

Exploring Being Autistic: An evaluation of a post-identification programme for autistic adults

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Background

Accessing an autism diagnosis can be a difficult and lengthy process, for children and adults. Many adults choose not to seek a formal diagnosis of autism, but instead self-identify as autistic. In either case, the support offered to autistic people (post-diagnosis or post-identification) is sorely lacking.

Autism trainer and consultant Caroline Hearst aimed to address this gap in provision with the Exploring Being Autistic programme: a 10-week autistic-led peer support programme for diagnosed or self-identified autistic adults. In this report, we present the results of an initial evaluation of the Exploring Being Autistic programme.

About the programme



Exploring Being Autistic is a 10-week programme for approximately 6-8 autistic participants, led by an autistic facilitator.

Participants are encouraged to:

Learn about autism and find out if and how it affects them personally;

Process their emotional response to their diagnosis or identification;

Consider the pros and cons of disclosing that they are autistic to other people;

Develop strategies to capitalise on the strengths and mitigate the challenges associated with autism;

Socialise with autistic peers in a safe and welcoming environment.

The goals for participants are:

To develop a good understanding of what autism means;

To experience a connection with a peer group and decrease anxiety;

To be better able to build on autistic strengths and mitigate autistic challenges in real-life;

To be better able to explain their autism to others, and both request appropriate accommodations and adapt some of their own behaviour.

Who took part?



Exploring Being Autistic took place twice (once from May to July 2016 and once from September to November 2016). There were a total of 16 autistic people involved – nine took part in group 1 and seven took part in group 2. Attendees ranged in age from 18 to 71 years and there were five men and eleven women. Nine had formal diagnoses of autism, and seven self-identified as autistic.

About the evaluation



Exploring Being Autistic was evaluated by a team led by Laura Crane, who works at Centre for Research in Autism and Education (CRAE) at UCL Institute of Education. Laura worked with Caroline to design a questionnaire, which all participants completed before attending the programme. Then, Laura interviewed everyone who took part: immediately after the programme, then again six months later.

Laura and her team used a technique called thematic analysis to identify common themes from the questionnaires and interviews, to find out what participants thought about the Exploring Being Autistic programme.



Why did attendees take part in the programme?

1. Exploration of Autism

Many attendees wanted to gain a better understanding of autism: both in general and, more specifically, in relation to themselves. They wanted to deepen their existing knowledge as well as gain a better understanding of some more specific aspects of autism (e.g. the links between autism and mental health). Some attendees wanted to investigate whether they were autistic and, if so, work out whether it would be worthwhile to get a formal diagnosis. Other attendees wanted to explore issues around the disclosure of autism in different settings.

2. Empowerment

The majority of attendees spoke about a desire to feel accepted as a major motivation for taking part in the programme. They explained that they wanted to meet other people like them, to feel less isolated and gain confidence in themselves. Many attendees also wanted to learn more about the positive (as opposed to the negative) aspects of autism.

3. Developing Practical Strategies and Coping Mechanisms

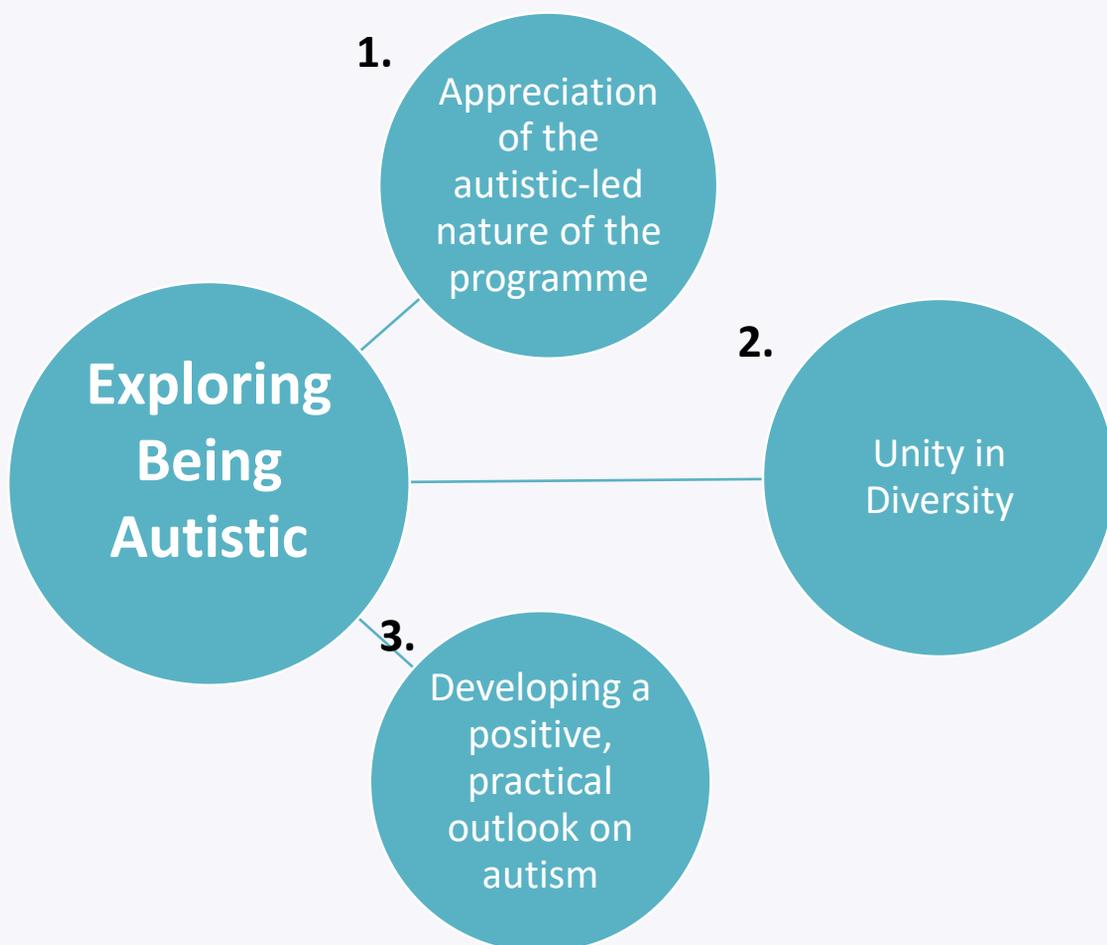
Attendees wanted to learn from one another. Specifically, they wanted to hear about, and learn from, the experiences of other autistic people in order to develop practical coping strategies. Some attendees hoped that the programme itself could be used as a coping mechanism, helping them work through their mixed emotions following an autism diagnosis.

What did attendees think about the programme?



After taking part in the programme, the attendees told us about their experiences (straight away, and again six months later).

We organised their feedback into three key areas:



1. Appreciation of the autistic-led nature of the programme



“Essential that she’s autistic. Absolutely essential”

Initially, some of the attendees didn’t know that the programme was organised and led by an autistic person. However, this was seen as being as one of the most valuable aspects of the programme:

“it was really important that she was autistic herself. I don’t think I would have been quite so keen to come otherwise...it made me feel like she was much more understanding and you could open up more, and you could be really honest...I don’t think I would have done that if it was someone who didn’t have the personal understanding and experience of being autistic themselves” (Danielle).

Caroline’s positive outlook on autism was seen as a real strength (in facilitating the group, but also in giving attendees confidence and boosting their self-esteem):

“If there was more people like Caroline in this world, we would be able to achieve what we came to achieve, or accept ourselves as who we are, and acknowledge that actually we are just as important and acceptable as everybody else...I can’t express the importance of Caroline and what she does in this world” (Paula).

2. Unity in diversity



Despite their varied diagnoses and life experiences, the autistic adults involved reported a real sense of belonging that came as a result of being part of the group. They described a sense of community that they hadn’t felt in other groups:

“just talking to each other about our experiences was, to me, the strong point...you feel legitimised by other people having the same experiences, so it means you’re not just one weird outpost” (Callum)

“my friends and family could never understand why I had so much difficulty, whereas the people in the group completely understood...knowing that other people were going on that journey with me, it made it a lot easier and I’ve come out from it feeling so much lighter than I’d been since my early teens....it’s been absolutely life-changing” (Katherine)

3. Developing a positive, practical outlook on autism



The programme helped attendees develop a new outlook on autism that had a positive impact in their day-to-day life:

“since I’ve been coming to the group there’s been a marked difference in how I am and how I see the world” (Katherine)

The course content was important for attendees struggling with their diagnosis or identification with autism. Attendees felt empowered by learning more about areas of strength and difficulty in autism:

“Becoming aware that I had Asperger’s, it kind of made me focus on my weaknesses ... [the facilitator] presented a very full view of being on the spectrum, which included a lot of really positive stuff as well and strengths ... [this] gave me a more rounded picture of being on the spectrum and made me feel that actually, there were a lot of positive things that I had that I could focus on” (Brooke).

The programme also gave participants practical solutions to tackle difficulties they faced, particularly in relation to mental health and anxiety. Attendees spoke about how it might be useful to have a **“continuation space” (Callum)** so they didn’t lose the valuable support that had been built from the programme

Case studies



Callum is 32 years old, living with his partner and in full-time work. Callum experienced difficulties throughout his life and his mother (a teacher) had felt from early on that he was not developing typically. Despite Callum being diagnosed with dyspraxia (at 13 years) and social phobia (at 19 years), he and his mother were – initially – resistant to the idea that he might be autistic; a possibility suggested by an autistic family friend.

At the suggestion of the family friend, Callum had attended Autscape (an annual conference retreat for autistic people). This experience confirmed Callum’s belief that he was not autistic, as he felt the autistic people in attendance were significantly more disabled than him. Yet ongoing difficulties since that time forced him to reconsider the idea of autism. When he came to the Exploring Being Autistic programme (almost two years later), he was awaiting a formal diagnosis of autism.

The programme gave Callum his first experience of meeting a variety of autistic people that he felt positive about, who he felt he could relate to. He found it helpful to know that others had experienced – and had managed to overcome – the sort of difficulties that he was experiencing in his job. This made Callum feel less alone and gave him the confidence to request appropriate accommodations at work. This, in turn, made Callum’s work life much more bearable. Callum says that being in the group gave him valuable experience of, for the first time, being accepted for who he really is.

Paula is 40 years old, and the mother of three children, one of whom attended Exploring Being Autistic with her.

Paula was a solitary child, whose bright and eccentric behaviour was excused because she was “artistic”. One of Paula’s children also displayed atypical behaviours and was eventually diagnosed as autistic. This process led to Paula receiving a formal autism diagnosis.

Before attending the programme, Paula felt very negative about her autism diagnosis – it made her feel that things were hopeless, as she felt her difficulties were entrenched in her character and there was nothing that could be done about them. She was struggling to accept that she was autistic as she felt there was a lot of stigma associated with the diagnosis.

By attending the programme, Paula she met a group of supportive, like-minded people. The material covered during the programme introduced Paula to new ways of thinking about autism – with a focus on both strengths as well as challenges. Experiencing a more nuanced and positive view of what it meant to be autistic enabled Paula to change the way she viewed both autism and herself. As a result of attending the programme, Paula says she feels more positive and in control of her life.

Summary



Overall, both the programme and the associated evaluation were a huge success. Almost all attendees who started the programmes remained until the end, and there were high rates of participation in the evaluation.

Feedback concerning the programme was extremely positive, with the points for improvement (e.g., the need for further follow-up sessions and more ongoing peer support) being factors that have been addressed in future iterations of the programme.