

'Who, When, How to Share'

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‘Who, When, How to Share’: Pilot study of a new disclosure decision-making programme for autistic adults

Autism

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Abstract

In this pilot study, we report on the feasibility, acceptability and potential impact of ‘Who, When, How to Share’, a new disclosure decision-making programme for autistic adults. We evaluated this programme using pre-post mixed-methods surveys that included questions about participants’ experiences of the programme and four psychosocial outcome measures. While 32 autistic adults completed the pre-programme survey and enrolled into the programme, there was high attrition, with only 19 autistic adults completing the programme and post-programme survey. We found that it was feasible to deliver the programme in a guided self-help format, although a minority of participants (who completed the programme or provided reasons for withdrawing from the programme) found it challenging to work through the programme independently and within the study time frame. High levels of satisfaction and positive qualitative feedback also suggested that the programme was acceptable to autistic adults. Participants provided useful recommendations for improvement, such as more interactive elements to enhance engagement. The programme showed potential to improve decisional conflict, disclosure-related distress, stigma-related stress and internalised stigma among autistic adults, though further evaluation of the impact of the programme is needed.

Lay abstract

‘Who, When, How to Share’ is a new programme that aims to support autistic adults in making decisions around sharing their autistic identity with others. The programme involves working through a self-help guide independently over 3 weeks with optional peer support. We wanted to find out if autistic adults would join the programme and find it useful. Thirty-two autistic adults took part in the programme and 19 of them completed it. Most participants who completed the programme liked the programme and found it helpful, but some felt that they needed more time and support to complete it. They suggested that the programme would be more accessible if it was more interactive, such as including videos and other ways to gain feedback on their progress. Surveys filled in by participants before and after the programme suggested that they became more confident and less stressed about sharing their autistic identity with others, but some felt they still needed to build more confidence in order to handle negative attitudes from others. More work is needed to improve and test the programme further.

Keywords

autism, autistic adults, decision-making, disclosure, feasibility, intervention, pilot, programme, stigma, support

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Introduction

Autistic adults often face a dilemma of whether and how much to conceal or reveal about their autistic identity. Research from the perspective of non-autistic people suggests that disclosure generally leads to more positive attitudes and behavioural intentions towards autistic people (Flower et al., 2021; McMahon et al., 2021; Sasson & Morrison, 2019). However, research eliciting autistic perspectives reveals mixed outcomes – disclosure can sometimes lead to increased understanding and support, but other times lead to judgement and discrimination (Huang et al., 2022; Romualdez et al., 2021; Thompson-Hodgetts et al., 2020). Conversely, concealment and camouflaging may offer some protection from public stigma, but have also been associated with internalised stigma, stress and anxiety among autistic adults (Botha & Frost, 2020; Cage & Troxell-Whitman, 2019; Cook et al., 2021). Consequently, disclosing an autistic identity is a complex personal decision in which the risks and benefits have to be weighed carefully depending on context. A recent study found that autistic adults' disclosure decisions are influenced by a range of external and internal factors, including how safe they feel in a particular environment, how much energy they have at the time and what they hope to achieve by disclosing (Love et al., 2023).

To improve disclosure experiences, it is essential to reduce public stigma and create more inclusive environments, as well as empower autistic people to make informed and strategic disclosure decisions. Autism acceptance training programmes for non-autistic people have been developed and evaluated (Gillespie-Lynch et al., 2022; Jones et al., 2021), with ongoing efforts to improve both the programmes and their evidence base. While there are a number of support programmes for autistic people that include a segment on disclosure (Crane et al., 2021; Laugeson et al., 2011), none have specifically focused on disclosure. Outside of the autism field, a promising intervention to support disclosure decision-making is Honest, Open, Proud (HOP) (Corrigan et al., 2013). The original HOP programme was delivered in a peer-led group format for adults with mental health conditions, and it comprised three main sessions. Session 1 guided participants in challenging hurtful self-beliefs and evaluating the pros and cons of disclosure in different settings. Session 2 introduced participants to different ways of disclosing and taught them to judge how others may respond before disclosing. Session 3 supported participants in crafting empowering personal narratives as a basis for potential disclosure. HOP's theory of change is that supporting disclosure decisions can reduce stress associated with stigma and internalised stigma, thus contributing towards improved well-being (Scior et al., 2020). A recent meta-analysis of five randomised controlled trials showed that HOP had a positive impact on stigma stress and internalised stigma for people with

mental health conditions, while its impact on depression was less consistent (Rüsch & Kösters, 2021). HOP has been adapted for different populations, including people with Tourette's syndrome and people with dementia. Given that disclosure decisions could vary based on disability type, we recognised the importance of involving autistic people in determining whether and how HOP could be suitably adapted for autistic people.

To inform our potential adaptation of HOP, we conducted a consultation survey with 124 autistic adults as primary stakeholders and 38 parents/caregivers of autistic people as secondary stakeholders (Han et al., 2023). The survey presented information on the premise and goal of HOP, the original target group and delivery format, as well as a summary of the content of its three main sessions, to elicit feedback prior to any proposed adaptation. Both autistic adults and parents/caregivers thought it was important for autistic adults to have support in managing disclosure and stigma, and that it would be suitable to adapt HOP for autistic adults. However, concerns were raised that the programme may place an onus on individuals to disclose or challenge stigma. For the programme to be helpful, respondents stressed that it should be positive (i.e. promote self-acceptance) and practical (i.e. teach context-specific strategies for disclosure). Concerns were also raised about the group format of the original HOP programme, which could be challenging and inaccessible for some autistic people, especially those who were worried about disclosure or stigma. Given the heterogeneity of the autistic population, flexibility and choice were highlighted as key facilitators to taking part in such a programme. In particular, autistic adults preferred the programme to be led by autistic peers with shared experience, who would be best placed to understand and accommodate various needs (Han et al., 2023).

Based on the above feedback, we adapted HOP in a guided self-help format supplemented by optional peer support, that is, with the option to contact a trained autistic facilitator and/or join an online forum with other participants. We named this adapted programme 'Who, When, How to Share', as the goal of the intervention is not to persuade individuals to disclose, but rather to guide them in reaching safe and personally meaningful disclosure decisions. Throughout the original material (Corrigan et al., 2017; Wisconsin Initiative for Stigma Elimination & Corrigan, 2018), references to mental health challenges and the journey to recovery were replaced with appropriate language discussing an autism diagnosis/autistic identity and the journey to acceptance. Participants were encouraged to craft a personal narrative based on the neurodiversity paradigm (Kapp et al., 2013; Walker, 2021), including identifying and describing their strengths and interests as an autistic person, as well as their challenges and needs. General pros and cons of disclosing a mental health condition were replaced with autism-specific pros and cons of

Table 1. Content of self-help guide.

Section	Content
When to share	1.1. Weighing the pros and cons of disclosure in different settings 1.2. Weighing the pros and cons of different levels of disclosure
How to share	2.1. Drafting your personal story 2.2. Choosing what to share from your story 2.3. Replacing hurtful self-beliefs in your story
Who to share with	3.1. Identifying a good person to share with 3.2. Being prepared with responses and support 3.3. Putting it all together

disclosing in different contexts (e.g. to family/friends, educators/employers and public service providers). Quotes from autistic people were taken from existing research studies to ensure that examples were grounded in autistic people's lived experiences. A table detailing and explaining the key changes we made to each section of the guide is available in Supplementary File 1.

The Medical Research Council (MRC) outlines four phases in intervention research: (1) development, (2) feasibility testing, (3) evaluation and (4) implementation (Skivington et al., 2021). While traditionally overlooked, the MRC emphasises that feasibility testing is a valuable step to guide decisions on whether and how to proceed to the evaluation phase. Therefore, the primary aim of this study was to assess the feasibility and acceptability of the 'Who, When, How to Share' programme. A secondary aim was to explore the potential impact of this new programme on psychosocial outcomes for autistic adults.

Methods

This study was conducted according to the MRC framework for developing and evaluating complex interventions (Skivington et al., 2021). A single-arm, pre-post design was employed. Participants completed a mixed-methods survey on Qualtrics within the 2 weeks prior to the start of the programme and within 2 weeks of completion of the programme (a copy of the survey is available in Supplementary File 2). Ethical approval was obtained via the Department of Psychology and Human Development at IOE, UCL's Faculty of Education and Society.

Participants

Eligible participants were adults over the age of 18 in the United Kingdom who either had a formal diagnosis of autism or self-identified as autistic.¹ The study was first advertised to participants from our consultation survey (Han et al., 2023), followed by social media advertising. We aimed to recruit 20–30 autistic adults, following the rule of thumb for sample sizes in pilot studies (Julious, 2005; Lancaster et al., 2004).

Intervention

Participants were allocated to two iterations of the programme that ran in September and November 2022, respectively.² All participants received a PDF of the full self-help guide and worksheets from the guide in Word format (available on the Open Science Framework at <https://osf.io/vhry3/>). We recommended that participants work through the self-help guide within 3 weeks corresponding to the three core sections of content: (1) when to share, (2) how to share and (3) who to share with (Table 1). We estimated that each section would take about 60–90 min to complete, but participants could work at their own pace. An example of a worksheet in the guide is shown in Figure 1. During the 3-week period, participants received weekly check-in emails from their assigned facilitators and were also given access to an optional online forum on Slack that was moderated by facilitators. The forum was organised into five 'channels': a general channel for introductions, programme-wide questions, announcements and clarifications, three separate channels to discuss thoughts and reflections specific to the three content sections, and a resources channel for sharing any additional resources outside of but related to the programme. Facilitators were the autistic members of our research team who had previous experience supporting autistic peers. Facilitators underwent a 3-h training session focused on checking understanding of fundamental concepts in the self-help guide, filling in key worksheets and discussing their role in the programme.

Measures

Primary outcome measures. Feasibility of the intervention was assessed by (1) rates of recruitment and retention, including any given reasons for not participating or dropping out, and (2) levels of reported engagement (in the post-programme survey) and observed engagement (based on emails to facilitators and posts on the online forum), including any given reasons for not engaging. Acceptability was assessed via the post-programme survey, including (1) quantitative data on levels of satisfaction with and perceived helpfulness of the programme and

Worksheet 2: Pros and Cons of the Five Levels of Disclosure

Setting: _____

1. Social avoidance: Not telling anyone that you are autistic and avoiding situations where people may find out about it.	
Pros:	Cons:
2. Secrecy: Participating in activities, but keeping your autism diagnosis/autistic identity a secret.	
Pros:	Cons:
3. Selective disclosure: Telling a few select individuals you are autistic, but not everyone.	
Pros:	Cons:
4. Open disclosure: Making the decision to no longer hide that you are autistic, but not actively telling people that you are autistic.	
Pros:	Cons:
5. Advocacy: Actively seeking out and educating people about autism to challenge false beliefs about autistic people.	
Pros:	Cons:

Figure 1. Example of worksheet in the guide.

(2) qualitative data on participants' expectations of the programme and whether these expectations were met, what they liked most/least about the programme, as well as suggestions for improvement.

Secondary outcome measures. Potential impact of the intervention was assessed quantitatively using four psychosocial outcome measures identified from previous evaluations of HOP, complemented by qualitative data on perceived impact of the programme. Autistic team members were involved in ensuring that the chosen measures were suitable and/or advising how they needed to be adapted for an autistic population. Adapted versions of the following measures were included in the pre- and post-intervention surveys, alongside free-text questions asking participants whether they found the measures appropriate and easy to

complete (to inform any future trials of the programme) and whether the programme had changed their thoughts on disclosure and stigma.

Decisional Conflict Scale. The scale contains five subscales measuring perceptions of feeling: (1) uninformed, (2) unclear about personal values, (3) unsupported in decision-making, (4) uncertain about choosing options and (5) ineffective at decision-making (O'Connor, 1995). The 16 items are scored on a 5-point Likert-type scale (0 – strongly agree to 4 – strongly disagree). We retained all items in their original wording but added a preface to the scale clarifying that it pertained to a decision on whether or not to share an autism diagnosis/autistic identity with others. Overall scores and subscale scores were expressed as a percentage of the maximum possible score, ranging

from 0 (no decisional conflict) to 100 (extremely high decisional conflict). The scale was previously validated (O'Connor, 1995), and internal consistency was found to be excellent³ in this study (Cronbach's $\alpha=0.963$ pre-test, $\alpha=0.940$ post-test).

Disclosure-Related Distress Scale. The original scale asked,

In general, how comfortable would you feel talking to a [item 1: friend or family member; item 2: teacher or employer] about your mental health, for example, telling them you have a mental health diagnosis and how it affects you? (Mulfinger et al., 2018)

We replaced references to 'mental health' with 'autism' and 'teacher' with 'educator', given that our target group was autistic adults. We also added a third item on disclosing to a public service provider (e.g. health professional, police officer) to correspond with the three disclosure contexts addressed in our programme. Each item was scored on a 7-point Likert-type scale (1 – not at all to 7 – very much). It was not possible to appraise the psychometric quality of the scale as it is an unvalidated measure previously used as a screening tool for HOP (Mulfinger et al., 2018), and it was expected that participants would answer each item differently.

Stigma Stress Scale. This 8-item scale contains two subscales, with four items measuring perceived harm caused by stigma and four items measuring perceived resources to cope with such harm (Rüsch et al., 2009). We replaced references to 'people with mental illness' with 'autistic people', and 'prejudice' with 'stigma' to maintain consistency in terminology. Each item was scored on a 5-point Likert-type Scale (1 – strongly disagree to 5 – strongly agree), and an overall stress appraisal score was calculated by subtracting perceived coping resources from perceived harm. Internal consistency of the scale was good in this study (Cronbach's $\alpha=0.836$ pre-test, $\alpha=0.851$ post-test).

Internalised Stigma of Mental Illness. Internalised Stigma of Mental Illness (IMSI-10) is the brief, 10-item version of the Internalised Stigma of Mental Illness scale, measuring alienation, discrimination experience, social withdrawal, stereotype endorsement and stigma resistance (Boyd et al., 2014). We replaced references to 'mental illness' with 'autism' and 'mentally ill people' with 'autistic people'. Item 3, 'I don't socialize as much as I used to' was changed to 'I don't socialize as much as I would like to', as autism is a lifelong condition. Item 9, 'I can have a good, fulfilling life, despite my mental illness' was changed to 'I can have a good, fulfilling life as an autistic person', as there may be people who feel they can have a good life because of their autism or cannot distinguish what is because of or despite,

since autism is an intrinsic part of them. Each item was scored on a 5-point Likert-type scale (1 – strongly disagree to 5 – strongly agree), and items 2 and 9 were reverse-coded before calculating an overall score. Internal consistency was acceptable pre-test (Cronbach's $\alpha=0.751$) but not post-test (Cronbach's $\alpha=0.495$), the potential reasons for which are explored in the 'Discussion' section.

Data analysis

Quantitative analysis. Descriptive statistics were used to report rates of recruitment, retention and engagement, levels of satisfaction and perceived helpfulness of the programme, as well as pre-post scores on outcome measures. Inferential statistics were used to explore whether there were any statistically significant changes in scores on outcome measures before and after the programme. Q-Q plots and Shapiro–Wilk tests were first used to determine normality. Where assumptions of normality were met, a parametric paired sample *t*-test was used to compare pre-post scores, and where assumptions of normality were not met, the non-parametric Wilcoxon signed-rank test was used instead. Based on the recommendations for exploratory studies (Armstrong, 2014), no Bonferroni adjustments were made and *p* values of <0.05 were considered statistically significant.

Outcome measures were fully completed by all participants in the pre-programme survey, but post-data was missing for one case on the DCS. This case was excluded from the analysis of pre-post changes on the DCS, but included in the analysis of other outcome measures.

Qualitative analysis. Qualitative data in the survey was analysed using qualitative content analysis (QCA), following the eight main steps outlined by Schreier (2012): (1) deciding on the research question, (2) selecting the material, (3) building a coding frame, (4) dividing the material into units of coding, (5) trying out the coding frame, (6) evaluating and modifying the coding frame, (7) main analysis and (8) interpreting and presenting findings. The first author created main categories deductively based on the survey questions (see Supplementary File 2) and then developed sub-categories inductively from the data. To ensure reliability, a second researcher independently coded all the data. Intercoder agreement on codes ranged from 78% to 100%, with only 2 out of 28 coding categories achieving less than 80% agreement (as number of codes were small, a single discrepancy resulted in a large percentage difference). All discrepancies were discussed and consensus was reached on the final coding frame and frequencies.

Following separate analysis, quantitative and qualitative data were integrated narratively in the 'Results' section, organised around the research question they answered (feasibility, acceptability or potential impact).

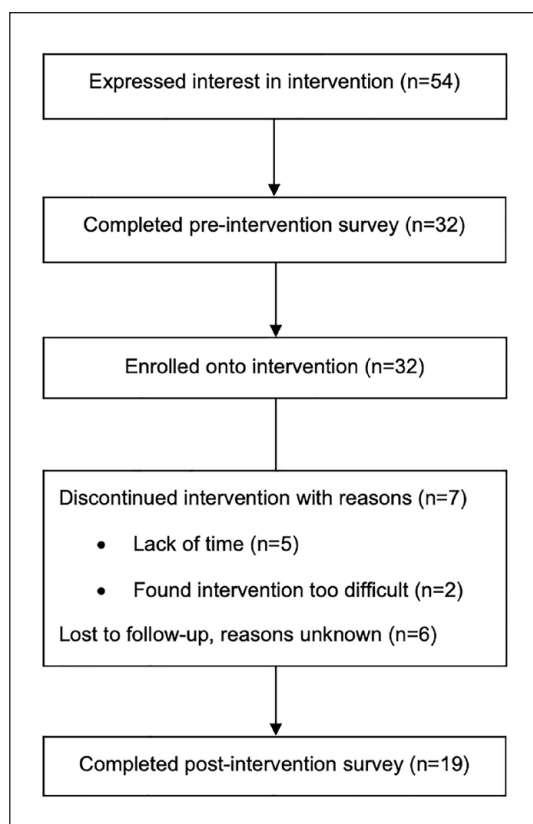


Figure 2. Participant flowchart.

Community involvement

The research topic was informed by autistic people's priorities, preferences and experiences as identified from previous literature (Han et al., 2022), consultation with the community (Han et al., 2023) and direct input from two autistic team members. Our autistic team members were involved in developing and delivering the intervention, determining inclusion criteria and recruiting participants, as well as choosing and adapting outcome measures. However, they did not have direct access to survey responses, given that their dual role as facilitators may have prevented participants from critiquing the programme openly. Nonetheless, they had the opportunity to review findings after analysis and share their reflections, which are incorporated in the 'Discussion' section.

Results

Feasibility of the intervention

Recruitment and retention. Of 32 participants who completed the pre-programme survey and were enrolled into the programme, 19 (59%) completed the post-programme survey (Figure 2). Five participants withdrew due to lack of time and another two withdrew as they found the

programme too difficult to complete on their own.⁴ Six participants were lost to follow-up for unknown reasons (they had little/no visible engagement since the start of the programme and ultimately became uncontactable).

Participants' characteristics are presented in Table 2, with percentages calculated relative to the number of participants in each column (i.e. percentage of completers or non-completers, respectively). At first glance, these percentages may suggest that rates of completion were higher among participants who identified as male, were more highly educated and were employed. However, the small raw numbers make it difficult to draw any conclusions about differences in attrition based on visual inspection of the data and also preclude statistical comparison of the characteristics of completers versus non-completers.

Engagement. Reported and observed engagement with the programme was high among those who were not lost to attrition, especially with the self-help guide (Table 3). Among the minority who reported in the post-programme survey that they used but did not complete the guide, reasons included needing more time, focusing on sections of the guide that were most relevant or important to them, and the emotional burden of some of the content and exercises. These participants expressed an intention to either continue working on the guide or return to it at a more appropriate time. Reasons for not engaging with the facilitator or forum included not having the time to do so, not needing help or support, and social anxiety.

Acceptability of the intervention

Satisfaction and perceived helpfulness. Quantitative data indicated that most participants who completed the post-programme survey were overall satisfied with the format, content and duration of the programme (Table 4). All participants found the guide helpful, and those who used facilitator support also found it helpful. Perceived helpfulness of the forum varied, as half of those who used it found it helpful while the other half did not.

Qualitative data gave further insight into participants' experiences, as presented next.

Motivations and expectations. The most common motivation for taking part in the programme was to learn more about disclosure and 'make better informed disclosure decisions', whether in general or in relation to a specific situation: 'I was looking to disclose my autism to a new line manager and a new colleague but wanted help to decide when to disclose and how much exactly to disclose' (P21). Some participants were seeking support following a recent or late diagnosis: 'I'm fairly recently diagnosed and have not disclosed my diagnosis to many people yet' (P13). A few participants wanted to help other autistic people:

Table 2. Participants' characteristics.

	Completers (<i>n</i> = 19, %)	Non-completers (<i>n</i> = 13, %)
Age		
25–34 years	2 (10.53%)	2 (15.38%)
35–44 years	6 (31.58%)	4 (30.77%)
45–54 years	5 (26.32%)	6 (46.15%)
55–64 years	4 (21.05%)	0 (0.00%)
65+ years	2 (10.53%)	1 (7.69%)
Gender identity		
Male	7 (36.84%)	1 (7.69%)
Female	12 (63.16%)	11 (84.62%)
Non-binary	0 (0.00%)	1 (7.69%)
Ethnicity		
White-British	13 (68.42%)	11 (84.62%)
Other White background	5 (26.32%)	1 (7.69%)
Middle Eastern	1 (5.26%)	0 (0.00%)
Mixed White and Asian	0 (0.00%)	1 (7.69%)
Education		
Secondary education	0 (0.00%)	1 (7.69%)
College/further education	1 (5.26%)	2 (15.38%)
University education	18 (94.74%)	10 (76.92%)
Employment status		
Full-time employment	10 (52.63%)	4 (30.77%)
Part-time/temporary/self-employment	7 (36.84%)	5 (38.46%)
Unemployed	1 (5.26%)	2 (15.38%)
Student	0 (0.00%)	1 (15.38%)
Retired	1 (5.26%)	1 (7.69%)
Autism diagnostic status		
Formally diagnosed	16 (84.21%)	11 (84.62%)
< 1 year	4 (21.05%)	1 (7.69%)
1–3 years	5 (26.32%)	3 (23.08%)
4–6 years	3 (15.79%)	5 (38.46%)
7–9 years	2 (10.53%)	1 (7.69%)
10 years or longer	2 (10.53%)	1 (7.69%)
Self-identified	3 (15.79%)	2 (15.38%)
< 1 year	1 (5.26%)	0 (0.00%)
1–3 years	1 (5.26%)	1 (7.69%)
4–6 years	0 (0.00%)	0 (0.00%)
7–9 years	0 (0.00%)	0 (0.00%)
10 years or longer	1 (5.26%)	1 (7.69%)
Openness about autistic identity/diagnosis		
Not open	0 (0.00%)	1 (7.69%)
Selectively open	15 (78.95%)	8 (61.54%)
Open	2 (10.53%)	3 (23.08%)
Very open	2 (10.53%)	1 (7.69%)
Other diagnoses/conditions ^a		
Physical disability	2 (10.53%)	4 (30.77%)
Learning disability	4 (21.05%)	5 (38.46%)
Intellectual disability	0 (0.00%)	1 (7.69%)
Affective condition (e.g. depression and anxiety)	12 (63.16%)	8 (61.54%)
Behavioural condition (e.g. ADHD, Tourette syndrome)	3 (15.79%)	2 (15.38%)
Mental health condition (e.g. bipolar disorder, schizophrenia)	2 (10.53%)	3 (23.08%)

ADHD: attention-deficit hyperactivity disorder.

^aThe total percentages exceed 100% as some participants had multiple co-occurring diagnoses. Participants' level of openness about their co-occurring diagnoses varied, with a few noting that it was easier to talk openly about visible than non-visible conditions.

Table 3. Self-reported and observed engagement.

Self-reported engagement	Did not use	Used	Completed
Self-help guide	0 (0.00%)	19 (100%)	14 (73.68%)
Facilitator support	7 (36.84%)	12 (63.16%)	N/A
Online forum	5 (26.32%)	14 (73.68%)	N/A
Observed engagement	Never	Once	More than once
Emailed facilitator	4 (21.05%)	11 (57.89%)	4 (21.05%)
Posted on forum	5 (26.32%)	7 (36.84%)	7 (36.84%)

N/A: not applicable.

Table 4. Levels of satisfaction and perceived helpfulness.

Level of satisfaction	Very satisfied	Satisfied	Neither satisfied nor dissatisfied	Dissatisfied	Very dissatisfied
Overall	8 (42.11%)	9 (47.37%)	2 (10.53%)	0 (0.00%)	0 (0.00%)
Format	9 (47.37%)	8 (42.11%)	1 (5.26%)	1 (5.26%)	0 (0.00%)
Content	9 (47.37%)	8 (42.11%)	2 (10.53%)	0 (0.00%)	0 (0.00%)
Duration	4 (21.05%)	12 (63.16%)	1 (5.26%)	2 (10.53%)	0 (0.00%)
Level of helpfulness	Very helpful	Quite helpful	Not very helpful	Not helpful at all	N/A – did not use
Self-help guide	11 (57.89%)	8 (42.11%)	0 (0.00%)	0 (0.00%)	0 (0.00%)
Facilitator support	5 (26.32%)	8 (42.11%)	0 (0.00%)	0 (0.00%)	6 (31.58%)
Online forum	3 (15.79%)	5 (26.32%)	6 (31.58%)	2 (10.53%)	3 (15.79%)

N/A: not applicable.

‘helping and advising others about disclosure and why it is important although [it’s] the individual’s decision’ (P12). Many participants reported that their expectations of the programme were met: ‘My hopes and aims for the programme were fully met. It has given me the tools – and the understanding – to make much better sharing decisions’ (P24). Some felt that there were aspects of the programme that met their expectations and aspects that did not, as explored next.

Most liked or helpful aspects. Participants mentioned the clear structure as their favourite aspect of the programme: ‘I like the way it takes me through a process of understanding – it gives me a structure in which to think it all through’ (P19). They liked that the self-help guide had explanations and examples of different disclosure strategies and scenarios that were detailed and easy to understand: ‘I especially liked the way that the elements of disclosure were unpacked, together with the risks and opportunities of disclosing’ (P20). This explanatory and contextual information was balanced with practical exercises: ‘Useful worksheets to think through in clear stages the different options, and workshoping/trying them out’ (P09). Participants also appreciated that autistic peer support was ‘available but optional’, both via email and the forum. Even those who did not actively engage with their

facilitators or other participants acknowledged that it was ‘good to hear from others’ and comforting to know they could reach out if they needed help: ‘I only engaged minimally, but I think it is very important to know there is an autistic person on the other end available for support’ (P17). Finally, a few participants liked that the programme was self-guided, ‘so there was time to think without pressure or expectations’ (P07).

Least liked or challenging aspects. Many participants chose participating in the forum as their least favourite component of the programme. Some explained that they were not ready to participate because it felt ‘too much like group disclosure’, they were still learning about the topic or they did not have the capacity to handle negative emotions being shared on the platform: ‘Became a dumping ground for negative emotions, which takes a lot of energy to engage with, and isn’t a stage I’m at or need to be involved in in my own processing about disclosure’ (P09). Several participants thought that the guide was too ‘wordy’ and found it challenging to complete the programme within the recommended time frame and/or stay motivated with self-study: ‘structuring time to do a course like this alone can be really hard – procrastination and avoidance certainly came to play for me, especially when the topic of disclosure is such a personal and distressing thing’ (P02). Finally,

a few cited personal struggles that they attributed to their own background and experiences, rather than to the programme itself: ‘Not a criticism of the programme, but I am still struggling with developing a personal narrative (more to do with the complexities of my history and circumstances)’ (P29).

Suggestions for improvement. A common recommendation was improving the way information was presented in the self-help guide, in particular having more interactive elements: ‘I think it would be better presented as a web app, it would feel more interactive thus improve the user’s experience. It could incorporate video, and give you an option for downloading your responses’ (P07). Several participants also suggested conducting the programme over a longer time scale with ‘more monitoring of progress’ and initiation from facilitators rather than putting the onus on participants to initiate discussion: ‘[I] feel the peer support group could have been facilitated a bit more to guide or encourage participation’ (P23). Other participants proposed additional content, such as examples of what to say in response to potential negative disclosure reactions, so that they would feel more equipped to handle stigma. A summary of the qualitative coding frame and frequencies is presented in Table 5.

Potential impact of the intervention

Impact on disclosure. Overall mean scores on the Decisional Conflict Scale (DCS) significantly decreased following the programme, as did scores on all subscales (Table 6). These findings suggest that participants felt (1) more informed, (2) clearer about personal values regarding benefits and risks, (3) more supported in decision-making, (4) more certain about their decision and (5) more effective at decision-making by the end of the programme. Mean scores on the adapted Disclosure-Related Distress Scale (DRDS) also increased significantly, reflecting lower levels of disclosure-related distress. Score differences on individual DRDS items showed that participants felt more comfortable disclosing to (1) a family member or friend, (2) an employer or educator and (3) a public service provider after the programme, although only changes on the first two options reached statistical significance.

Qualitative data gave additional insight on participants’ perceptions of how the programme changed their feelings about disclosure. A sense of empowerment was apparent, including feeling ‘more informed’, ‘more in control’ and ‘more confident’ about disclosure: ‘the powerful thought

Table 5. Qualitative coding frame and frequencies.

Categories	Sub-categories (<i>n</i> = 19, %)	
Motivations and expectations	Before the programme	Help oneself with disclosure (<i>n</i> = 14, 73.68%) Support for recent/late diagnosis (<i>n</i> = 7, 36.84%) Help others (<i>n</i> = 3, 15.79%)
	After the programme	Expectations fully met (<i>n</i> = 8, 42.11%) Expectations partially met (<i>n</i> = 5, 26.32%)
Most liked or helpful aspects	Availability of peer support (<i>n</i> = 15, 78.95%)	
	Clear structure (<i>n</i> = 11, 57.89%)	
	Explanations and examples (<i>n</i> = 11, 57.89%)	
	Practical exercises (<i>n</i> = 9, 47.37%)	
Least liked or challenging aspects	Self-guided format (<i>n</i> = 4, 21.05%)	
	The forum (<i>n</i> = 9, 47.37%)	
	Personal struggles (<i>n</i> = 6, 31.58%)	
	Working independently (<i>n</i> = 5, 26.32%)	
	Time pressure (<i>n</i> = 4, 21.05%)	
Suggestions for improvement	Lengthy text (<i>n</i> = 3, 15.79%)	
	More facilitation (<i>n</i> = 8, 42.11%)	
	More interactive presentation (<i>n</i> = 5, 26.32%)	
	Longer time scale (<i>n</i> = 3, 15.79%)	
Impact of the programme	Additional content (<i>n</i> = 3, 15.79%)	
	Impact on disclosure	Clarify thought process (<i>n</i> = 9, 47.37%)
		Sense of empowerment (<i>n</i> = 4, 21.05%)
		Nuanced approach (<i>n</i> = 5, 26.32%)
		Reaffirmed previous thoughts (<i>n</i> = 2, 10.53%)
		Tool/framework to go back to (<i>n</i> = 7, 36.84%)
		Apply learning to other ‘hidden’ identities (<i>n</i> = 7, 36.84%)
	Impact on stigma	Knowledge and techniques to counter stigma (<i>n</i> = 7, 36.84%)
		No change/still need more confidence (<i>n</i> = 5, 26.32%)
		Understanding how stigma affects self (<i>n</i> = 2, 10.53%)

Table 6. Pre-post change in scores on outcome measures.

Measure		Pre-intervention means (SD)	Post-intervention means (SD)	Pre-post change (Student's <i>t</i> /Wilcoxon <i>W</i> statistic, <i>p</i> value, effect size)
DCS	Overall	54.08 (23.92)	25.09 (15.65)	$t(17)=5.16, p<0.001, d=1.22$
	Subscale 1	57.41 (28.71)	14.81 (15.00)	$W=120.00, p<0.001, r=1.00$
	Subscale 2	53.70 (29.04)	19.44 (15.12)	$t(17)=6.46, p<0.001, d=1.52$
	Subscale 3	48.15 (22.24)	29.17 (16.73)	$t(17)=2.89, p=0.010, d=0.68$
	Subscale 4	64.81 (27.35)	38.89 (26.51)	$t(17)=3.35, p=0.004, d=0.79$
	Subscale 5	48.26 (25.44)	23.61 (18.26)	$W=135.00, p=0.006, r=0.76$
DRDS	Overall	3.16 (1.68)	4.14 (1.40)	$t(18)=-2.79, p=0.012, d=-0.64$
	Item 1	3.26 (2.00)	4.11 (1.88)	$W=10.50, p=0.025, r=-0.73$
	Item 2	2.68 (1.63)	4.00 (1.76)	$t(18)=-3.25, p=0.004, d=-0.75$
	Item 3	3.53 (1.95)	4.32 (1.80)	$t(18)=-1.56, p=0.135, d=-0.36$
SSS	Overall	0.29 (1.41)	-0.39 (1.63)	$t(18)=2.02, p=0.058, d=0.46$
	Subscale 1	3.33 (0.89)	3.07 (1.08)	$t(18)=1.22, p=0.237, d=0.28$
	Subscale 2	3.04 (0.84)	3.46 (0.98)	$t(18)=-1.89, p=0.075, d=-0.43$
ISMI-10	Overall	2.41 (0.59)	2.27 (0.41)	$t(18)=1.52, p=0.146, d=0.35$

DCS: Decisional Conflict Scale; DRDS: Disclosure-Related Distress Scale; SSS: Stigma Stress Scale; ISMI: Internalised Stigma of Mental Illness.

for me was to stop and think about my objective in telling someone. I think I felt that some people almost had a right to know ... But I now realise the choice is mine' (P07). Participants learned to take a more nuanced approach to disclosure: 'I [no] longer view it as binary; I can tailor disclosure according to needs and situations' (P20). Some participants felt that the programme reaffirmed previous thoughts about disclosing and had applications to their other concealable identities:

it confirmed that I should be open about my hidden disabilities (tinnitus and partial hearing loss) ... others cannot help me if they aren't aware of my difficulties. Disclosure has already resulted in my [employers] agreeing to certain adjustments at work. (P21)

Other participants spoke of how the programme helped to clarify their reasoning, even if they had not reached a final decision: 'Even though I haven't come to conclusions yet, I am much clearer in my mind about what to consider, which is actually a big relief' (P19). Participants felt that they had gained 'a tool to go back to' beyond the duration of the programme: 'It has given me a valuable framework upon which I can make future disclosure decisions' (P24).

Impact on stigma. There was a statistically non-significant reduction in overall mean scores on the adapted SSS, with subscale scores showing that participants perceived less harm caused by stigma and more resources to cope with stigma after the programme. There was also a non-significant reduction in overall mean scores on the ISMI-10, as shown in Table 6.

Qualitative data illuminated participants' perceptions of the impact of the programme on their approach to stigma. Some participants stated that the programme gave them

knowledge and techniques to counter stigma: 'framing things more positively ... gauging people's understanding and working from there' (P29). Others felt that the programme helped them to understand how stigma affects them at an individual level: 'It's made me realise I still have some accepting to do of my diagnosis and that often the stigma that comes from other people feeds into my own anxieties about myself' (P07). A few expressed that they still needed to develop more confidence to challenge stigma: 'I would like to get to a stage where I can be an advocate and directly address stigma but need to build more confidence first' (P23).

Discussion

We sought to assess the feasibility, acceptability and potential impact of a new disclosure decision-making programme for autistic adults using a single-arm pre-post design. Overall, recruitment of participants was successful, and we exceeded our target sample size. The programme garnered the interest of many autistic adults who were seeking support with disclosure, showing that the programme addressed a need in the community. However, attrition was high (41%), which could be attributed to a few factors. First, based on the reasons provided for withdrawing and feedback from those who completed the programme, some participants found it challenging to work through the programme independently and within the recommended time frame. Similar challenges were observed in a self-guided version of HOP for mental health professionals, where time constraints and lack of active peer support likely contributed to high dropout rates (31%) (Scior et al., 2021). Indeed, while online self-help interventions generally reach a wider audience than in-person interventions, they tend to have poorer retention as

participants are less closely supervised (Eysenbach, 2005; Geraghty et al., 2010). A self-guided format may increase the accessibility of stigma-related interventions by offering more privacy (Mills et al., 2020; Thomas et al., 2015), but our study shows that this approach may be challenging for participants who may need more practical or emotional support to engage.

Another possible factor contributing to the low retention rate could be the broad inclusion criteria we implemented for our study. Specifically, our study included all autistic adults regardless of their level of openness about their autistic identity (see Note 1 for an explanation). In contrast, some previous HOP studies more narrowly targeted individuals who had not fully disclosed or were worried about disclosing (e.g. Mulfinger et al., 2018; Scior et al., 2021). It is noteworthy that four of our six participants who were lost to follow-up for unknown reasons had indicated that they were already very open about their autistic identity before the start of the programme. While they still expressed interest in taking part after we clarified the purpose and target group of our intervention, it is possible that they realised upon starting the programme that it was indeed not relevant or helpful to them. However, as these participants did not provide a reason for withdrawing and there were no observable differences in levels of openness between completers and non-completers at baseline, no conclusions can be drawn on whether the programme is more suitable for autistic adults who are less open about their autistic identity. The only participant who reported being 'not open' at the beginning was lost to attrition, while there were four completers who were open about their autistic identity and still found the programme helpful.

Encouragingly, among those who completed the programme, levels of engagement and satisfaction were high. Reported and observed engagement with the self-help guide were higher than with the facilitators and forum. Similarly, all participants who used the guide and facilitator support found them helpful, while perceived helpfulness of the forum was mixed. Compared to online autistic communities that are larger, ongoing and with regular members (Brownlow & O'Dell, 2006; Parsloe, 2015), the forum in this programme involved a time-limited, small group of individuals who were unsure about disclosing their autistic identity. Although we hoped that a forum would feel less intrusive and anxiety-inducing than synchronous group sessions, some participants still did not feel comfortable or ready to participate. Yet, many also said that it was reassuring to know that they could get direct support from another autistic person if they needed it, affirming the value of autistic-led peer support based on shared identity and experience (Crane et al., 2021; Shea et al., 2022). Interestingly, participants also found their learning on the programme applicable to other 'hidden' identities, including physical health and mental health conditions. This observation points to the possibility of taking

a more intersectional approach to the programme in the future, although it also raises the question of whether facilitators can meaningfully support participants in considering the disclosure of other identities and experiences that they may not share (Corrigan et al., 2018).

Facilitators reflected on participants' varied feedback, from those who struggled to complete the programme due to past negative experiences to those who became more confident about disclosure as they progressed through the programme, which aligned with the diversity of the autistic population. They stressed the importance of being willing to listen to participants, take feedback on board and make adjustments as a recognition of individuality, rather than imply that it is the fault of the person. Reflecting on their own experiences, they expressed that it took time to warm up to their roles and become more confident as facilitators. They empathised with participants' struggles using the forum and agreed that future iterations could include more guidance for facilitators on when to intervene or topics to discuss on the forum so they can provide more structured support to participants. Facilitators also felt that it would have been helpful for them to work through the whole guide beforehand (although they tried out parts of it during the training session) to better familiarise themselves with the content and give participants a better gauge of the time needed to complete each section.

While the primary aim of this study was not to assess the effectiveness of the programme, our preliminary results suggest that the programme has potential to improve psychosocial outcomes for autistic adults. The programme was associated with improvements in decisional conflict and disclosure-related distress, as well as reductions in stigma-related stress and internalised stigma. Qualitative data corroborated quantitative data, as participants reported that the programme gave them a greater sense of clarity, confidence, control and choice over disclosure, as well as some knowledge and techniques to counter stigma, but they still needed to work on developing self-acceptance and confidence to deal with stigma. This is understandable considering that the programme focused more on disclosure than on stigma, and unhelpful self-beliefs can be deeply ingrained and take a long time to change. Moving forward, adding booster sessions and follow-up measures may help to enhance the effects of the intervention and give insight into its long-term impact.

Most participants found the outcome measures appropriate and easy to complete (see Supplementary File 3 for examples of comments), which was supported by little missing data (among those who were not lost to attrition). However, many also pointed out that the scales contained general and binary statements that could not fully capture the nuances of disclosure taught on the programme, echoing common problems identified by autistic people with other measures (Nicolaidis et al., 2020). For example, while the DRDS asked about disclosing to a family

member or friend, participants remarked that their level of comfort would differ depending on the specific person. With the ISMI-10, participants highlighted that items on social avoidance were tricky as they may avoid social situations not because of stigma but because they do not enjoy socialising. They also commented that it was difficult to answer questions about what other people thought, and they were unsure whether some questions were asking about their own beliefs or others' beliefs. It is noteworthy that the ISMI-10 was the only measure used in this study that had reverse-scored items and was also the one with low internal consistency. High levels of internal consistency on the other measures without reverse-scored items could be due to demand characteristics and participants' tendency to respond positively. Finally, as we scored the SSS and ISMI-10 on 5-point Likert-type scales for consistency in response options (instead of their original 7-point and 4-point scales, respectively), this limits the comparability of the scores in our study with other studies. In a future trial, analysis of whether greater quantitative improvement in outcomes are more apparent among those who qualitatively report a positive impact would help to provide greater evidence for the validity of measures.

Our initial findings should be interpreted with caution given the small sample size, nature of the study design and high attrition rate. Despite the high engagement and satisfaction rates among completing participants, the programme may not have been feasible and acceptable to participants who dropped out. Unfortunately, there is limited information on the latter group of participants, apart from those who provided reasons for withdrawing. As there were two participants who withdrew from the study due to reading-related difficulties, the existing text-heavy nature of the programme may limit its accessibility across the spectrum. It is also a limitation that data on motivation to enrol was only collected at post-test, as a more accurate indicator might be attained at pre-test and allow exploration of whether motivations differed between completers and non-completers. Due to the small sample size, it was not possible to statistically analyse differences in retention, engagement or satisfaction based on demographic characteristics, diagnostic status or openness about autistic identity. Furthermore, our sample was highly educated and more highly employed compared to the population-level demographics of autistic people in the United Kingdom (Office for National Statistics, 2022), which limits the generalisability of our findings. Moreover, due to the absence of a control or comparison group, it is unknown if similar changes in outcomes would have occurred naturally over time or with the support of friends, family, therapists or through online forums. It is also impossible to comment on whether the 'Who, When, How to Share' programme is better than broader support programmes for autistic people that have a segment on disclosure, such as the UCLA

PEERS programme (Laugeson et al., 2011) or Exploring Being Autistic programme (Crane et al., 2021).

All in all, the current study shows that further development and evaluation of the 'Who, When, How to Share' programme is warranted. The high recruitment, engagement and satisfaction rates, favourable qualitative feedback and minimal missing data suggest that the intervention and data collection procedures were generally feasible and acceptable. The positive psychosocial outcomes also provide evidence of promise regarding the intervention's impact. At the same time, participants and facilitators provided useful suggestions that can be implemented to improve the intervention, strengthen the evaluation and increase participant retention. First, more audio and visual materials should be incorporated to motivate greater attention and make the programme more accessible to those who find it challenging to read lengthy documents. Second, while this study had a restricted time frame for data collection purposes, a more flexible timeline may remove a barrier to completion, although this would need to be accompanied by closer monitoring of participants' progress to prevent feelings of disengagement. Third, while our facilitators adopted a 'light touch' approach to moderating the forum, amplifying the role of facilitators in leading interactive exercises or providing prompt questions may promote greater engagement. A sufficiently powered randomised controlled trial would be needed to evaluate the effectiveness of this programme and examine factors that may be associated with variation in outcomes.

Declaration of conflicting interests

The author(s) declared the following potential conflicts of interest with respect to the research, authorship and/or publication of this article: The authors disclosed their involvement in both the development and evaluation of the programme reported in this article. They declare no other conflicts of interest.

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Ethics

Ethical approval for this study was obtained via the Department of Psychology and Human Development at IOE, UCL's Faculty of Education and Society. Informed consent for participation and publication was obtained from all study participants.

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Data accessibility

Ethical approval and participant consent were not obtained for raw data sharing. Due to the confidential and sensitive nature of our data, there is no data that can be disclosed beyond that contained within the manuscript and supplemental material.

Supplemental material

Supplemental material for this article is available online.

Notes

1. As the programme focuses on disclosure decision-making, it was originally envisaged that it may be more suitable for autistic adults with a formal diagnosis and who had not fully disclosed. Indeed, our consultation survey suggested that not all autistic adults might need such a programme or find it helpful, such as those who are already confident about disclosure (Han et al., 2023). For similar reasons, some previous HOP (Honest, Open, Proud) studies have used pre-existing levels of disclosure as an inclusion criterion (e.g. Scior et al., 2021). However, our autistic team members were concerned that requiring a formal diagnosis may be seen as ‘gatekeeping’ and reinforcing the lack of support available for undiagnosed autistic adults. Furthermore, during the recruitment process, a number of prospective participants who were openly autistic still expressed an interest in the programme. We included these participants as long as they provided a reason for participating that was broadly in line with the goal of our programme, showing that they understood it and thought it would be beneficial to them. For example, some felt that they had been too open in the past and wanted to become more selective and strategic with disclosure.
2. Between the first and second iteration, minor adjustments were made to the programme materials based on participant feedback to improve accessibility, namely increasing font size and spacing, decreasing colour contrast and enabling text-to-speech and speech-to-text functions. All other aspects remained the same.
3. Reliability assessment of Cronbach’s alpha values followed the rules of thumb provided by George and Mallery (2003): $\alpha > 0.9$ is excellent, $\alpha > 0.8$ is good, $\alpha > 0.7$ is acceptable, $\alpha > 0.6$ is questionable, $\alpha > 0.5$ is poor and $\alpha < 0.5$ is unacceptable.
4. One participant disclosed dyslexia and the other disclosed general difficulties in reading and comprehension. After minor adjustments were made to the self-help guide based on their feedback (see Note 2 for details), both participants were offered the opportunity to try out the materials again, but neither responded.

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