

Embrace Autism

An Evaluation of Autistic-Led and Designed Pre and Post-Diagnostic Support for Autistic Adults

December 2024

**Autistic
Knowledge
Development**
CIC



**National
Autistic
Society
Scotland**

INSPIRING SCOTLAND



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“FOR YEARS
I THOUGHT
I WAS A
CRAP HORSE,
TURNS OUT
I'M A
FABULOUS
ZEBRA.”

Embrace Autism Participant

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FOREWORDS

Autistic Knowledge Development

“We cannot change being autistic. What we can change is how we feel about being autistic.

We can help people navigate a society that was not designed for autistic people, more effectively and with less negative impact on us as individuals. We can help people feel less alone and isolated in their autistic experience.

Autistic Knowledge Development believes that being born autistic should not automatically mean a life of poor mental health and less opportunity. However, today’s society is one that is not designed for us and in many cases purposefully excludes autistic people. Poor mental health such as anxiety and depression are a likelihood for many autistic people as they are shaped by this negative experience of our current society.

I am later-in-life diagnosed autistic and ADHD. I am also a professional. I have encountered much prejudice as an openly autistic professional, including within the autism sector. It is sad to say, but as I speak now, many autistic professionals keep being autistic a guarded secret in the workplace.

Currently, we live in a society where autism is one of the last minority groups that are generally not represented in employed roles in organisations that are for autistic people. There is still a cultural acceptance of this here that has yet to catch up with what are now societal norms for the representation of women or people of colour in our society, in organisations for and about them. Imagine in 2024 that a women’s support service was entirely designed and delivered by men; this would rightly get called out very quickly. Why should this be any different for the autism sector?

It is great that Inspiring Scotland and the Scottish Government realise that the autism sector does need to change its approach to supporting the autistic community. Funding the Autistic Adult Support Fund is a great start; however, we need to look at long-term provision, not just short-term solutions. Spending a relatively small amount of money upfront enabling an autistic person to lead a happier and more fulfilled life, before they have reached crisis point, should be a priority.

We need our non-autistic allies to include us in more paid roles, to remove the ‘glass ceiling’ for more senior autism sector roles and to follow the evidence and act on it. We are proud to see the number of autistic people our programme partner National Autistic Society Scotland has employed in the time we have worked with them on this Embrace Autism support programme.

There is an overdue change coming for the autism sector. One that is led by evidence and that is created both by and for autistic people.”

Sean Macaskill, Director.

**Autistic
Knowledge
Development**
CIC

National Autistic Society Scotland

Our strategy 'From Vision to Reality' 2023-2026 is underpinned by an ambition to work in partnership wherever we can and to offer programmes of support shaped by and delivered by autistic people.

I'm proud that the Embrace Autism programme meets those ambitions and I am hugely heartened by the feedback we have received from participants which has been extremely positive. Receiving a diagnosis or starting to identify as autistic can be daunting and scary. Historically, autistic adults would be sent on their way with a leaflet from their GP (if lucky!) and left to try and figure out what being autistic meant to them as a person, their identity, their career, relationships and so on.

Embrace Autism tackles that deficit in support by offering a safe and welcoming space for adults to explore their identity with peers and build confidence in who they are. I strongly believe that good quality support at this critical point in people's lives, helps to set them on a positive pathway and prevent crisis later in life.

The success of Embrace Autism is in no small part down to the fact it is an equal partnership with Autistic Knowledge Development and I thank them for all of their hard work. Our pooled expertise, experience and passion has created something which I hope will continue to grow and thrive for the benefit of the autistic adult community.

It is also important to credit the Scottish Government and Inspiring Scotland. They have recognised the deficit of support for adults and set up and funded the Autistic Adult Support Fund through which Embrace Autism is funded. Their support has been invaluable, and we look forward to continuing to work with them.

Too many autistic adults find themselves in crisis, but it does not have to be this way. It is our hope that programmes like Embrace Autism will become the norm – helping people onto a positive pathway, confident in who they are and empowered to achieve what they want to achieve.

Rob Holland, Director.



EXECUTIVE SUMMARY

Embrace Autism is a Scotland-wide programme of support for autistic adults who are looking to explore their autistic identity and learn how to navigate life. It is a time-limited, but highly effective intervention for autistic adults living anywhere in Scotland with a recent diagnosis or who have recently begun to identify as autistic.

The programme is an equal partnership between Autistic Knowledge Development (AKD), an autistic-led not-for-profit autism think tank, and National Autistic Society Scotland (NAS), a registered charity and membership organisation. Embrace Autism is funded by Inspiring Scotland through the Scottish Government's Autistic Adult Support Fund (AASF), which 'aims to help adults with an autism diagnosis, self-identified autistic adults, and their families and carers understand what neurodivergence means for them and improve their wellbeing.'

The programme is entirely designed and directly delivered by professionals who are themselves autistic and is founded on a clear evidence-base and repeatable methodology, which is explained later in this report. Through external evaluation and via a continued embedded evaluation framework, it can be shown that the support provided through Embrace Autism positively changes the way autistic people feel about being autistic. The programme also normalises the experience of being autistic by ensuring that every professional a participant engages with, either for support or through the online content, is also openly autistic.

There are two elements to the programme: an online resource of short videos (also available as audio-only and in written form) and a block of six group sessions. The block of six group sessions is held online over a six-week period with a 90-minute session each week covering clear themes, as well as more open related discussion. The themes for both the group sessions and videos are:

- o **Welcome and What is Autism**
- o **Identity and Intersectionality**
- o **Masking and Energy**
- o **Relationships and Communication**
- o **Legal Protections, Reasonable Adjustments and Benefits**
- o **Employment and Next Steps.**

Pre and post-diagnostic support programmes like Embrace Autism are crucial in improving outcomes for autistic adults. Sadly, it is well known that autistic people face significantly poorer outcomes than the general population. Autistic people are more likely to die younger, commit suicide, face unemployment, be socially isolated, and experience health problems than the general population.

It is also very challenging, if not impossible, for autistic adults to access a diagnosis, and when an individual does manage to get a diagnosis, whether privately or through the NHS, there are very limited or no support options available to them. This means that many autistic adults are driven into situations requiring crisis support, which not only comes with an untenable human cost but is also unsustainably expensive.

Effective pre and post-diagnostic support, like Embrace Autism, can give people the knowledge and the tools they need to live meaningful, happy and healthy lives, preventing people from experiencing crisis situations requiring acute support.

It is clear from the independent evaluation of Embrace Autism, that it improves autistic adults' sense of purpose, their understanding of their autism, and most importantly how they feel about being autistic.

The benefits of the programme indicate that Embrace Autism can be viewed as a preventative spend which supports autistic adults' wellbeing.

1 in 4 felt no purpose in life when they started the programme, which reduced to 1 in 10 afterwards

94% felt it was very important that the programme is led by autistic professionals

92% of participants said that the programme was either very or quite valuable and worthwhile

Before taking part, 6% of participants had a clear idea of what being autistic meant to them which increased to 33% after taking part

33% of participants felt acceptance about being autistic and 13% felt positive about it before starting the programme, which increased to 51% and 27% respectively afterwards

Before taking part, 44% did not feel part of a community at all, which reduced to 14% after taking part

Our recommendations for government and funders are:

1

Rapidly expand the availability of professional autistic-led and designed pre and post-diagnostic support for autistic adults which is evidence-based and can measure positive impact on the supported individual.

2

Ensure that pre and post-diagnostic support programmes are sustainably funded, in order to avoid gaps in provision and the prevalence of short-term interventions.

3

Integrate pre and post-diagnostic support programmes with other forms of support, including more intensive support and peer support.

4

Ensure that pre and post-diagnostic support programmes for autistic adults are designed and delivered by autistic professionals.

5

Ensure that pre and post-diagnostic support is open to those who self-identify as autistic to mitigate the poor access to diagnosis in Scotland.

6

Develop shared quality assurance measurements for programmes of pre and post-diagnostic support for autistic adults, so we know what works across the sector.

ABOUT EMBRACE AUTISM

Autistic Professionals Leading the Way

There is an important part of the narrative of Embrace Autism, that runs through its content, delivery, and evaluation: it was created by and for the autistic community.

In too many instances autistic involvement in the autism and wider third sector has either not been effective or has been tokenistic at best. Embrace Autism has been successful because every autistic person with a paid role in the programme is a professional with relevant skills, relevant background, and proven experience, which can ensure a high-quality of support is provided. These professionals also have a positive sense of self linked to being autistic and are all openly autistic. This is very important for normalising the experience of being autistic and to enable future fellow autistic people to 'be what you see'.

All the content for the block of six group sessions offered through Embrace Autism, was created by the openly autistic Directors at AKD, Sean Macaskill and Leila Talmadge. This content was informed by their action research findings and input from the autistic community both in previous projects and in services that they have created at AKD. The group delivery and one-to-one onboarding of group participants was also all done by openly autistic professionals.

Embrace Autism's short videos were created by Leila and Sean from AKD, as well as Katie Forbes, the founder of Autistic Flair, who is an openly autistic media professional and autism influencer. The social media activity for this project was also led by openly autistic media and communications professionals.

The organisation that conducted the externally evaluated report on this service, Assenti Research, is led by its company Director Sinead Assenti, an openly autistic research professional. We felt it was important to have an autistic researcher lead the independent evaluation to ensure there was no 'othering' of the autistic participants and their experiences.

The autistic professionals working on Embrace Autism are also autistic at the weekends too. There is a level of insight that comes from being both a professional in this sector and having the lived experience of being autistic that is evident in the positive outcomes of people who have been supported through Embrace Autism. Indeed, emerging research indicates that lived experience interventions can play a positive role in supporting individuals.¹ We also hope this approach goes some way to challenging some of the stereotypes around autistic people, particularly around autistic people in the workplace.

“THIS IS EXACTLY WHAT I HAVE BEEN LOOKING FOR EVER SINCE DIAGNOSIS, I'M SO HOPEFUL NOW.”

Embrace Autism Group Participant

¹Slade, M. et al., Effectiveness and cost-effectiveness of online recorded recovery narratives in improving quality of life for people with psychosis experience (NEON Trial): a pragmatic randomised controlled trial, The Lancet, 2024.

Partnership Working Across the Sector

Autistic Knowledge Development (AKD) is a relatively new autistic-led think tank, not-for-profit Community Interest Company. National Autistic Society Scotland (NAS) is an established autism charity and is one of the most recognisable autism charities in Scotland. Both organisations believe that much more can be done by working together positively to serve the autistic community more effectively.

AKD is designed to work in partnerships where there is a natural synergy. As such, in some cases, it effectively functions as an external evidence-based autistic-led Research and Development service with larger partner organisations. Sean Macaskill and Leila Talmadge, both Directors of AKD, aim for the maximum social impact possible for the autistic community.

NAS Scotland's Strategy 2023-2026 sets out the importance of collaboration and meaningful autistic involvement throughout the organisation and its services. Embrace Autism, as a collaborative effort with an autistic-led organisation, symbolises the new direction NAS Scotland is heading in.

In this equal partnership between two very different organisations, a service has been created that is greater than the sum of its individual parts. NAS Scotland has provided the infrastructure, brand visibility and reach needed for a Scotland-wide service. AKD developed the entirely autistic-led content for the groups and videos. Both organisations have had a role to play in delivery. AKD provided the openly autistic facilitators for the group sessions and one-to-one additional support. Autistic colleagues at NAS also provided the onboarding and safeguarding processes, as well as support at the group sessions.

It has been a mutually beneficial partnership that has already been extended from 2023-2024 (Phase one), into financial year 2024-25 (Phase two). We are hopeful that this is a partnership that will be funded much further into the future and for longer periods at a time, in order to deliver this essential service for the autistic community in Scotland.

Both organisations would agree that they have learnt from each other. The work involved in navigating two different organisations' approaches has led to a much better service being created in Embrace Autism. The evidence of its effectiveness shows this to be true.

“ I DIDN'T THINK TAKING PART IN A SIX-WEEK COURSE WOULD HAVE SUCH A BIG EFFECT ON ME. FOR THE FIRST TIME IN MY LIFE, I HEARD PEOPLE TALK VERY OPENLY ABOUT CHALLENGES THAT WERE VERY SIMILAR TO MY OWN. ”

Embrace Autism Group Participant

The Inclusion of Self-identified Autistic People

Autistic people with a later-in-life formal autism diagnosis have always been autistic, before they were fortunate enough to get a diagnosis and before they realised that they might be autistic. They have been autistic since birth, with or without a piece of paper that states this.

The emerging evidence from school aged children suggests that autistic people are closer to being somewhere between 1 in 10 and 1 in 20 in the population not 1 in 100. This would also suggest that autistic people are a natural population difference, like being left-handed, as opposed to autism being something to be treated or cured. The current system cannot cope with 1 in 100 people and the immediate future likely has less funding for public services, not more. This indicates that a different approach is required in how we support autistic people.

With Embrace Autism, we have taken a bold, new approach of including people on waiting lists for a formal autism diagnosis, people who self-identify, as well as people who have a formal autism diagnosis. This is because accessing a formal adult autism diagnosis is extremely challenging, and sometimes impossible for many people across Scotland.

The data from the independent evaluation of Embrace Autism has shown that some group participants who self-identify as autistic felt that the six group sessions were enough for them to feel personally validated. They reported that they felt more confident to now say openly that they were autistic, even though they might not have a formal diagnosis yet.

Some group participants were on waiting lists for a formal diagnosis whilst they attended the group sessions. Some of these people have now been fortunate enough to get a formal diagnosis. This formal diagnosis has validated what they knew to be true after attending the sessions, where they discussed their personal experiences and identified with fellow autistic people over shared experiences, both positive and negative.

“ IT WAS A SAFE SPACE TO EXPLORE A RELATIVELY NEW AREA OF MY LIFE AS SELF-IDENTIFYING AS AUTISTIC AND I WAS VERY GRATEFUL THAT I WAS ALLOWED TO BE PART OF THE GROUP.”

Embrace Autism Group Participant

Online Videos

The suite of six online videos for Embrace Autism function in a few different ways. They can be an additional information support tool for people on the groups. Some group participants have also provided feedback that these were a great resource for sharing with family members, friends and loved ones to help them better understand what it is to be autistic.

There are many parts of the autistic community that will not attend group support or one-to-one support. These videos go some way to addressing the need for support for this part of the autistic community. There is also a resource pack available with the videos that has more useful information and signposting links.

Not everyone will choose to go on to get group support, but for those that do, the videos also serve as an introduction for what to expect from the groups. It also equips people with more knowledge to shape what they would like to get from the groups individually and acts as a refresher both pre and post-group sessions.

In short, this element of Embrace Autism functions as a safe, first landing space online for reliable and relatable autism information and signposting.

The videos are available on the Embrace Autism webpage on the National Autistic Society Scotland's website, as well as on the National Autistic Society's YouTube channel. They were promoted using paid posts across the National Autistic Society Scotland's and Autistic Flair's social media channels during the initial six-month period. Engagement statistics for this first six-month period alone are below:

Facebook (teaser videos):

155,469 Views

X (teaser videos):

6,184 Views

YouTube (full-length videos):

11,552 Views

Watch time:

516.6 Hours

Instagram (teaser videos):

78,329 Views



A New Approach to Measuring Positive Impact

There is a simple five question quantitative evaluation framework embedded within this support model. The most important question it asks is 'How do you currently feel about being autistic?'. This framework was developed by AKD through their previous project work and versions of this are used in all their direct delivery provision.

These five questions are answered on a one to five scale, with one being the most negative, three being neutral, and five being the most positive. This evaluation framework is a radical departure from many evaluations as its sole concern is the measurable before and after difference that support makes to a person's life.

This framework also maps onto the CHIME recovery framework, used across parts of Social Services and the NHS.

CHIME stands for:

- o Connectedness
- o Hope and optimism (about the future)
- o Identity
- o Meaning and purpose (in life)
- o Empowerment

Using AKD's quantitative evaluation framework we can evidence that the support provided through Embrace Autism positively changes people's perception of what it is to be autistic and increases their understanding of autism.

“ IT'S GIVEN ME SOME HOPE WHERE THERE WAS NONE BEFORE. I LIKE THE IDEA OF CONTINUING WITH THE GROUP, EVEN WHEN I FIND BEING IN A GROUP DIFFICULT. ”

Embrace Autism Group Participant

EXTERNAL EVALUATION: METHODOLOGY AND FINDINGS

Methodology

Assenti Research undertook an independent evaluation of the first phase of the Embrace Autism programme (October 2023 - April 2024), which included the quantitative evaluation framework developed by AKD. Assenti Research is led by Sinead Assenti, who is a later-in-life diagnosed openly autistic professional researcher.

The research evaluated the experience of participants enabling us to understand how they have benefited and how the programme could be improved in the future.

The research approach included the following elements:

- o An online survey for participants before they took part in the programme (63 completes).
- o An online survey for participants on completion of the six sessions (51 completes).
- o Ten depth interviews with participants after the programme ended.
- o Two depth interviews with people on the waiting list about the online videos.
- o A focus group with Autistic Knowledge Development and National Autistic Society Scotland at the end of the programme.

“UNDERSTAND MYSELF A LITTLE BETTER. FEEL OK ABOUT SELF-IDENTIFYING AS AUTISTIC NOW.”

Embrace Autism Group Participant

Findings: Who Took Part?

In the six months covering 2023-2024, Embrace Autism provided direct support for

70 autistic adults.

94%

attended five or six sessions, which anecdotally is a very high and consistent engagement level for any form of autism support.

63 people completed the survey before taking part and 51 completed it after taking part.

Of the participants who completed the pre-programme survey, the majority already had an autism diagnosis.

40%

had an NHS diagnosis and

24%

had a private diagnosis.

One fifth were still on a waiting list for an NHS diagnosis.

13%

self-identified as autistic.

Over three quarters of participants said they had received little or no support since being diagnosed or deciding to self-identify as autistic. This is not surprising as we know that there is little to no pre and post-diagnostic support available to autistic adults in Scotland, and very little support for those self-identifying.

Most participants had not received support from either organisation before.

Almost half of participants (49%) heard about the programme through National Autistic Society Scotland.

There were participants in every age bracket:

- o 10% aged 18-25
- o 22% aged 26-35
- o 30% aged 36-45
- o 24% aged 46-55
- o 11% aged 56-65
- o 3% aged 65+

12 out of 32 Scottish local authority areas were represented.

Key Points:

Some of the participants had been searching for support for some time, and some had never accessed support before.

The Embrace Autism programme reached individuals who had never been supported by either organisation before.

Participants who self-identified as autistic found the programme helpful despite not having a diagnosis. It helped to give them more confidence in their self-identification and validated their experiences.

“I HAVE GAINED KNOWLEDGE ABOUT MYSELF AND MY AUTISTIC PARTNER. WHERE BEFORE I TENDED TO JUDGE MYSELF AND MY PARTNER MORE HARSHLY, NOW I CAN IDENTIFY TRAITS AS PART OF AUTISM, NOT AS 'MORAL FAILINGS'.”

Embrace Autism Group Participant

Findings: The Benefits of the Programme

Before taking part, one in four felt no purpose in life

This reduced to one in ten after taking part

Before taking part, 44% did not feel part of a community at all

This reduced to 14% after taking part

Before taking part, 6% had a clear idea of what being autistic meant to them

After taking part, 33% had a clear idea of what being autistic meant to them

Before taking part 33% felt acceptance about being autistic, 13% (eight people) felt positive about being autistic

After taking part 51% felt acceptance about being autistic and 27% (14 people) felt positive about being autistic

Diagnosis or choosing to self-identify can be life-affirming experiences. However, without the appropriate support in place it can be challenging for people to accept what it means to be autistic, or even understand how being autistic affects their life.

The independent evaluation of Embrace Autism explored how people felt before and after participation. It is clear from the evaluation that Embrace Autism not only improved people's understanding of autism, but it also helped them to feel better about being autistic which is crucial for autistic people's overall health and wellbeing.

Appropriate pre and post-diagnostic support is also crucial in helping to improve outcomes for autistic people. Autistic people are more likely to experience social isolation and loneliness than the general population and are also more likely to experience anxiety and depression.

The evaluation of Embrace Autism indicates that the programme helped to improve participants' sense of connection and community. It also helped to give people a sense of purpose and hope, which was not there before for some participants.

It is clear from the evaluation that participants in the Embrace Autism programme have experienced considerable benefits, particularly in relation to their understanding of autism and how they feel about being autistic. It is also evident that programmes like Embrace Autism have a crucial role to play in helping to address the poor outcomes faced by autistic people by helping them to feel part of a wider community and, in some cases, restoring a sense of purpose.

“IT WAS NICE TO MEET OTHER AUTISTIC PEOPLE AND LEARN THAT THE DIFFICULTIES I HAVE FACED ARE LIKELY TO BE DUE TO THE AUTISM AS THEY HAD VERY SIMILAR EXPERIENCES. THIS HELPED ME REALISE A LITTLE BIT MORE OF THE IMPACT AUTISM HAS HAD ON MY LIFE.”

Embrace Autism Group Participant

Key Points:

There is not enough support for autistic adults who have just received a diagnosis or who are seeking a diagnosis.

AKD has developed and tested a measurement tool of five core questions that tracks how people feel before and after participating in Embrace Autism. These questions were included in the independent evaluation and the results indicate that Embrace Autism makes an incredibly positive and measurable difference to a person's life:

- o Embrace Autism can improve autistic adults' understanding of autism and how they feel about being autistic.**
- o Embrace Autism can help autistic adults to feel part of a community and connected with other people, reducing social isolation and loneliness.**
- o Embrace Autism can help to validate autistic adults' experiences and give them a sense of purpose, improving mental health.**

“ I DON'T KNOW WHAT IS AND ISN'T AUTISM AND WHAT IS AND ISN'T MASKING. I WANT TO KNOW WHO I ACTUALLY AM.”

Embrace Autism Group Participant, before joining the group support.

Reflections on the Programme

There were a lot of different and varied things that participants wanted to get out of the programme:

- 83% To understand what being autistic means to me
- 70% To learn more about autism in general
- 78% To learn more about how to navigate life as an autistic person
- 73% To find out more about resources and support services
- 84% To meet other autistic people
- 71% A safe space to talk or ask questions
- 13% To improve my mental health and wellbeing
- 54% Other

“ BURNOUT. MELTDOWN AND RESULTANT FALLOUT HAD ME AT MY LOWEST BUT I’M STILL HERE AND DETERMINED TO NOT JUST GO BLUNDERING BACK INTO THE WORLD. I’M HOPING TO LEARN HOW TO TAKE MEASURED STEPS AND PRIORITISE MY OWN NEEDS.”

Embrace Autism Group Participant, before joining the group support.

It is clear from the evaluation that the programme met most participants' expectations. The Embrace Autism programme is helping to address a significant gap in support for autistic adults. However, with the current level of funding it can only be a short, time-limited intervention.

92%

of participants said that the programme was either quite or very valuable and worthwhile.

80%

said they would recommend it to another autistic adult.

94%

felt it was very important that the programme is led by autistic professionals.

90%

said they learned something new and helpful.

Only a minority of participants (6%) said it did not meet their expectations and this cohort was consistent in their feedback, indicating that the programme was not appropriate for their needs. Indeed, there were a small number of participants who likely required more intensive support or a crisis intervention, for which Embrace Autism cannot be a substitute.

“ I FEEL I'M BENEFITTING FROM THE COMMUNITY ASPECT ALSO AS WE ARE ALL NOW IN A GROUP CHAT SINCE THE SESSIONS HAVE FINISHED. GREAT SEEING FRIENDLY FACES WEEK TO WEEK AND I DON'T FEEL SO ALONE OR LOST. ”

Embrace Autism Group Participant

Key Points:

- o Almost all participants felt the programme met their expectations.
- o The programme was seen as worthwhile by participants, and they would recommend it to another autistic adult.
- o It is important that pre and post-diagnostic programmes like Embrace Autism are designed and delivered by autistic professionals.
- o In general, participants wanted to experience the programme for longer; with more funding this would be possible.
- o There is demand for one-to-one support from participants and this is offered in phase two (2024-2025) of Embrace Autism at the discretion of facilitators but is limited by funding. A possible enhancement to the programme would be to increase funding to allow for a combined group session and one-to-one support offer for all participants.
- o It is important that evidence-based, professional pre and post-diagnostic support programmes like Embrace Autism link into ongoing support, possibly peer-support.
- o Embrace Autism and similar pre and post-diagnostic support programmes are a great solution for many people. However, more intensive support and crisis intervention will always be needed for some autistic adults. **It is important that Embrace Autism is seen as a preventative spend, helping people avoid crisis point.**

“ PRIOR TO ATTENDING I HAD BEEN QUITE SOCIALLY ISOLATED, SO THE GROUP HAS HELPED ME REACQUAINT MYSELF WITH COMMUNICATING WITH OTHERS IN GENERAL. I FEEL A BIT MORE CONFIDENT ABOUT WHO I AM AND THE VALIDITY OF THAT PERSON WITHIN SOCIETY.”

Embrace Autism Group Participant

WHAT NEXT FOR EMBRACE AUTISM?

The qualitative data also offers an insight into some of the most common suggestions for improvement. These included building on the peer connections and community elements of the programme.

We have listened to this feedback and implemented new additions of ongoing support and community building for phase two of Embrace Autism. This qualitative feedback also demonstrates the real need for more support like Embrace Autism.

“I WILL MISS THE WEEKLY SESSIONS, AS I THINK THEY BECAME AN IMPORTANT PART OF MY AUTISTIC JOURNEY. I'M REALLY NOT SURE WHERE I GO FROM HERE TO ACCESS SIMILAR SUPPORT.”

“I WISH THE GROUP COULD CONTINUE THE REGULAR MEETINGS. IT WAS A SUPPORTIVE AND SAFE ENVIRONMENT, AND I FEEL A LITTLE BEREFT NOW THAT IS OVER.”

“MAKE IT A LONGER PROGRAMME. SIX WEEKS FEEL SLIGHTLY TOO SHORT. WE WERE JUST DEVELOPING A SUPPORTIVE COMMUNITY WHEN IT WAS CUT SHORT.”

“THE PROJECT IS REALLY GOOD. I WISH THE COURSE WAS ONGOING OR THERE WERE MORE COURSES.”

“I THINK, IF FUNDING WERE AVAILABLE, MY IMPRESSION WAS THAT MANY MEMBERS WOULD GO FOR MORE THAN SIX SESSIONS. IT WENT BY VERY QUICKLY.”

Quotes from Embrace Autism Participants

A closed Facebook group was created for phase two of delivery. Only participants who have completed the six online group sessions can access this Facebook group. This is to ensure that everyone in the Facebook group is on an equal footing for knowledge base.

The closed Facebook group is an autistic-only space and is moderated by professional autistic facilitators, making it a safer space for autistic people. The content builds on the knowledge and understanding participants gained during the group sessions. It also aims to normalise the diversity of autistic experiences by encouraging people to share their own experiences. It showcases more autistic-created and autistic-led content, including interviews with a wide range of autistic people. It has already become a well-used resource, and we hope this is something we can continue post-May 2025.

Increasing the number or length of the sessions were the most common suggestions, with people indicating that they wanted to experience more of the same kind of support. Some people also wanted the programme to link into formal peer-support. Indeed, it is clear from the feedback that the programme ending, and the lack of available ongoing support was a source of anxiety for some participants.

It is clear from this feedback that there is a real need for more support like Embrace Autism, and that there is room for enhancements to and expansion of the programme. While the closed and moderated Facebook group has addressed the demand for continued support to an extent, there is undoubtedly more that could be done with further and additional funding.

Some participants would have preferred age/stage specific groups. We are hoping to offer more age and gender specific groups in the near future. This includes providing group support specifically for men, which is a hugely underserved part of the autistic community in Scotland. We are also hoping to provide more age specific support groups, particularly looking at the needs of older autistic people.

We recognise that there will always be some people with more acute and immediate needs, that might not be suitable for group support alone. To start to address this in phase two, we have a small budget allocated to provide one-to-one support at the discretion of the autistic-facilitators and autistic onboarding team.

This has been a huge help with both safeguarding concerns and in being able to provide immediate support before a person has reached crisis point. In many cases it has enabled a person to go back to engage with group support successfully. A possible enhancement to the programme would be to increase funding to allow for combined group sessions and one-to-one support.

Phase Two of Embrace Autism (April 2024 - March 2025):

Group delivery to a further

160+

participants. Including a mens only group and reaching out to rural communities in Scotland.

Closed Facebook Group

90+

participants, and counting, have joined as of December 2024. All future Embrace Autism participants are invited. Community engagement and Facebook Lives with Autistic professionals.

RECOMMENDATIONS

The evaluation of Embrace Autism clearly shows that it is helping to fill a significant gap in support for autistic adults. Feedback from participants also indicates that autistic adults want to be able to access more of this kind of support and for longer periods of time. Based on our analysis of the evaluation, our recommendations for government and funders are:

- 1** Rapidly expand the availability of professional autistic-led and designed pre and post-diagnostic support for autistic adults, which is evidence-based and can measure positive impact on the supported individual.
- 2** Ensure that pre and post-diagnostic support programmes are sustainably funded, to avoid gaps in provision and the prevalence of short-term interventions.
- 3** Integrate pre and post-diagnostic support programmes with other forms of support, including more intensive support and peer support.
- 4** Ensure that pre and post-diagnostic support programmes for autistic adults are designed and delivered by autistic professionals.
- 5** Ensure that pre and post-diagnostic support is open to those who self-identify as autistic to mitigate the poor access to diagnosis in Scotland.
- 6** Develop shared quality assurance measurements for programmes of pre and post-diagnostic support for autistic adults, so we know what works across the sector.

“ I STOPPED FEELING LIKE AN 'ALIEN' WITH NO PART TO PLAY IN MAINSTREAM SOCIETY. I WAS ABLE TO UNMASK IN A SAFE AUTISTIC SPACE FOR THE FIRST TIME EVER, WHICH IMPROVED MY MENTAL HEALTH CONSIDERABLY.”

Embrace Autism Group Participant

APPENDIX:

Autistic Knowledge Development

<https://autisticknowledgedevelopment.org/>

Embrace Autism

<https://www.autism.org.uk/what-we-do/scotland/embrace-autism>

Embrace Autism You Tube

<https://www.youtube.com/watch?v=evX0UiRNJA8>

National Autistic Society Scotland

<https://www.autism.org.uk/what-we-do/scotland>

National Autistic Society Scotland Strategy

<https://www.autism.org.uk/what-we-do/news/the-nas-scotland-launches-three-year-strategy>

NICE Guidelines

<https://www.nice.org.uk/guidance>

SIGN Guidelines

<https://www.sign.ac.uk/>

Related Research Links:

Importance and Cost Effectiveness of Lived Experience in Recovery Journeys

<https://www.nottingham.ac.uk/news/neon-trial-results>

Self-scoring and Self-identification Autism Research

<https://link.springer.com/article/10.1007/s40489-023-00361-x>

Autism Online Tool Diagnosis Effectiveness

<https://journals.sagepub.com/doi/10.1177/13623613241228329?fbclid=IwAR22JRvK7-LOUr5JR2jzNTT5hImGUf4DazP1MQFCRZeloHHTgJKz48MEMq4>

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