specifically, (1) the session on problem-solving and goal setting was scheduled earlier in the program; (2) some session titles were adjusted to reflect their content more accurately (e.g., 'understanding autism part 2' was changed to 'experiences of autism and strengths'), and (3) some minor changes to the content were made (e.g., discussion about what to do if you are not given the support you need in session 5 was replaced with discussion about how to ask for support and reasonable adjustments). Table 2 provides an outline of the beta program and a summary of the changes made following beta testing.

[Insert Table 2 about here]

All groups were delivered by two facilitators. Some of the groups (4 of 7, 57%) were co-facilitated with an autistic facilitator, though the facilitator's neurology was not explicitly stated to attendees.

## **Evaluation Methods**

### **Team Reflections on the Co-Design Process**

We collected team reflections on the co-design process from the co-design leader (BR) as well as two co-design panel members (LA & LP) in two ways. First, BR provided written reflections after each co-design session, guided by 18 pre-determined questions (see Supplementary Materials C). Second, LC led an online discussion between LA, LP, and BR, where they provided verbal reflections about what went well with the co-design process, and what could be improved. JD noted and summarized these reflections, which LA, LP, and BR reviewed and agreed. All authors agreed upon the final reflections, which are presented in key thematic areas.

### **Feedback on the *Understanding You, Discovering You* Program**

We gathered feedback from seven groups (including the beta group) who took part in the *Understanding You, Discovering You* program between February 2023 and August 2023. Participants completed one optional questionnaire before attending the program and another optional questionnaire after taking part.

### **Participants**

Advertisements for *Understanding You, Discovering You* were circulated via Ambitious about Autism's social media platforms, newsletters, and Youth Network, as well as at events and through the charity's individual contacts. In total, 60 autistic young adults took part in seven iterations of the program between February and August 2023 (average group size = 9, range = 5 – 13, SD = 2.54). Of those, 39 (65%) completed a pre-program questionnaire and, of those, 16 (of 39, 41%) completed a post-program questionnaire. Independent t-tests and Chi-Square tests of independence (or Fisher's Exact tests, where necessary) indicated there were no significant demographic differences between attendees who chose to complete both the pre- and post-program questionnaire ( $n = 16$ ) and those who only completed the pre-program questionnaire ( $n = 23$ ). Table 3 presents characteristics of attendees who completed each questionnaire. Overall, attendees tended to be aged around 20

years, identify as female, and be of a White ethnicity. Most attendees had a formal autism diagnosis, which was received between 3 and 24 years of age.

[Insert Table 3 about here]

## **Materials**

**Pre-Program Questionnaire.** We designed a pre-program questionnaire based on a questionnaire previously used to evaluate a post-diagnostic support program for autistic adults.<sup>33,34</sup> The questionnaire was hosted online using Qualtrics software.<sup>51</sup> Participants were offered a paper version of the questionnaire, if they preferred, though no participants requested this option. A link to the questionnaire was sent to attendees via email, one-week before attending the first session, and a link to the survey was presented in the chat at the end of the first session of the *Understanding You, Discovering You* program. In the pre-program questionnaire, we gathered demographic information about the participants, including their age, gender identity, ethnicity, and information about whether they had an autism diagnosis. We also asked participants about their experience of other support groups, including how useful they had been, and the things that had been particularly good or not so good about them. Next, we asked who recommended the program to them and about their motivations for attending. We also asked about the things they were most or least looking forward to about the program. Finally, we asked whether participants had received enough information before starting the program and, if not, what information they would have liked.

**Post-Program Questionnaire.** A bespoke post-program questionnaire was developed and hosted online using Qualtrics software.<sup>51</sup> A link to the post-program questionnaire was presented in the chat at the end of the final session of the *Understanding You, Discovering You* program, and again via email immediately afterwards. In the post-program questionnaire, we gathered information about how many sessions each attendee had attended, and which sessions, if any, were the most and least helpful. We collected an overall rating for the program between 1 and 10, where 10 was the highest score, and we also asked closed questions about whether they would recommend the program to other autistic people, and whether the program should continue to be offered. Participants could explain their answers to the closed questions using open-ended text boxes. Finally, we asked additional

open-ended questions about the most and least beneficial aspects of the program, as well as what changes, if any, could be made to improve the program.

Note: the pre- and post-program questionnaires also contained quantitative measures on quality of life, well-being, Autistic identity, social support, and loneliness. The findings from these measures are not reported here as they were included to inform preparation for a subsequent feasibility trial of the program.

### **Procedure**

We received ethical approval from the Research Ethics Committee at University College London's Faculty of Education and Society (REC1737). Participants provided informed consent to take part. Pre-program and post-program questionnaires took approximately 20 minutes each to complete.

### **Data Analysis**

We analyzed quantitative questionnaire data descriptively ( $n$ , %). To assess whether there were any demographic differences between the participants who chose to complete the post-program questionnaire and those who did not, we conducted independent t-tests and Chi-Square or Fisher's Exact Tests, using IBM SPSS Statistics (Version 29).<sup>52</sup>

We analyzed qualitative questionnaire data using reflexive thematic analysis, within a critical realist framework.<sup>53–55</sup> The first author (JD) led the analyses, with support from the other authors. The process involved JD independently familiarizing herself with the data by reading and re-reading responses. Next, she reviewed the semantic content (i.e., the explicit or surface meanings) of the responses and generated summary 'codes' to aspects she perceived as salient to the evaluation of the *Understanding You, Discovering You* program. JD then grouped together codes that she viewed as similar and/or related to one another, to generate summary themes. For example, the codes '*desire to connect with others*' and '*a need to feel understood by others*' were perceived as being closely related and were therefore grouped together under the theme of 'social connection'. When all themes had been generated, JD wrote a draft of the findings which was reviewed by all members of the team to ensure there were meaningful links and relationships between themes but also clear and identifiable distinctions. No changes to the themes were suggested at this stage.

## **Results and Lessons Learned**

### **Team Reflections on the Co-Design Process**

We organized our reflections on the co-design of the *Understanding You, Discovering You* program in three areas: (1) maximizing success through preparation; (2) facilitating effective, respectful communication, and (3) empowering meaningful collaboration.

***Reflection One: Maximizing Success Through Preparation***

Adequate preparation was perceived as a critical factor in optimizing the co-design process. Panel members particularly appreciated receiving the one-page profiles and meeting agendas (featuring photographs/pictures) in advance of each session, as it removed uncertainties around the sessions and allowed them to thoughtfully engage. However, panel members also highlighted several areas in which further preparation could have improved experiences. First, they stressed the importance of facilitators being well-versed in the rules for engagement and consistently upholding them. Based on this feedback, group agreements should be co-produced as part of the first session of the program to give collective responsibility. Second, maintaining the same facilitators for each session was felt to be important to create a more cohesive and organized process. Where this was not possible, having facilitators review notes from previous sessions was important to ensure continuity and seamless transitions between discussions. Finally, the co-design panel requested more regular updates on the program's progress and any subsequent changes made. Indeed, the co-design facilitator shared regrets about not having time to send regular updates to the panel. To ensure success in future initiatives, proactive planning should include sending timely updates and facilitating informed discussions. Providing a formal recognition of contribution (e.g., a certificate) was also felt to help boost morale while acknowledging individual and collective efforts.

***Reflection Two: Facilitating Effective, Respectful Communication***

Effective communication played a pivotal role in the perceived success of the co-design process. Panel members appreciated a diversity of communication modes, which accommodated different communication styles and preferences. The 'hand-raising' function within Zoom, in particular, made them feel respected and listened to, as it allowed them to speak uninterrupted. Additionally, establishing clear rules of engagement, especially the rule encouraging respect for diverse opinions, fostered an environment conducive to open and constructive dialogue. Pre-

determining these rules facilitated respectful and fair decision-making (i.e., majority vote).

Breakout rooms were well-received, providing opportunities for in-depth discussions where panel members felt comfortable sharing personal experiences if they wished to do so. This supportive setting contributed to the development of meaningful long-term relationships within the team. Specified routes for communication outside of sessions allowed panel members to connect and exchange ideas beyond scheduled meetings.

Overall, the panel's passion for the project contributed to a positive and collaborative atmosphere. Shared lived experiences played a crucial role in facilitating discussions and promoting an understanding of alternative viewpoints, especially when disagreements arose. Some co-design panel members already knew each other (e.g., via other initiatives within the charity), which made it easier for them to be open and honest, thus fostering a comfortable environment where personal experiences were readily shared. Similarly, the development of strong relationships between facilitators and co-design panel members promoted open communication and created a supportive group dynamic.

### ***Reflection Three: Empowering Meaningful Collaboration***

The panel appreciated being actively involved in determining the topics to be covered in the program, the order in which they should be addressed, and the inclusion of various elements in each session. They also valued the structured and facilitated nature of the sessions, provided by the team at Ambitious about Autism, as this support ensured tasks were completed in the allotted time frame. Indeed, knowing there was a professional purpose for the sessions helped keep the discussions on track. One of the panel members (LA) described the collaboration using a building analogy: while members of staff at Ambitious about Autism built and established the core foundations (i.e., structuring and organizing the co-design sessions), most of the actual building work (i.e., creatively designing the program) was undertaken by the co-design panel.

Table 4 contains a list of specific recommendations, within these three areas, for future online co-design processes.

[Insert Table 4 about here]

## **Feedback from the *Understanding You, Discovering You* Program**

Following our reflections on the co-production of *Understanding You, Discovering You*, we present initial feedback regarding the program, comprising attendees' motivations for attending the program, as well as a qualitative analysis of attendees' experiences. Participant quotes are presented verbatim, including any spelling/grammatical errors, and are accompanied by a participant ID so that quotes from the same participant can be identified.

### ***Motivations for Attending the Program***

Most attendees had heard about the program and signed up to take part themselves ( $n = 18$ , 46.2%) or had the program recommended to them by a parent/carer ( $n = 16$ , 41.0%). The remaining participants had the program recommended to them by a medical professional ( $n = 3$ , 7.7%), or by another professional, such as a teacher ( $n = 2$ , 5.1%). We organized qualitative responses to the pre-program questionnaire into three key areas: (1) self-discovery and understanding autism; (2) social connection, and (3) giving and receiving practical support.

**Motivation 1: Self-Discovery and Understanding Autism.** With many participants recently receiving their autism diagnosis, they were attending the program to *“learn about my autism better”* (Participant 28; henceforth, P28) and *“enhance my understanding of how autism relates to me”* (P34). In the absence of support immediately following their diagnosis, they valued the opportunity for support provided as part of the program: *“Being diagnosed as an adult, there is not really much support or resources available after a diagnosis to help understand what this actually means”* (P16). As such, participants felt the program offered a unique opportunity to learn more about themselves, and *“develop my identity post-diagnosis”* (P07).

**Motivation 2: Social Connection.** Participants appreciated the opportunity to *“speak with more people about autism”* (P33) and *“form more connections”* (P01). Participants particularly looked forward to *“meet[ing] other people my age with autism”* (P10) as well as people *“who understand what I’m going through”* (P09). By connecting with similar others, participants hoped they may *“feel less alone”* (P12), *“gain new friends”* (P20) and *“find some kind of community”* (P29). Nonetheless, participants also shared anxiety around the social aspects of the program: *“[I am least looking forward to] meeting new people as I find that a bit stressful”* (P18).

**Motivation 3: Giving and Receiving Practical Support.** Participants wanted to learn about the support they receive, and learn practical skills, such as “*how I can advocate for myself*” (P34), “*how to function*” (P35), and to learn how to “*teach others how best to help me*” (P28). Some participants also felt they could support other attendees: “*I want to help other young people to understand themselves*” (P03).

In the pre-program questionnaire, we also asked participants if they received sufficient information before attending the program. Most participants (n = 35 out of 38<sup>1</sup>, 92.1%) indicated that they did. A minority (n = 3 out of 38, 7.9%) expressed a desire for more detailed information about each session before starting, rather than just information about the first session.

### ***Initial Feedback on the Understanding You, Discovering You Program***

On average, the 16 participants who completed the post-program questionnaire attended 5 of the possible 6 (83.3%) *Understanding You, Discovering You* sessions (range = 4 to 6 sessions, SD = 0.63). Providing an overall rating of the program from 1 (lowest possible rating) to 10 (highest possible rating), participants, on average, rated the program 8 (SD = 1.83), suggesting high regard for the program. No participants said they would *not* recommend the program to other people: 13 (81.3%) said they would recommend the program to others, and 3 (18.8%) said they were unsure. The sentiment among those who were unsure was that it ‘*depends on the person*’. Promisingly, all participants said the program should continue to be offered.

Qualitative responses to the post-program questionnaire largely mapped onto the motivations for attending the program. First, participants appreciated the opportunity for **self-discovery and understanding autism**. Since attending the program, participants suggested that their understanding of autism and its relation to their lives had improved: “*[I have enjoyed] understanding what autism is all about*” (P22). One participant reported the course made them “*more confident in [their] diagnosis*” (P01). Second, participants appreciated the **social connection** the program afforded. Participants said they enjoyed “*meeting like-minded people*” (P14) and “*[having] a space for us all, [which] seldom exists [elsewhere]*” (P21). Yet, many wanted more opportunities for social connection, with one participant noting: “*more social interaction [would be appreciated] as I feel i didnt really get to know the other*

---

<sup>1</sup> Note: one participant chose not to answer this question.



people very well” (P15). The diversity of the group was felt to affect connections: *“although everyone on my particular session would be considered ‘high-functioning’, we were all of completely different abilities, meaning that there wasn’t really that peer group that we each had hoped for”* (P13). Similarly, some felt in-person sessions would have improved connection within the group: *“[because] the sessions were over Zoom, nobody got a chance to get to know each other ... this meant that none of us found the peer group we were seeking...it would be [better] in person”* (P23). Nonetheless, participants felt *“solidarity with people attending”* (P26) and added that *“it was nice to meet people who understood me”* (P25). Finally, participants appreciated **receiving practical support**: *“the most beneficial [sessions] were the parts that can be used everyday”* (P06). Examples of beneficial content included *“how to put some of my issues into words”* (P27), *“learning about rights, reasonable adjustments, and the social aspect of being able to make friends”* (P06), and *“where best to receive support and what help is needed”* (P22). Relatedly, participants felt the program was *“practical and inspiring”* (P21) with attendees *“[coming] away feeling more supported”* (P01).

Participants also reflected on **practical aspects of the program**. Overall, feedback regarding the course facilitators and the overall culture within the program was positive: *“[the program] had a very open and welcoming atmosphere and the staff were very friendly”* (P11). Similarly, participants were positive about the session structure (*“small groups so all questions can be answered, jamboards were easy to use [and] there was a recap of what we looked at last week so we could remember and reflect”*; P11) and content: *“the slides were clear and it was entertaining”* (P01). Nonetheless, one participant reflected that the resources *“were more aimed towards a younger audience, or toward Autistic individuals with higher support needs”* (P13) and suggested having more tailored groups. Similarly, for some attendees, the presence of non-autistic facilitators hindered their ability to express their most authentic selves: *“I didn’t feel comfortable enough to stop masking as the people/person I was talking to the most were the predominantly neurotypical [Ambitious about Autism] team”* (P11).

## Discussion

In this article, we presented the co-design of a peer support program for autistic young adults, alongside initial feedback from program attendees. Reflections on the co-design process include the importance of empowering meaningful

collaboration, facilitating effective, respectful communication, and maximizing success through preparation. These reflections complement existing principles for participatory work<sup>43,44</sup> and extend existing knowledge to demonstrate how principles of good participatory practice can be embedded within co-design processes to contribute to their success. Initial feedback from attendees of the co-designed peer support program indicated they found the program acceptable and useful. Through attending the program, attendees hoped to understand more about autism and how it related to their own experiences, connect with similar others, and gain and receive practical support. Preliminary feedback on the program mapped onto attendees' motivations for attending. Attendees said they appreciated the opportunity for self-discovery and understanding of autism, which was especially valuable for those who had recently received their autism diagnosis and lacked immediate support. Additionally, participants valued the social connections formed during the program, as it allowed them to meet like-minded peers; though, some expressed a desire for more extensive opportunities for social interaction. Practical aspects of the program, such as developing key skills and coping mechanisms, were perceived as particularly beneficial. However, some participants reported feeling unable to be their authentic selves when they believed sessions were led by non-autistic facilitators. It should be reiterated that some of the *Understanding You, Discovering You* groups (4 of 7, 57%) were co-facilitated with an autistic facilitator, but the facilitator's neurology was not explicitly stated.

Our findings closely map onto existing evaluations of peer support programs. For example, Crane and colleagues<sup>33,34</sup> evaluated motivations for, and experiences of, attending an autistic-led peer support program. They found that autistic adults attended the program to learn more about autism, feel empowered about their identity through meeting similar others, and develop practical strategies and coping mechanisms. Similarly, the authors reported that attendees benefitted from the autistic-led nature of the program and appreciated the opportunity to meet like-minded others and develop a positive and practical outlook on autism. These findings highlight the benefit of working *with* autistic people to develop programs of support, to ensure they are relevant and effective for the people they seek to benefit. Being explicit about the facilitator's neurology (as in the program evaluated by Crane et al<sup>33,34</sup>) may be beneficial in future programs to ensure attendees feel comfortable in discussing their experiences.

The co-design of the *Understanding You, Discovering You* program highlights the potential value of meaningful collaboration in developing peer support for autistic young adults that addresses their needs for self-discovery, social connection, and practical support. By working directly with autistic young adults, we were able to design a program that was perceived, by attendees, as beneficial and something they would recommend to others. Our findings underscore the power of such collaborative efforts and highlight the feasibility of working with autistic young adults, a group who are not always listened to, and for whom parental voices may often take precedence (see Bertilsdotter Rosqvist et al.<sup>56</sup> for a review). We hope that by transparently documenting our process, we can encourage other researchers and practitioners to engage in meaningful co-design to ensure support programs truly meet the needs of autistic people.

### **Limitations**

While this study offers valuable insights, it is not without limitations. First, while autistic young adults played an integral role in co-designing the program, there was no direct involvement of autistic people in interpreting the feedback on the program. Second, there was a notable lack of diversity in the participants who took part in the pre- and post-program questionnaires. It is unclear whether this discrepancy is indicative of a broader issue of underrepresentation within the program's attendee demographic, or whether this reflects a specific subgroup's choice to (not) participate in the research. The former would suggest the program may not have effectively reached or engaged with a diverse population of autistic young adults, which could have implications for the program's ability to address the varied needs of the broader autistic community. This finding is in line with existing research which highlights broad inequalities in access to support and services.<sup>57</sup> It should be emphasized that we did not explicitly consider the recruitment of participants from diverse communities, which may have limited our sample. Future research may seek to understand the mechanisms underpinning these inequalities, alongside exploring strategies to ensure programs are accessible to a diverse range of autistic people.<sup>58</sup> Researchers should also commit to improving diversity within their samples by making explicit considerations about how they will recruit diverse samples during the planning stages of their research to ensure that their findings are representative and applicable to the broader autistic community. Addressing underrepresentation is not only an ethical imperative but also essential for

developing effective and inclusive support programs. Finally, the attrition rate for the completion of the post-program questionnaire was high (59%), meaning that important insights from a substantial portion of participants were not captured. While the exact reasons behind the high attrition rate remain unclear, factors such as survey fatigue, unclear instructions regarding how to complete the questionnaire, recruiting young people in a stage of transition who may not have time, or an insufficient number of follow-ups and reminders may have contributed. To more rigorously evaluate the *Understanding You, Discovering You* program, a robust trial is needed. Such an evaluation should explore strategies to improve participant retention rates, to enhance the overall robustness of findings.

## **Acknowledgements**

The authors would like to thank the participants who generously took the time to speak with our team, as well as Alison Worsley and the Ambitious Youth Network for their crucial contributions in setting up the *Understanding You, Discovering You* program. Research at the Centre for Research in Autism and Education (CRAE) is generously supported by Pears Foundation.

## **CRedit Authorship Statement**

Jade Davies: Formal Investigation, Formal analysis, Writing – Original draft, Writing – Review & editing

Ben Redmayne – Conceptualization, Methodology, Writing – Review & editing

Leon Allain – Conceptualization, Writing – Review & editing

Lucy Portway – Conceptualization, Writing – Review & editing

Will Mandy – Conceptualization, Writing – Review & editing

Kate Cooper – Conceptualization, Writing – Review & editing, Supervision

Laura Crane – Conceptualization, Methodology, Writing – Review & editing, Supervision, Funding acquisition

## **Author Disclosure Statement**

No competing financial interests exist.

## **Funding Information**

Ambitious about Autism received philanthropic funding from The Bally's Foundation to co-design the Understanding You, Discovering You program. Part of the funding from The Bally's Foundation was awarded to LC, to undertake the work presented in this article.

## **Supplementary Material**

Supplementary Materials A. Example Agenda.

Supplementary Materials B. Additional Information Regarding the Co-Design Process

Supplementary Materials C. Author Reflections Guide Questions.

## References

1. Crane L, Chester JW, Goddard L, Henry LA, Hill E. Experiences of autism diagnosis: A survey of over 1000 parents in the United Kingdom. *Autism*. 2016;20(2):153-162. doi:10.1177/1362361315573636
2. Crane L, Batty R, Adeyinka H, Goddard L, Henry LA, Hill EL. Autism Diagnosis in the United Kingdom: Perspectives of Autistic Adults, Parents and Professionals. *J Autism Dev Disord*. 2018;48(11):3761-3772. doi:10.1007/s10803-018-3639-1
3. Huang Y, Arnold SRC, Foley KR, Trollor JN. Choose your Own Adventure: Pathways to Adulthood Autism Diagnosis in Australia. *J Autism Dev Disord*. 2022;52(7):2984-2996. doi:10.1007/s10803-021-05169-4
4. Jones L, Goddard L, Hill EL, Henry LA, Crane L. Experiences of Receiving a Diagnosis of Autism Spectrum Disorder: A Survey of Adults in the United Kingdom. *J Autism Dev Disord*. 2014;44(12):3033-3044. doi:10.1007/s10803-014-2161-3
5. Lewis LF. A Mixed Methods Study of Barriers to Formal Diagnosis of Autism Spectrum Disorder in Adults. *J Autism Dev Disord*. 2017;47(8):2410-2424. doi:10.1007/s10803-017-3168-3
6. Aggarwal S, Angus B. Misdiagnosis versus missed diagnosis: diagnosing autism spectrum disorder in adolescents. *Australasian Psychiatry*. 2015;23(2):120-123. doi:10.1177/1039856214568214
7. Bargiela S, Steward R, Mandy W. The Experiences of Late-diagnosed Women with Autism Spectrum Conditions: An Investigation of the Female Autism Phenotype. *J Autism Dev Disord*. 2016;46(10):3281-3294. doi:10.1007/s10803-016-2872-8
8. Leedham A, Thompson AR, Smith R, Freeth M. 'I was exhausted trying to figure it out': The experiences of females receiving an autism diagnosis in middle to late adulthood. *Autism*. 2020;24(1):135-146. doi:10.1177/1362361319853442
9. Shenouda J, Barrett E, Davidow AL, et al. Prevalence and Disparities in the Detection of Autism Without Intellectual Disability. *Pediatrics*. 2023;151(2). doi:10.1542/peds.2022-056594

10. Tromans S, Chester V, Gemegah E, et al. Autism identification across ethnic groups: a narrative review. *Advances in Autism*. 2021;7(3):241-255. doi:10.1108/AIA-03-2020-0017
11. de Broize M, Evans K, Whitehouse AJO, Wray J, Eapen V, Urbanowicz A. Exploring the Experience of Seeking an Autism Diagnosis as an Adult. *Autism in Adulthood*. 2022;4(2):130-140. doi:10.1089/aut.2021.0028
12. Beresford B, Mukherjee S. Providing psychoeducation after an autism diagnosis: findings from an evidence-based consultation project. University of York . doi:10.15124/yao-myeq-qn63
13. Dillenburger K, McKerr L, Jordan JA. Lost in Translation: Public Policies, Evidence-based Practice, and Autism Spectrum Disorder. *Intl J Disabil Dev Educ*. 2014;61(2):134-151. doi:10.1080/1034912X.2014.905059
14. Stagg SD, Belcher H. Living with autism without knowing: receiving a diagnosis in later life. *Health Psychol Behav Med*. 2019;7(1):348-361. doi:10.1080/21642850.2019.1684920
15. Wilson RB, Thompson AR, Rowse G, Smith R, Dugdale AS, Freeth M. Autistic women's experiences of self-compassion after receiving their diagnosis in adulthood. *Autism*. 2023;27(5):1336-1347. doi:10.1177/13623613221136752
16. Arnold SRC, Huang Y, Hwang YI (Jane), Richdale AL, Trollor JN, Lawson LP. "The Single Most Important Thing That Has Happened to Me in My Life": Development of the Impact of Diagnosis Scale—Preliminary Revision. *Autism in Adulthood*. 2020;2(1):34-41. doi:10.1089/aut.2019.0059
17. Huang Y, Arnold SR, Foley KR, Trollor JN. Diagnosis of autism in adulthood: A scoping review. *Autism*. 2020;24(6):1311-1327. doi:10.1177/1362361320903128
18. McLinden H, Sedgewick F. 'The girls are out there': professional perspectives on potential changes in the diagnostic process for, and recognition of, autistic females in the UK. *British Journal of Special Education*. 2023;50(1):63-82. doi:10.1111/1467-8578.12442
19. Raymond-Barker P, Griffith GM, Hastings RP. Biographical disruption: Experiences of mothers of adults assessed for autism spectrum disorder. *J Intellect Dev Disabil*. 2018;43(1):83-92. doi:10.3109/13668250.2016.1262011

20. Spain D, Stewart GR, Mason D, et al. Autism Diagnostic Assessments With Children, Adolescents, and Adults Prior to and During the COVID-19 Pandemic: A Cross-Sectional Survey of Professionals. *Front Psychiatry*. 2022;13. doi:10.3389/fpsyt.2022.789449
21. Beresford B, Mukherjee S, Mayhew E, et al. Evaluating specialist autism teams' provision of care and support for autistic adults without learning disabilities: the SHAPE mixed-methods study. *Health Services and Delivery Research*. 2020;8(48):1-200. doi:10.3310/hsdr08480
22. Huang Y, Arnold SRC, Foley KR, Trollor JN. A Qualitative Study of Adults' and Support Persons' Experiences of Support After Autism Diagnosis. *J Autism Dev Disord*. Published online December 9, 2022. doi:10.1007/s10803-022-05828-0
23. Huang Y, Arnold SRC, Foley KR, Trollor JN. Experiences of Support Following Autism Diagnosis in Adulthood. *J Autism Dev Disord*. Published online November 21, 2022. doi:10.1007/s10803-022-05811-9
24. Marcia JE. Development and validation of ego-identity status. *J Pers Soc Psychol*. 1966;3(5):551-558. doi:10.1037/h0023281
25. Arnett JJ. Emerging Adulthood: What Is It, and What Is It Good For? *Child Dev Perspect*. 2007;1(2):68-73. doi:10.1111/j.1750-8606.2007.00016.x
26. Arnett JA. *Emerging Adulthood: The Winding Road from the Late Teens Through the Twenties*. 2nd ed. Oxford University Press; 2014.
27. Han E, Scior K, Avramides K, Crane L. A systematic review on autistic people's experiences of stigma and coping strategies. *Autism Research*. 2022;15(1):12-26. doi:10.1002/aur.2652
28. Mogensen L, Mason J. The meaning of a label for teenagers negotiating identity: experiences with autism spectrum disorder. *Children, Health and Well-being: Policy Debates and Lived Experience*. Published online June 3, 2015:83-97. doi:10.1002/9781119069522.CH7
29. Jones JL, Gallus KL, Viering KL, Oseland LM. 'Are you by chance on the spectrum?' Adolescents with autism spectrum disorder making sense of their diagnoses. *Disabil Soc*. 2015;30(10):1490-1504. doi:10.1080/09687599.2015.1108902



30. Cribb S, Kenny L, Pellicano E. 'I definitely feel more in control of my life': The perspectives of young autistic people and their parents on emerging adulthood. *Autism*. 2019;23(7):1765-1781. doi:10.1177/1362361319830029
31. Davies J, Cooper K, Killick E, et al. Autistic identity: A systematic review of quantitative research. *OSF PrePrints*. Published online 2023.
32. Anderson KA, Sosnowy C, Kuo AA, Shattuck PT. Transition of Individuals With Autism to Adulthood: A Review of Qualitative Studies. *Pediatrics*. 2018;141(Supplement\_4):S318-S327. doi:10.1542/peds.2016-4300I
33. Crane L, Hearst C, Ashworth M, Davies J, Hill EL. Supporting Newly Identified or Diagnosed Autistic Adults: An Initial Evaluation of an Autistic-Led Programme. *J Autism Dev Disord*. 2021;51(3):892-905. doi:10.1007/s10803-020-04486-4
34. Crane L, Hearst C, Ashworth M, Davies J. Evaluating the online delivery of an autistic-led programme to support newly diagnosed or identified autistic adults. *Autism Dev Lang Impair*. 2023;8. doi:10.1177/23969415231189608
35. Crompton CJ, Hallett S, McAuliffe C, Stanfield AC, Fletcher-Watson S. "A Group of Fellow Travellers Who Understand": Interviews With Autistic People About Post-diagnostic Peer Support in Adulthood. *Front Psychol*. 2022;13. doi:10.3389/fpsyg.2022.831628
36. Sanders EBN, Stappers PJ. Co-creation and the new landscapes of design. *CoDesign*. 2008;4(1):5-18. doi:10.1080/15710880701875068
37. McKercher K. *Beyond Sticky Notes: Co-Design for Real: Mindsets, Methods and Movements*. Beyond Sticky Notes; 2020.
38. Connolly M, Casey S, Conroy É, et al. Co-Designing a Mental Health Support Programme with Young Adults Experiencing Homelessness. *Dublin Simon Community*. Published online 2023.
39. Tindall RM, Ferris M, Townsend M, Boschert G, Moylan S. A first-hand experience of co-design in mental health service design: Opportunities, challenges, and lessons. *Int J Ment Health Nurs*. 2021;30(6):1693-1702. doi:10.1111/inm.12925

40. Steen M, Manschot M, De Koning N. Benefits of Co-design in Service Design Projects. *International Journal of Design*. 2011;5(2):53-60.
41. den Houting J, Higgins J, Isaacs K, Mahony J, Pellicano E. 'I'm not just a guinea pig': Academic and community perceptions of participatory autism research. *Autism*. 2021;25(1):148-163. doi:10.1177/1362361320951696
42. 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. doi:10.1177/1362361318786721
43. Hobson H, Linden A, Crane L, Kalandadze T. Towards reproducible and respectful autism research: Combining open and participatory autism research practices. *Res Autism Spectr Disord*. 2023;106:102196. doi:10.1016/j.rasd.2023.102196
44. 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. doi:10.1177/1362361319830523
45. Fletcher-Watson S, Brook K, Hallett S, Murray F, Crompton CJ. Inclusive Practices for Neurodevelopmental Research. *Curr Dev Disord Rep*. 2021;8(2):88-97. doi:10.1007/s40474-021-00227-z
46. Stark E, Ali D, Ayre A, et al. Coproduction with Autistic Adults: Reflections from the Authentistic Research Collective. *Autism in Adulthood*. 2021;3(2):195-203. doi:10.1089/aut.2020.0050
47. Bottema-Beutel K, LaPoint SC, Kim SY, Mohiuddin S, Yu Q, McKinnon R. An evaluation of intervention research for transition-age autistic youth. *Autism*. 2023;27(4):890-904. doi:10.1177/13623613221128761
48. Fletcher-Watson S, Bölte S, Crompton CJ, et al. Publishing standards for promoting excellence in autism research. *Autism*. 2021;25(6):1501-1504. doi:10.1177/13623613211019830
49. Dawson M, Fletcher-Watson S. Commentary: What conflicts of interest tell us about autism intervention research—a commentary on Bottema-Beutel et al. (2020). *Journal of Child Psychology and Psychiatry*. 2021;62(1):16-18. doi:10.1111/jcpp.13315

50. Niner E. "True support is having acceptance, warmth and help from everyone in my life": Exploring post-diagnostic support for autistic young people. *Ambitious about Autism*. Published online 2019.
51. Qualtrics. Qualtrics. <https://www.qualtrics.com>.
52. IBM Corp. IBM SPSS Statistics for Mac (Version 29). Published online 2022.
53. Braun V, Clarke V. *Thematic Analysis: A Practical Guide*. Sage; 2022.
54. Braun V, Clarke V. *Successful Qualitative Research: A Practical Guide for Beginners*. Sage; 2013.
55. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol*. 2006;3(2):77-101. doi:10.1191/1478088706QP063OA
56. Bertilsdotter Rosqvist H, Brownlow C, O'Dell L. 'An Association for All'-Notions of the Meaning of Autistic Self-Advocacy Politics within a Parent-Dominated Autistic Movement. *J Community Appl Soc Psychol*. 2015;25(3):219-231. doi:10.1002/casp.2210
57. Smith KA, Gehricke JG, Iadarola S, Wolfe A, Kuhlthau KA. Disparities in Service Use Among Children With Autism: A Systematic Review. *Pediatrics*. 2020;145(Supplement\_1):S35-S46. doi:10.1542/peds.2019-1895G
58. Davies J, Islaam L, Carter S, et al. Examining the support experiences of underserved groups of autistic young people. doi:10.31219/osf.io/ybm2a

**Table 1.**

*Summary of each co-design session.*

<b>Session</b>	<b>Attendees</b>	<b>Meeting objectives</b>	<b>Content covered / tasks completed</b>	<b>Decisions made / outcomes achieved</b>
1	<ul style="list-style-type: none"> <li>● 7 panel members</li> <li>● 2 co-facilitators</li> <li>● 1 break-out room support</li> </ul>	<ul style="list-style-type: none"> <li>● Meet the panel members.</li> <li>● Understand the project and what the panel is for.</li> <li>● Understand the co-design process.</li> <li>● Make decisions on the structure of the program and start gathering ideas for the first session of the program.</li> </ul>	<ul style="list-style-type: none"> <li>● Introductions and ice-breaker question.</li> <li>● Summary of rules of engagement and how to access support.</li> <li>● PowerPoint providing an overview of the project.</li> <li>● Jamboard to decide a framework for the co-design of the program.</li> <li>● Jamboard avatar exercise.</li> <li>● Jamboard to propose topics the program should cover.</li> <li>● Mentimeter choosing which topic to co-produce first.</li> <li>● Breakout groups to discuss the chosen topic.</li> </ul>	<ul style="list-style-type: none"> <li>● Agreed on some of the topics the program should cover.</li> <li>● Chose which topic to co-produce first.</li> </ul>
2	<ul style="list-style-type: none"> <li>● 6 panel members</li> <li>● 2 co-facilitators</li> <li>● 1 break-out room support</li> </ul>	<ul style="list-style-type: none"> <li>● Recap the decisions made in the previous meeting.</li> <li>● Explore more topics for the program.</li> <li>● Create a plan for two program sessions.</li> <li>● Choose a name for the program.</li> </ul>	<ul style="list-style-type: none"> <li>● Introductions and ice-breaker question.</li> <li>● Reminder of rules of engagement and how to access support.</li> <li>● Recap of the co-design framework created in session 1.</li> <li>● Recap of the program topics identified in session 1.</li> <li>● Choose a topic via group vote within the Zoom chat.</li> <li>● Jamboard to brainstorm ideas for a program</li> </ul>	<ul style="list-style-type: none"> <li>● Agreed the program name.</li> <li>● Confirmed a framework for co-design.</li> <li>● Began developing a plan for the format and structure of the program sessions.</li> </ul>

			<ul style="list-style-type: none"> <li>session based on the chosen topic.</li> <li>● Mentimeter to select program name.</li> <li>● Google Doc demonstration of a session plan.</li> <li>● Breakout groups to create a session plan for two topics.</li> <li>● Group discussion and feedback on the session plans.</li> </ul>	
3	<ul style="list-style-type: none"> <li>● 8 panel members</li> <li>● 1 facilitator</li> <li>● 1 session support</li> <li>● 1 break-out room support</li> </ul>	<ul style="list-style-type: none"> <li>● Identify the top 5 key topics that the program should cover.</li> <li>● Create a draft outline of the program.</li> <li>● Share feedback about the youth panel sessions.</li> </ul>	<ul style="list-style-type: none"> <li>● Introductions and ice-breaker question.</li> <li>● Reminder of rules of engagement and how to access support.</li> <li>● Recap of session 2, via PowerPoint.</li> <li>● Review of the topics identified in session 1.</li> <li>● Group discussion to choose the topics to be covered throughout the program.</li> <li>● Jamboard to develop a draft outline for the program.</li> </ul>	<ul style="list-style-type: none"> <li>● Agreed on the top 5 topics the program should cover.</li> <li>● Decided on the structure of the program and developed a draft program outline.</li> </ul>
4	<ul style="list-style-type: none"> <li>● 8 panel members</li> <li>● 1 facilitator</li> <li>● 1 session support</li> <li>● 2 clinician researchers</li> </ul>	<ul style="list-style-type: none"> <li>● Discuss feedback of the program outline from the researchers.</li> <li>● Finalize the program outline following feedback from the researchers.</li> </ul>	<ul style="list-style-type: none"> <li>● Introductions and ice-breaker question.</li> <li>● Reminder of rules of engagement and how to access support.</li> <li>● Researcher feedback on the program, via PowerPoint.</li> <li>● Amendments to the course outline via group discussion.</li> </ul>	<ul style="list-style-type: none"> <li>● Finalization of the program outline.</li> </ul>

**Table 2.**

*'Beta' program outline and changes made following the beta testing.*

Session	'Beta' program outline	Program outline following beta testing
1	<p data-bbox="353 523 779 603"><b><i>Welcome to the course and understanding autism part 1</i></b></p> <ul data-bbox="353 676 846 1011" style="list-style-type: none"> <li data-bbox="353 676 846 836">● Introduction to the online course, rules of engagements, signposting to support and meet each other.</li> <li data-bbox="353 852 846 922">● Group discussion of existing knowledge of autism.</li> <li data-bbox="353 938 846 967">● What is autism?</li> <li data-bbox="353 983 846 1011">● Key terms and language.</li> </ul>	<p data-bbox="882 523 1218 558"><b><i>Understanding autism</i></b></p> <ul data-bbox="882 676 1373 1011" style="list-style-type: none"> <li data-bbox="882 676 1373 836">● Introduction to the online course, rules of engagements, signposting to support and meet each other.</li> <li data-bbox="882 852 1373 922">● Group discussion of existing knowledge of autism.</li> <li data-bbox="882 938 1373 967">● What is autism?</li> <li data-bbox="882 983 1373 1011">● Key terms and language.</li> </ul>
2	<p data-bbox="353 1021 792 1056"><b><i>Understanding autism part 2</i></b></p> <ul data-bbox="353 1139 846 1302" style="list-style-type: none"> <li data-bbox="353 1139 846 1168">● Autistic features.</li> <li data-bbox="353 1184 846 1212">● Autism and strengths.</li> <li data-bbox="353 1228 846 1302">● Group discussion and views on being autistic.</li> </ul>	<p data-bbox="882 1021 1290 1101"><b><i>Experiences of autism and strengths</i></b></p> <ul data-bbox="882 1139 1373 1302" style="list-style-type: none"> <li data-bbox="882 1139 1373 1168">● Autistic features.</li> <li data-bbox="882 1184 1373 1212">● Autism and strengths.</li> <li data-bbox="882 1228 1373 1302">● Group discussion and views on being autistic.</li> </ul>

3	<b><i>Autistic identity</i></b>	<b><i>Problem-solving and goal setting</i></b>
	<ul style="list-style-type: none"> <li>• How to explain autism to other people.</li> <li>• When to disclose to others.</li> <li>• Group discussion on how other people respond to autistic identity and how to learn from these conversations.</li> </ul>	<ul style="list-style-type: none"> <li>• Benefits of problem-solving and goal setting.</li> <li>• Tools to problem-solve and set goals.</li> <li>• Peer-supported problem-solving and goal setting.</li> </ul>
4	<b><i>Problem-solving and goal setting</i></b>	<b><i>How to explain autism to other people</i></b>
	<ul style="list-style-type: none"> <li>• Benefits of problem-solving and goal setting.</li> <li>• Tools to problem-solve and set goals.</li> <li>• Peer-supported problem-solving and goal setting.</li> </ul>	<ul style="list-style-type: none"> <li>• How to explain autism to other people.</li> <li>• When to disclose to others.</li> <li>• Group discussion about the autistic community and autistic identity.</li> </ul>
5	<b><i>What support is on offer and where to find it</i></b>	<b><i>What support is on offer and where to find it</i></b>
	<ul style="list-style-type: none"> <li>• What services are available and where to access them.</li> <li>• What are you legally entitled to in school/college/the workplace?</li> </ul>	<ul style="list-style-type: none"> <li>• What services are available and where to access them.</li> <li>• What are you legally entitled to in school/college/the workplace?</li> </ul>

- What to do if you are not given the support you need.

- Discussion about how to ask for support and reasonable adjustments.

---

**6**

***Identifying your social needs***

- Approaches and tools to identify your social needs.
- Discussion about social groups and friendship and how to advocate for your social needs.
- Tips and ways to find new social groups.

***Identifying your social needs***

- Approaches and tools to identify your social needs.
- Discussion about social groups and friendship and how to advocate for your social needs.
- Tips to find new social groups.
- Conclusion of course, review of outcomes and what next.



**Table 3.***Characteristics of 'Understanding You, Discovering You' attendees*

	Completed pre-program questionnaire ( <i>n</i> =39)	Completed post-program questionnaire ( <i>n</i> =16)	<i>p</i> <sup>a</sup>
<b>Age M (SD)</b>	20.4 (2.48)	20.6 (2.36)	.66 <sup>b</sup>
<b>Gender</b>			.41 <sup>c</sup>
Female	22 (56.4%)	7 (43.8%)	
Male	11 (28.2%)	6 (37.5%)	
Other	6 (15.4%)	3 (18.8%)	
<b>Ethnicity</b>			.74 <sup>c</sup>
White	33 (84.6%)	13 (81.3%)	
Asian	3 (7.7%)	1 (6.3%)	
Chinese	1 (2.6%)	1 (6.3%)	
Black	1 (2.6%)	1 (6.3%)	
Prefer not to say	1 (2.6%)	0 (0.0%)	
<b>Autism diagnosis</b>			.71 <sup>c</sup>
Have a formal autism diagnosis	36 (92.3%)	14 (87.5%)	

Awaiting a formal autism diagnosis	2 (5.1%)	1 (6.3%)	
Self-identify as autistic	1 (2.6%)	1 (6.3%)	
<b>Age at autism diagnosis M (SD)</b>	14.1 (6.22)	12.3 (5.56)	.16 <sup>b</sup>
<b>Attended previous support group</b>			.18 <sup>d</sup>
Yes	14 (35.9%)	8 (50.0%)	
No	25 (64.1%)	8 (50.0%)	

---

<sup>a</sup> Tests examining differences between attendees who chose to complete both the pre- and post-program questionnaire ( $n=16$ ) and those who only completed the pre-program questionnaire ( $n=23$ ); <sup>b</sup> Independent t-test; <sup>c</sup> Fisher's Exact test; <sup>d</sup> Chi-square test.

**Table 4.**

*Recommendations for future online co-design processes.*

---

<b>Recommendation</b>	<b>Description</b>
<b>1. Ensure adequate preparation</b>	<ul style="list-style-type: none"><li>a. Co-design facilitators should send one-page profiles about themselves in advance of the first meeting. The profile should contain a photograph of themselves and information about them and their role. Panel members may also create one-page profiles about themselves.</li><li>b. Co-design facilitators should send meeting agendas before each meeting, with expected content, activities, and timings.</li><li>c. Co-design facilitators should be aware of the agreed rules for appropriate engagement. These rules should be explicitly communicated to panel members, and consistently upheld.</li><li>d. Where possible, co-design facilitators should remain consistent over time. Where this is not possible, clear notes should be given to new facilitators, so they are aware of previous developments.</li><li>e. Panel members should be regularly updated with progress and future developments, even if the formal co-design process has ended.</li></ul>

---

---

**2. Facilitate effective, respectful communication**

- a. Offer multiple methods for participation/engagement (e.g., text-based, verbal, anonymous contributions/voting)
- b. Provide clear expectations for respectful communication (e.g., using 'hand-raising' function to indicate attendee has something to contribute without interrupting others)
- c. Provide clear rules for respectful and fair engagement (e.g., acknowledging, and respecting, diversity in views while making fair decisions by choosing majority votes)
- d. Provide opportunities for in-depth discussions between panel members (e.g., via breakout rooms)
- e. Offer routes of communication outside of co-design sessions so panel members can connect and exchange ideas beyond scheduled meetings.
- f. Consider group dynamics when assembling the co-design panel. Having shared lived experiences plays a crucial role in promoting understanding and respect. Similarly, existing relationships between panel members may impact the success of their working relationships.
- g. Co-design facilitators should begin developing positive relationships with panel members before meeting as a group.

---

**3. Create processes for**

- a. Panel members should be actively involved in all aspects of decision-making.
- b. Co-design sessions should be structured, but flexible.

---

**meaningful  
collaboration**

## Supplementary Materials A. Example Agenda.

**Name of workshop/project:** Post-Diagnosis Support Youth Panel – Meeting 2

**Date and time:**

**Zoom joining details:** [LINK]

Meeting ID: / Passcode:

**Co-Facilitator:** [name]

**Co-Facilitator:** [name]


**Break-out room support** [name]




### Objectives




- To look at what we decided and created in the previous meeting
- To explore more topics for the online course
- To create a plan for two sessions
- To choose a new name for the online course

### Structure

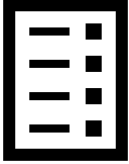


- Zoom with PowerPoint slides, Murals, Mentimeter and Jamboards

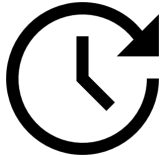
Timings	Item	Details	Who will lead?
10 Mins	Introduction 	Everyone will introduce themselves: 1. Name 2. Pronouns 3. Where you are from 4. Icebreaker Question	[facilitator(s)]

3 Mins	Agenda 	[BR] will talk through today's agenda	[facilitator(s)]
5 Mins	Rules of engagement and Support 	<p>[BR] will remind the group of the rules of engagement that we use at Ambitious about Autism.</p> <p>[BR] will talk remind the group of the support available throughout sessions, including:</p> <ol style="list-style-type: none"> <li>1. The option for breakouts with [session support] and <u>Ambitious Youth Network signposts</u> page</li> <li>2. [BR] will talk about trigger warnings and ask everyone to warn the group if they think something they are discussing may cause distress.</li> <li>3. Using zoom reactions to ask questions, put your hand up, or to let us know when you don't want to answer questions.</li> </ol>	[facilitator(s)]
7 Mins	Last meeting recap 	<p>[BR] will show what we created in the last meeting. [BR] has taken the Youth Panel thoughts/notes and categorised them into sections on <u>Mural</u>.</p> <ol style="list-style-type: none"> <li>1. How we will co-produce as a group</li> </ol> <p><b>Decision:</b> The Youth Panel will decide if they agree to this co-production framework or if it needs anything changing</p> <ol style="list-style-type: none"> <li>2. The subjects and topics the panel want to explore in the online course (from the Avatar exercise)</li> </ol>	[facilitator(s)]

10 Mins	Exploring topics continued 	<p><b>Decision:</b> The Youth Panel will <b>choose a topic</b> that needs more content and work together in a group to answer the questions using Jamboard.</p> <p>We will ask the questions:</p> <ol style="list-style-type: none"> <li>1. What questions might a young person have about the topic?</li> <li>2. What a young person might not know about the topic?</li> <li>3. How do we answer these questions?</li> </ol>	[facilitator(s)]
10 Mins	BREAK 		
5 Mins	Course Name Vote 	<p>We will look at the name suggestions for the course from last weeks 'at home task'.</p> <p><b>Decision:</b> Using Mentimeter, we will vote for our favourite names until we have a new name for the course! The most popular suggestions so far are:</p> <ol style="list-style-type: none"> <li>1. Let me be Me</li> <li>2. Exploring your Autistic Identity</li> <li>3. Understanding You / Discovering You</li> <li>4. I am Autistic</li> </ol>	[facilitator(s)]



10 Mins	<p>How to create a session plan</p> 	<p>We will explore how we create a session plan. We will use a template as a guide, but we can also change this template.</p>	[facilitator(s)]
20 Mins	<p>Breakout: Create plan for a session</p> 	<p>The group will split into 2 breakout rooms, and we will create a plan for two topics.</p>	[facilitator(s)]
5 Mins	<p>Feedback</p> 	<p>We will come back together. [Facilitators] will show each groups plans. We will have time for an open discussion between the two groups.</p>	[facilitator(s)]

5 mins	Next Steps and Check Out 	[BR] will talk about what we will do in the next session. [BR] will also talk about optional at home tasks and explain the reflection Jamboard. We will checkout together and say our goodbyes. The next meeting will be on [INSERT].	[facilitator(s)]
--------	---	--	------------------



**At Home Tasks:** *(optional)*

**Create your own session plan!**

- Choose another topic we haven't covered and create your own plan using the template, mural and resources
- We can share these in the next session, or you can send to Ben first
- [BR] will post the templates, mural and resources on the Youth Panel group on the network

**Read draft consent forms and information sheet**

- One of the research teams would like the panel to read the draft information sheets that participants will receive before the online course.
- They want to see if you think it makes sense and has the right information available.
- [BR] will post the draft forms on the Youth Panel group on the AYN

## Supplementary Materials B. Additional Information Regarding the Co-Design Process

There were three co-design sessions. Each session started by asking panel members to introduce themselves and answer an ice-breaker question (e.g., “what would be your superpower and why?”). The facilitator (BR) then summarized the rules of engagement, which were co-created by members of the charity’s broader Youth Network (see Table 1). Information about how to access support, if needed, was also provided. The remaining session content was guided by the session objectives.

**Table 1.**

### *Rules of engagement.*

1	Mute your microphone unless it’s your turn to speak.
2	Raise your hand if you want to say something or use Zoom reactions to ask questions.
3	No swearing or inappropriate actions.
4	Keep it positive.
5	Always respect different opinions and viewpoints, even if you don’t always agree.
6	Keep things confidential. Don’t share personal stories outside the Youth Panel. <i>[Added in session 2]</i>

### **Co-Design Session 1**

Session 1 aimed to introduce the project and establish a framework for the co-design process. First, the facilitator provided an overview of the project, including the aims of the program and co-design process. This information served as a foundation for subsequent discussions and activities. Panel members used a tool called Google Jamboard to reflect on examples of positive experiences of online groups or workshops, to establish a framework for the co-design process. Jamboard is an online whiteboard tool that allows users to collaborate in real-time by drawing, typing, and adding images to a digital canvas. [Note: Jamboard will be discontinued in October 2024]. The principles identified via the Jamboard were used to collectively

develop guidelines and principles for collaboration throughout the project, which focused on promoting structure, accessibility, and support (see Table 2). This process ensured that everyone had a shared understanding of the expected process and outcomes.

**Table 2.**

*Principles for collaboration.*

---

**Structure/Knowing What to Expect**

- Basic structure - sent out in advance.
- Asking individuals what they expect.
- Pictures/one-page profiles of the people running the sessions.
- Have a structure that allows participants to shape the session as they go.
- Setting rules/guidelines for working together at start of each session.
- Having the aim visible for the duration of the session.
- Quick questionnaire at the end to see how much participants understood.
- Some sort of document that everyone can see at any point.

**Offering Support to Young People**

- Autistic role model.
- Having breaks when needed and checking in on participants.
- Having my thoughts put into words.
- Safe space.
- Friendly, chatty, flexible.
- Signposting support websites.
- Trigger warnings.
- Opportunity to communicate with facilitators for 30mins or so before and after the session.
- Someone in the session who mainly focuses on the participants rather than content delivery.
- Directing to resources so people can research more after the session.
- Explaining how tasks help to meet an aim.

**Accessible for Different Needs**

- Flexibility in the way you're able to communicate and express your views.

- Using different and engaging ways to discuss.
- Not being forced to speak or picked upon
- Accessible time around school, work etc.
- Visual information or that is verbal or written down.
- Self-paced or at least the opportunity to do on your own.
- All resources sent so no one misses out.
- Avoiding leading questions to get the most representative discussion.
- Allowing cameras and mics to be off.
- Explaining information in different ways, if not understood the first time.
- Don't pick on people or ask on the spot – send quiz/questionnaire by email before and after, or even during.

### **Tools for Support**

- Things that are easy to use for those who struggle with tech.
- Visual prompts and easy read.
- Visual timetable.
- Information booklet, each page has one particular topic very clear and visual and information of resources both physical and online versions.
- Videos of different groups and support services.
- Kahoot.
- PowerPoint.
- Discussion aids.
- Quizzes and games, interactivity.
- Toolkit/guide/cheat sheet.
- Quotes from autistic young people.
- Jamboard (and one for doodles).
- Padlet and Mentimeter.
- Videos.
- Anything that makes sure there are multiple ways to process the information.
- Using structured steps, like a flow chart.
- Drawing/crafts.

### **Social Space**

- Being able to meet other like-minded people online.

- Flash talks where you can hear young people talk about what they are interested in.
- Connecting people.
- We could have a forum for the people who have done the course so they can discuss it and make friends.

Next, as a group, the panel selected an avatar from four options (representing four different ethnicities, hairstyles, eye colours etc.) before choosing the avatar's name, age, gender, and pronouns. The panel was then asked to reflect on (1) what the avatar might be feeling after receiving their diagnosis; (2) questions the avatar may have about their diagnosis; (3) what support the avatar may need after receiving their diagnosis, and (4) what the avatar may not know or understand about their diagnosis. Panel members could anonymously upload their thoughts to a Jamboard canvas. This approach (i.e., using an avatar to guide reflections) was taken to provide a platform for panel members to share their experiences without disclosing possibly sensitive information to the other members of the group. The reflections uploaded to the Jamboard were used by the facilitators to guide discussion regarding program content.

When members had uploaded their initial thoughts onto Jamboard, a poll was used to determine the first topic that would be discussed by the group. The poll was created using a tool called Mentimeter, which allows users to respond to polls, quizzes, and surveys, displaying responses in real-time. 'Where to get support?' received the majority vote, chosen by three panel members, and was, therefore, the topic of discussion for the remainder of the session. Two breakout groups were created (using Zoom functionality), and group members reflected on what a session about 'where to get support?' should entail. Members could contribute verbally, using the chat function, or by anonymously uploading their ideas onto a Jamboard canvas. At the end of the session, the two breakout groups shared their ideas, and BR summarized what would happen in future sessions. An optional post-session activity involved generating ideas for a program name.

## **Co-Design Session 2**

In Session 2, panel members began refining the content and structure of the peer support program. To ensure continuity and shared understanding, the session began by recapping the co-design framework created in the previous session, as well as recapping the priority topics identified for the program. Members chose the next topic to discuss – self-advocacy - using the group vote function within the Zoom chat. Throughout the session, members could contribute verbally or using the chat function. Using Jamboard, panel members engaged in a mapping exercise to generate ideas for a program session based on self-advocacy, including (1) what questions people may have about self-advocacy; (2) what people may not know about self-advocacy, and (3) how the program could support with self-advocacy. Next, panel members voted to select the program name (using a Mentimeter poll), based on the seven suggestions made by panel members in the optional post-session activity, as well as three suggestions from the co-design facilitators. The agreed name was “Understanding You, Discovering You”, which was suggested by a panel member.

The remainder of the session centred around developing session plans for the program. First, BR demonstrated a session plan using Google Docs (an online word processing platform which allows multiple users to work on documents simultaneously). Members were then split into two breakout groups using Zoom functionality to discuss the format and structure of the sessions for the *Understanding You, Discovering You* program. Discussion points included: (1) how attendees of the program could interact with the course content; (2) what online tools should be used; (3) how program discussions could be led; (4) the possible use of at-home tasks, and (5) the possible flow of sessions (i.e., varying between giving information, doing activities, and having structured discussion). At the end of the session, representatives from the two breakout groups shared their ideas, and BR summarized what would happen in the final co-design session. An optional post-session activity involved creating a session plan on a topic of the attendee’s choice.

### **Co-Design Session 3**

In the final co-design session, panel members finalized the topics to be covered and developed a draft outline for the Understanding You, Discovering You program. First, BR provided a summary of the discussions and decisions made in the previous

session. The priority topics identified in Session 1 were then reviewed. This review process served as a reminder of the topics proposed earlier and allowed panel members to consider them in the context of more recent discussions. The group then discussed the topics (verbally or in the chat) to determine the specific topics that would be covered throughout the program. Through discussion, consensus was achieved regarding the most relevant and valuable areas to focus on. The remainder of the session was dedicated to developing a draft program outline, using Jamboard. At the end of the session, BR summarized what would happen in the feedback session. An optional post-session activity involved providing feedback about the co-design process, via Jamboard.

### **Feedback Session**

The feedback session was an opportunity for KC and WM to provide feedback on the co-designed program outline. KC and WM gave a short presentation, which involved introducing themselves and their research, before providing feedback on the program outline based on their experiences as clinical academics with expertise in supporting autistic young adults. Their feedback included general feedback (e.g., reducing the amount of information to cover and giving more opportunities for group discussion), as well as more specific feedback on sessions two, three, five, and six (e.g., having time for attendees to discuss their own views and experiences, and acknowledging that 'there is no one way to be a successful adult'). The group discussed the feedback, either verbally or using the chat function, and collaboratively identified specific areas for improvement. At the end of the session, BR discussed the next steps for the program. Following the feedback session, BR drafted an amended outline which was emailed to the panel with the chance to provide feedback and make further changes.

### **Developing the Course Manual**

When the program outline and objectives were agreed upon, BR used these to create a draft course manual. The development of the course manual involved gathering existing training materials from Ambitious about Autism, researching specific topics (e.g., about setting goals) and working with KC and WM to generate bespoke content (e.g., about identifying social needs). BR, KC, and WM worked together to edit and refine the course manual. When the course manual was agreed



upon, BR created all relevant material (e.g., PowerPoint slides, agendas, interactive activities). This material formed a 'beta' version of the program, which was attended by nine autistic young adults (two of whom were part of the co-design panel). Using informal feedback from the attendees of the beta program, additional changes to the course structure and content were made before the public pilot program commenced. For example, the session on problem-solving and goal setting was brought forward, and some session titles were adjusted to reflect their content more accurately (e.g. 'understanding autism part 2' was changed to 'experiences of autism and strengths').

## **Supplementary Materials D. Author Reflections Guide Questions.**

1. How has previous co-production work fed into the current session?
2. Have any external factors influenced the co-production process? If so, how has the process been changed by these external factors and why?
3. What documents were shared before the session? When were they shared?
4. Were there any pre-session activities to complete? If so, what was engagement with these activities like?
5. What was included in the session plan?
6. If relevant, how were the pre-session activities used during the session?
7. Did the session go to the plan? If not, why not?
8. How many young people attended?
9. How many people from Ambitious about Autism attended, and what were their roles?
10. What key decisions were made during this session?
11. How were the above decisions made?
12. Was there any conflict (e.g., conflicting opinions) during the session? If so, how was this resolved?
13. What tools were used to facilitate the co-design? (e.g., Zoom polls, Jamboard, Mural)
14. On reflection, how well did the above tools work?
15. How was power shared during the session? Did compromises have to be made?
16. Where on the ladder of participation do you think the decision-making in this session sits? Why?
17. Were any post-session activities set? What do they involve?
18. What was engagement with the post-session activities like?