

Autistic Adult Support Fund

Autistic Adult Support Fund Learning report

INSPIRING SCOTLAND

Executive summary

This report summarises the activity and learning from the Autistic Adult Support Fund over six months of operation between April 2024 and September 2024. This is the second six-month period for the fund marking a year of project delivery.

There are 15 projects in the portfolio. This fund supports organisations to provide support to autistic adults around diagnosis or to understand their autism. Three of the funded organisations are delivering large national projects with the rest receiving smaller amounts to deliver services locally or within a specific community of interest.

In terms of Health and Social Care Partnership provision of support for neurodivergent adults in Scotland a recent review of post diagnostic support found that access to support is inconsistent and where it does exist it may be contingent on meeting service thresholds[1]. This is verified by autistic adults supported by this fund who report challenges in obtaining a diagnosis and support locally. The third sector plays a pivotal role by providing this support.

The range of the type of support offered across this portfolio is key. One size does not fit all and autistic adults being able to choose from a range of different types of support for differing amounts of time is vital.

As projects settle into their operation, they report adapting the way they are delivering support, how they are increasing the amount of one-to-one support provided, and how they reach autistic adults in their communities.

The qualifications, experience and neurodiversity of project staff is an important area of learning. Some project support is being delivered by autistic professionals which is well received by recipients, other projects deliver their support by skilled and experienced support workers or family practitioners, who are not autistic. An important aspect of the fund is developing organisational practice and evidence of the components of effective support.

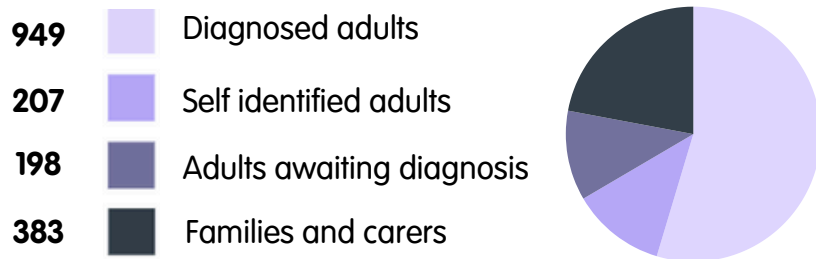
Emerging evidence of impact shows this fund is enabling organisations to provide an essential service to autistic adults, leading to improved health and wellbeing outcomes. This is a crucial addition to the autistic adult support landscape in Scotland.

[1] www.thirdspace.scot/wp-content/uploads/2024/04/Review-of-%E2%80%98Post-Diagnostic-Support-in-Health-and-Social-Care-Partnerships-in-Scotland-2024.pdf

Autistic adult support

One of the fund outcomes is that Scottish Government obtains additional insight on what works for autistic people and how to address gaps in support. Emerging learning is presented below with monitoring data compiled from a six-month report completed by each organisation.

Over this period the projects worked with and supported **1,354** autistic adults and their families.



In this period support included:

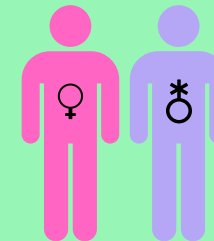
 766 one to one sessions

 442 group sessions for 867 attendees

Focus communities



AUTISTIC
ADULTS
WITH
ANOTHER
DISABILITY



WOMEN AND
NON-BINARY
PEOPLE



AUTISTIC
PARENTS



AGE
16-25



SOUTH ASIAN
COMMUNITIES



AGE
50+

Type of support

Projects provide a range of different types of support to autistic adults and this range is a key aspect of the funded work.

The menu of support available across the projects includes:



Group support – autistic staff-led support groups, peer support groups, themed groups such as art, employment support groups



One-to-one support including at home



Counselling



Creating and sharing resources to use with groups



Webinars



Community drop-in events

Some group support is a fixed term programme covering topics related to autism understanding and wellbeing, typically over 6-8 weeks. Other projects offer ongoing support through groups or on a one-to-one basis. Projects report high demand for their support with Swan courses for example being fully booked within an hour of being advertised.

Type of organisation

The fund supports **15 projects run by different organisations**, offering a diverse range of skills and specialisms.

One project is a partnership project between Autistic Knowledge Development and the National Autistic Society Scotland.

7 organisations specialise in mental health or family support

6 organisations are dedicated to supporting autistic people (including 2 that are autistic led)

2 specialise in supporting a range of neurodivergent people

This means the organisations were at a different starting point in terms of their autism expertise. However, each organisation has community expertise with a specific area of focus.

The third sector is very well placed to respond to the support needs of autistic adults as there is flexibility to respond to need, to adapt staffing roles and look for alternative funding sources.

Outcomes

93%

1254 of 1354 adults have a better understanding of autism and their next steps.

90%

346 of 383 families or carers have a better understanding of what it means to be autistic.

78%

1056 of 1354 autistic adults reported improved wellbeing.

77%

296 of 383 families of autistic people reported improved wellbeing.



What does this look like for autistic adults and their families?

The value of the support provided to autistic adults and their families is captured by organisations in different ways and the overall impact on autistic adults as seen above is very positive.

The impact on individuals includes:

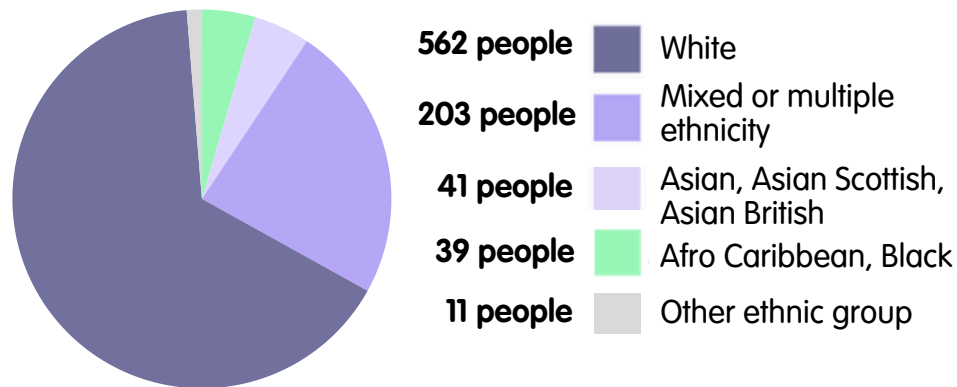
- Some group members became volunteers for the organisation they'd been supported by.
 - Participants report the sessions give structure to their week and encourage them to get up and out of the house.
 - Friendships have formed in groups and relationships are continuing outside of the sessions.
 - One project reports multiple participants have set up new businesses as a result of support provided.
 - Developing self-awareness and increased confidence, in some cases this is enough to have initial conversations with family members or employers about their neurodivergent profile.
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"It has been life changing, helping me to come to terms with being diagnosed and enabling me to understand myself. Given me tools and knowledge to go forward to a better future."

Demographic information

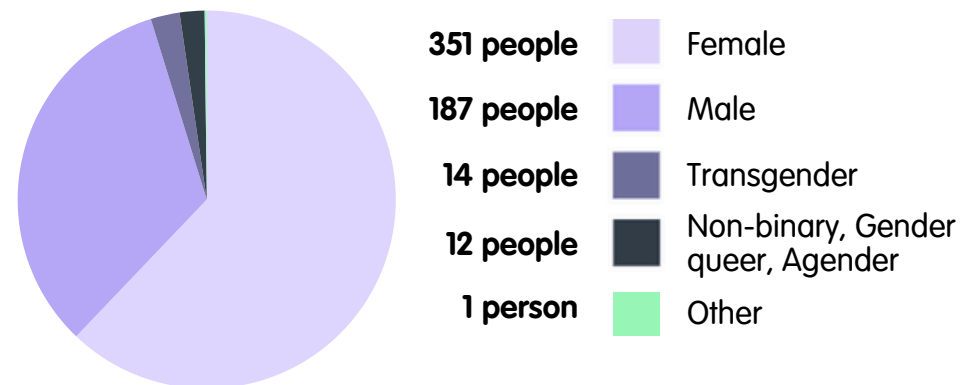
Ethnic group

Where ethnicity was known the following autistic adults were supported:



Gender

Where gender was known the following autistic adults were supported:

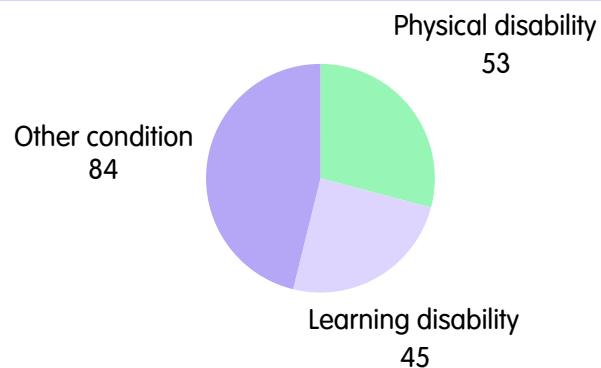


Other disabilities

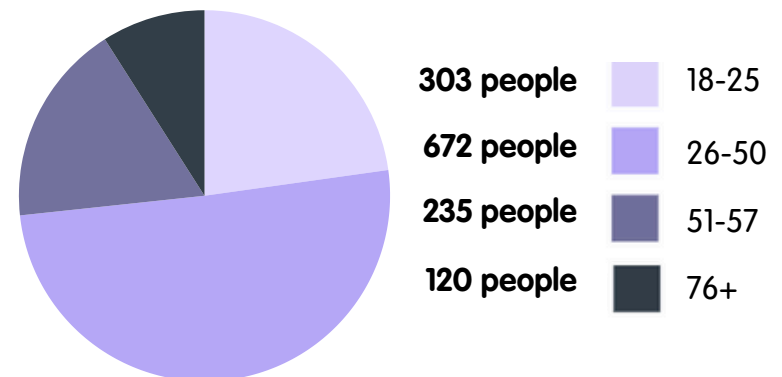
9 out of 15 organisations provided data regarding participants involved in their project with other disabilities.

All of the **121 people** supported by Cosgrove Care in this period were autistic adults with a learning disability.

The 8 other organisations were supporting 227 autistic adults in this period, of these the following number of people reported they had another disability or condition:



Age



The number of children of autistic adults supported was 228.

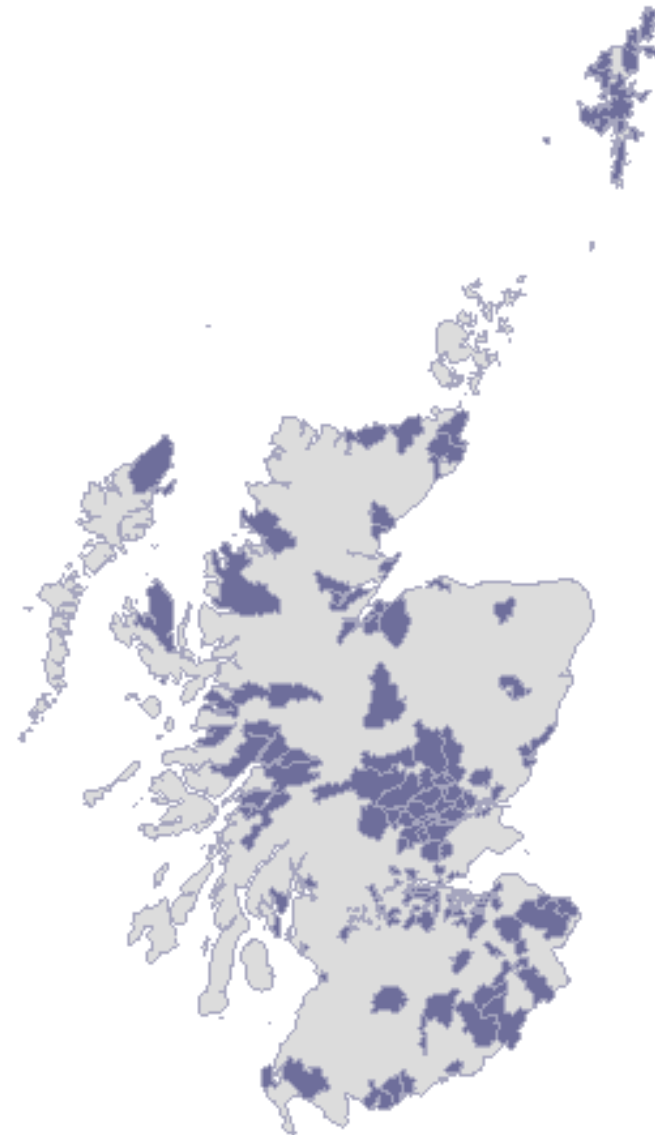
Areas covered

Where is support being provided?

The map shows the reach of people being supported by this fund. We are aware of where approximately one third of the people supported are as some people choose not to provide information about where they live.

There is good coverage across Scotland given the size of the fund.

“Amazing resource to be able to access. Diagnosis is a bit like moving house/country; the course welcomes us in and helps us get to know the people, the culture, the language. Thank you!!”



The following themes have been identified from project work

Adapting support delivery

Projects are adapting the delivery of their support based on the response and feedback of participants. This demonstrates their ability to listen and respond quickly. This is a huge benefit to autistic participants. Into Work facilitators for example take feedback and suggestions from participants at the end of each session and have incrementally adapted the course format to better meet the needs of different participants.

Navigating the dynamics of group support is something the projects manage skillfully – including offering an onboarding programme for new members, supporting positive relationships within the groups and responding swiftly to safeguarding concerns.

Many projects specified that participants liked the informal nature of groups and sessions. Flexibility means participants do not feel pressured, overwhelmed or anxious when they miss a session. It means they feel they are being listened to and their views matter, seeing changes in things like the timing of support and location. Some projects offer evening and weekend support options.

Salvesen Mindroom Centre extended their project this year to include 16 and 17 years olds, responding to an increasing number of referrals from this age group. They are very aware of the importance of providing support at this transition stage and found that there was little post diagnostic support available for this age group.

Increasing one to one support

Projects are identifying a need for increased one to one support with people to enable them to attend groups or courses or engage with the organisation. Perth Autism Support have surveyed their community and are now scoping a peer mentor project that they hope will encourage more autistic parents to take part in group support.

Coaching is being offered by Hope for Autism who have found that six sessions with a practitioner tend to work well but this needs to be flexible depending on the individual and their goal. They have also developed an outreach offer where staff visit potential participants at home to allow them to get to know staff in order to break down barriers around attending a group. Some autistic adults they are supporting find it very difficult to leave their home and engage with any support services therefore these pre group introductions can be essential in encouraging support to begin.

Home Start East Highland note that someone they are supporting felt that post diagnostic support available was limited as it focused on groups. That individual received one to one home visits to get to know staff in order to join groups where she was able to improve confidence, skills and build connections.

One to one support is reported as being a necessary stepping stone for a lot of autistic adults to access peer support settings which can be transformational to their wellbeing.

“We realise that the benefits of the groups spread to other areas of people’s lives for example if people try something new in our safe environment, this also makes them feel more confident to try something new in a different setting.”

Hope for Autism

Supporting autistic adults with a learning disability

A number of the projects work with autistic adults with a learning disability.

Cosgrove Care note a focus in statutory services on learning disability rather than autism leading to adults with a dual diagnosis not always getting the right specialist support they require, particularly around mental health and environmental changes. This is particularly important given the lower employment rates among this group, which leaves them more vulnerable to poverty, cost of living challenges and additional pressures on parents and carers.

Projects that are predominantly providing support to autistic adults without a learning disability have found that online group support with a mixed group is difficult to get right for all participants. They have found that in some cases it is best to refer individuals elsewhere (if this is available) to receive support that works best for them. Unsuitable referrals come from health and social care practitioners indicating that work needs to be done with different teams to develop appropriate referral pathways.

Ongoing support

Projects report autistic adults are looking for ongoing support and wanting to continue to meet after time limited courses. They are looking at ways to do this through either an informal online group, a moderated Facebook group or offering connection to their other services.

The need for reliable information about what is available is crucial, and to make sure this is easy to access and shared with key personnel across services.

Staffing

Some projects provide support delivered by autistic professionals. This model is well received by project participants and was very positively reported in the external evaluation of the Embrace Autism (delivered by the National Autistic Society and Autistic Knowledge Development) and Swan projects. Other community organisations have provided training for their staff and are delivering support by experienced community or support workers. This question is included in the external evaluation of the fund by Assenti Research and the response will be important evidence for informing support provision in the future.

Working with Health and Social Care Partnerships

The fund seeks to collaborate with Health and Social Care Partnerships (HSCPs) to deliver sustainable local models of post diagnostic support. Partnerships are already in place with some HSCPs to deliver other support work and for one of the portfolio organisations to deliver support to autistic adults outside of this fund. In these cases, there is a relationship there to build on but for others this is more difficult.

Projects cite difficulties in developing and maintaining consistent, reliable relationships with health and social care staff due to frequent changes in personnel. This inconsistency impacts awareness of their offer of support. Establishing connections and building relationships takes time and resource but projects report progress being made with referrals starting to come from GPs and community mental health teams.

To raise awareness of services the projects are highlighted to the Neurodevelopmental Network hosted by the National Autism Implementation Team. Projects also make use of local and national information platforms such as [ALISS](#).

Social care challenges

Projects raise huge challenges created by reduced individual social care support budgets and support available particularly placing pressure on autistic people with a learning disability. The risk is that the impact of these reductions diminish the positive impact of the social and wellbeing benefits of the support provided by this fund.

Recruitment challenges in social care impact on consistent and available care and support for autistic adults with a learning disability. Therefore, being able to offer consistent, regular activities which build capacity is of great benefit to supported people and their families.

Rurality and transport

Projects working in rural areas have been trying various approaches to provide support to autistic adults. For projects offering support solely online rurality and transport is not a concern. However, some projects are offering in person support exclusively due to the type of service they are providing or preferences expressed directly by their target population. This is in line with the challenges expressed by HSCPs in a recent scoping review of Health and Social Care Partnerships.

“While online resources and support groups are offered and are accessed by some neurodivergent adults, it was recognised that some individuals prefer and benefit more from in-person support groups.”[1]

In Dumfries and Galloway ICET tried running more events in rural areas outside of Dumfries and whilst they have been positively received numbers are small which makes the cost of delivery high.

Home Start Caithness tried a similar model by running events outside of Wick but found that numbers were low and delivery costs high so are now focusing most of their activity in Wick. They state transport costs to Wick are a significant barrier to participation and would like to be able to provide travel expenses for future work.

sensationALL have a rural demographic and have a wide geographical spread attending their online group, however they know that some people prefer in person support. For example, one of their group participants travels 3 to 4 hours to attend a group.

These are very familiar challenges to organisations operating in more rural areas. In the context of providing post diagnostic support to autistic adults, it demonstrates the need to consider the whole area and what access to in person support is like for individuals, and the need to factor in travel costs when developing project budgets.

[1] www.thirdspace.scot/wp-content/uploads/2024/04/Review-of-%E2%80%98Post-Diagnostic-Support-in-Health-and-Social-Care-Partnerships-in-Scotland-2024.pdf

“It's nice to join an environment where you don't need to put on a front or mask, you can turn up as yourself without worrying about what others are thinking about you. The group is a space where everyone is comfortable sharing personal struggles and details of their life without shame or judgement”.

Minority ethnic autistic communities

Networking Key Services (NKS) is the one organisation in the portfolio specifically supporting minority ethnic communities in one local authority area.

NKS report slowly overcoming barriers to autistic adults seeking support and the stigma surrounding autism in the South Asian community. They are providing autism awareness in a safe and familiar space and providing autistic adults opportunities to meet peers with similar experiences, background, culture, religion and language, without being judged.

NKS would prefer the fund was an all-age fund covering children and adults. They report that their activity in this area has generated interest from the South Asian community which is frequently from the parents of autistic children. They signpost to other organisations in these cases but feel that there are not necessarily culturally aware organisations to signpost to.

The lack of research and understanding about the experience of people from Black, Asian and minority ethnic groups means it can be harder for autistic people in these communities to get the support they need [1]. Both community and autistic organisations supporting autistic adults do not necessarily know what support works for minority communities and their wider family network, or how to provide it.

[1] www.autism.org.uk/advice-and-guidance/what-is-autism/autism-and-bame-people

Conclusions

This portfolio is meeting a wide range of needs; responding to different intersectionalities and considering how to make sure support is person-centred and neuro affirming. Conclusions are drawn at this stage from the themes outlined above.

Adapting support delivery

The portfolio can be flexible and adaptable which is essential to meeting individual needs.

Increasing one to one support

Projects are adapting their approaches based on learning and have increased the provision of one to one support, as they have found this is often required before participants will engage in group work.

Ongoing support

As is the case with all wellbeing support and services, it must be clear and accessible what is available to individuals and families and how to access it. There is still much more to be done nationally to improve awareness and accessibility of support.

Staffing

Autistic delivered support is well received but we need more evidence about the components of effective support and how to deliver it. This will be important evidence from the external evaluation.

Supporting autistic adults with a learning disability

Portfolio organisations providing this emphasise the need for specialism and for sharing practice across the sector.

Relationships with Health and Social Care Partnerships

There is a severe pressure on the health and social care system. This makes it more vital for the third sector and statutory sector to work better together and for the steps to do this to be clear.

Rurality and transport

Online support works well for some autistic adults but cannot be the default offer in a rural area. There is a need to look at ways to offer in person support in rural areas and in future project budgets need to incorporate more support for travel.

Minority ethnic autistic adult support

Trusted community organisations play a key role in developing practice and support. Responding to autistic intersectionalities requires input from a range of different organisations representing different communities.

Type of organisation:

Autism support organisation

Project offer:

Adult drop-ins, blocks of interest-focused groups and to support independence skills. Training sessions to parents of autistic adults and specific one-to-one support.

Background

J has been in the groups at HOPE since he was a boy. He has always loved being involved in the organisation and was delighted when we launched adults' services, and he could link back in. J attends the over 18s gaming group, walking group, cooking and chat and chill sessions.

Support

J joined the programme for social opportunities, fitness activities and to increase overall confidence. He has enjoyed the change to engage in activities that align with his interests such as gaming, walking and cooking. He joined with a goal to improve his fitness and to develop further person and professional skills.

Progress

Since joining the groups J's confidence has soared. Our CEO, was invited to an event at the Glasgow Warriors and asked if he would like to go with her. He accepted and also provided our CEO with all the information regarding where they should get the train, the trains times and how long it would take to walk there. He was delighted to have the opportunity to share with Glasgow Warriors what could be done to make their stadium and the matches more accessible for autistic people.

A few months passed and J started volunteering at the walking, cooking and gaming groups. He comments that he "loves it here" and is a great role model to younger people attending groups. Some group assistant hours became available, and we asked J if he would be interested in applying. He completed the form with support and took part in an informal interview. He got the job and is now working 4 hours a week to support our cooking and gaming groups.

Future plan

Going forward J plans to continue his role as a group assistant and we are hoping to offer more hours as he becomes more confident and settled in the role. We are proud to have a pathway in place for autistic people who attend our services. J's story has shown how our groups can change lives by increasing confidence, wellbeing, acceptance and providing a strong sense of belonging and community.

Type of organisation:

Services for South Asian women and their families to collectively address issues of concern to them living in Scottish society.

Project offer:

Support for autistic adults and their families in South Asian communities, to help address issues arising out of low knowledge and understanding of autism using suitable methods of engagement that are culturally sensitive. Reaching out to grass root communities.

Background

An autistic individual was isolated and experiencing loneliness as his family has limited community connections. His mother approached NKS for support to find ways for her son to engage socially and build connections.

Support

We recommended that he should join the NKS men's group. His mother agreed, and soon after joining, he formed a close bond with a volunteer, who is also autistic. When this autism focused project started, the young man eagerly participated with his mother's encouragement. The individual joined the group to connect with others, build friendship and reduce loneliness. His mother sought for her son to overcome isolation, build confidence and become more independent.

Progress

After four months of participation, his mother felt comfortable enough to leave him at our Young Autistic Adult group independently to enjoy the board games and adult colouring session. He was able to choose the activity he wanted to try without being told what he should do. He felt happy and relaxed, which marked a significant milestone. His artistic and creative side was encouraged and is now also attending a further class to improve skills. This progress helped build his mother's trust and confidence in NKS, and now he attends regularly, having made friends and becoming much happier. With this funding, NKS was able to create a dedicated autism focused project that not only provided a welcoming space for the young adult but also fostered trust and confidence within his family. This support made a significant impact, helping him form friendships, experience different activities, leading to self-improvement and independence.

Future plan

The individual will continue attending the NKS groups and is now comfortable and engaged. It is essential to continue offering such transformative programmes, that create meaningful change that strengthen community connections and improve the well-being of individuals and families.

Type of organisation:

Neurodiversity support, education, advocacy and research.

Project offer:

Support to young adults between the ages of 16-25. Where needed, also support the families and carers of autistic young adults.

Background

H has a diagnosis of autism and ADHD, receiving a diagnosis at 16. H felt he was diagnosed by medical staff and then they left him to deal with this without providing knowledge and support to understand what this meant for him. H is keen to understand his neurotype. H lives at home with his parents and currently is not in education or in paid employment. He volunteers at an animal sanctuary as he prefers to work with animals. A previous volunteering experience in an office was not successful as H found the staff, and the instructions they gave, overwhelming. Mostly H stays at home with little social outlet. Currently H is trialling bus training with his parents but likes to travel with them and not independently.

Support

H expressed a desire to understand his diagnosis and develop strategies to manage his life. At the first meeting he said, "I want to have strategies to survive the world." Over six meetings, we've worked on various topics, providing resources and discussions on autism and neurodiversity.

The sessions covered: understanding autism and neurodiversity, and how it impacts H's life; sensory experiences and how they relate to his work environments and future career options; communication differences and strategies to aid his interactions;

managing anxiety linked to sensory experiences and executive functioning challenges; identifying executive functioning difficulties and ways to improve organisation; and understanding reasonable adjustments and how to ask for them.

Progress

Since getting involved in the project H has a better understanding of his autism diagnosis and the impact it has on his life. He has created a profile of his strengths and sensory needs to help manage his environment and navigate certain situations. This is a profile he can share to build understanding among those who may work with him in the future. Additionally, H reported an increasing understanding of what to expect from a situation and what strategies he can employ to manage his anxiety. H said he is feeling more confident about who he is, the skills he has and what adjustments he can ask for. He said that in a short time he is feeling a bit more confident about asking for adaptations and adjustments to support his sensory and communication needs.

Next steps

H is becoming more confident in his abilities and is thinking about new volunteering opportunities. He plans to continue building on his coping strategies, particularly related to work environments. He is also considering applying for Adult Disability Payment (ADP) to help with paying for hobbies, gym classes, and other activities that will support his independence and wellbeing. As we continue working together, H will focus on strategies for managing anxiety and executive functioning challenges to expand his independence and explore new opportunities in both his personal and professional life.

Type of organisation:

Support provider for adults with additional support needs.

Project offer:

An Autism Family Support Practitioner provides direct support to families and autistic people. Weekly drop-in sessions that focus on wellbeing.

Background and support provided

M was referred to the project through her care manager. She has Down's Syndrome, is nonverbal and was experiencing a deterioration in her mental health and new behaviours as a result in recent reductions in her support and changes to routine. The family were under increasing pressure and concerned about the changes in M. M was referred by her care manager to receive support aimed at improving her wellbeing and to assist in securing a diagnosis of autism. This was identified as a key step towards supporting M.

M's personal aims for the project were to:

- Improve her wellbeing through targeted drop-in groups which focus on emotional and physical wellbeing.
- Support the family in securing a diagnosis of autism and making the necessary changes to support skills development and independence.
- Signpost to groups and activities to build skills, confidence and a positive future.

Progress

Since being referred to the project, M has been involved in two drop-in sessions per week - one focusing on art and expression and building a sense of self image, the other around yoga, movement and wellbeing. Her family have attended two one to one sessions. M has made noticeable progress with the project, M's mum said:

“There is no doubt that the connections, support and routine of the drop-in sessions has had a positive impact on M's mental health, mood and behaviour. She has demonstrated a real talent for art and expression and for the first time in many years, she has vocalised and improved eye contact and emotion. We are so proud of what she has achieved and moving to secure a diagnosis has helped deepen our understanding and help map out next steps for M and her future.”

Next steps

The next steps for M will involve continuing the drop-in sessions, which have proven to be beneficial for her mental health and personal growth. The family is working towards securing a formal autism diagnosis, which will help tailor future support to better meet M's needs and support her independence. The family will also continue to access activities and resources that can further build skills and confidence.

Type of organisation:

Autistic led organisation for autistic women, girls and non-binary people

Project offer:

Programme of autistic-led support this includes a pre-diagnosis group, post diagnostic courses, wellbeing webinars, one to one support, short term counselling, an accessible introductory video and a post-diagnosis handbook.

Background

I found out about SWAN through researching autistic support for women in Scotland. As a late discovered Autistic I had, and still do, have a plethora of questions on my journey as my authentic self. And at the time, unable to leave the house all previous attempts to attend groups hadn't been successful.

Support

The support which I have received from SWAN has been lifesaving, life-affirming and absolutely given with 1000% compassion, and understanding in an informed and pragmatic manner.

I received psychotherapeutic/counselling support which was funded by SWAN in their counselling service. This has given me the force and conviction to move forward in my management of the vagaries and nuances of ASD. This as well as weekly post-diagnosis support groups, direct access to a member of SWAN via email, and information available via the website and webinars have all provided me with the tools to work towards a more balanced and fulfilled life.

"SWAN has helped me more than I could have imagined."

Progress and future plans

I have managed to work on going outside my home more, previously impossible. I have commenced therapy with a new therapist after 20 sessions funded by SWAN. I am also due to start a Lifestyle Management course next week. This is all very new to me. Previously, impossible for me. Today, I am way more optimistic about my life that I was one year ago, and for many, many years previously.

I think SWAN effectively use all available tools to communicate and support autistic women. I would like to see more representation of the Autist perception of all around them as, in the main, it really is quite wonderful.

Thank you SWAN for helping me appreciate my life as an Autistic woman and bringing colour and light into my life, for that, I shall be forever grateful.

Appendix - the fund organisations





Autistic Adult Support Fund

INSPIRING SCOTLAND

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