Waiting Well

Improving people's access to support whilst waiting for an Autism assessment

Who we are

The Sheffield Autism Partnership Network (SAPN) is a network of organisations from the voluntary, social enterprise, public, private and statutory sectors who work with and for Autistic people, as well as Autistic individuals and their support systems (parents, carers, friends, partners, etc.). We share a vision and passion for a Sheffield where Autistic people can thrive.

SAPN is chaired by the Autism Partnership Lead at Voluntary Action Sheffield (VAS), a values led organisation dedicated to delivering our purpose of supporting people, communities and the Voluntary Community, Faith and Social Enterprise (VCFSE) sector to lead positive change – change that really matters to local people and will help them get the best results now and in the future.

What we did

In collaboration with Sheffield Adult Autism and Neurodevelopmental Service (SAANS) - the NHS service responsible for diagnosis in Sheffield - Voluntary Action Sheffield and The Sheffield Autism Partnership Network carried out a 6-month pilot project aimed at improving the experiences of people who are on the waiting list for an Autism assessment in Sheffield. We worked with a group of Autistic people to develop the project concept, and identify the priority groups we felt were particularly in need of support: people of colour; LGBTQ+ people; women and marginalised genders; and non-speaking people.

We partnered with 6 organisations, who were chosen to be part of this project due to their experience in providing wellbeing and practical support to people across a variety of communities in Sheffield, alongside their commitment to making their services accessible and friendly for Autistic people or those experiencing challenges that are associated with being Autistic. The organisations were granted a portion of the funding to improve their capacity during the project delivery period. They also completed training to upskill them on: their knowledge of Autism, particularly for the identified priority groups; statutory support such as benefits, access to work etc.; and other support which people can access before a formal diagnosis.

Over the course of March-August 2024, these organisations offered support to anyone in Sheffield who was waiting for a SAANS diagnostic assessment, to provide them with support and advice to help improve and maintain their wellbeing.

Recommendations from this project can be found at the end of the report.

Why we did it

The waiting list for an Autism diagnostic assessment in Sheffield is 15 months, at time of writing – at the time that the project was commissioned, this waiting time was around 14-16 months. The NICE guidelines state that nobody should wait longer than 13 weeks (approx. 3 months) for an assessment.

Organisations in the Sheffield Autism Partnership Network began reporting a marked increase in people using their services whilst waiting for an assessment. They noted that people were reaching crisis point during their waiting time due to a lack of sufficient support before they get to the front of the queue.

Autistic people were included in the national suicide prevention strategy for the first time in 2023, and in Sheffield the suicide and attempted suicide data from the council showed an increase in people waiting for assessment either dying by suicide or attempting to take their own lives – with the length of the waiting lists often being referenced in the first responders' notes.

This information was fed back to decision-makers as a cause for concern for neurodivergent people in Sheffield.

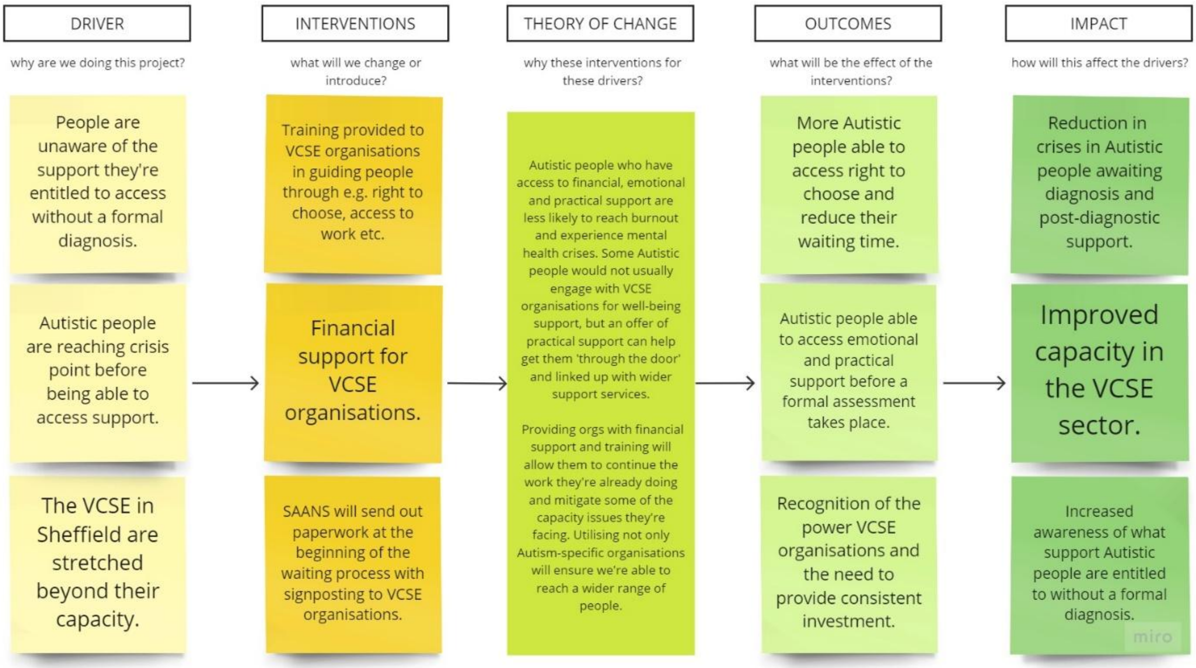
Reducing the length of the waiting list would require significant investment in SAANS, to allow for the recruitment of new diagnosticians to carry out assessments, so this project was commissioned as a way to connect people with support to help mitigate the impact of the long waiting period on their mental health and wellbeing.

How we did it

A project group was brought together, made up of the Autism Partnership Lead from VAS, two representatives from SAANS and three Autistic lived experience consultants from diverse backgrounds: a graduate student from India, a non-speaking wheelchair user and his support team, and a woman working in the education system.

Using lived experience alongside data from SAANS, we decided on 4 cohorts which we felt were most at risk of not having access to the right kind of support whilst waiting for an assessment: LGBTQ+ people, people of colour, women and marginalised genders and people who are non-speaking or have alternative communication needs.

Below is the theory of change that was developed at the project's inception.



DRIVER why are we doing this project?	INTERVENTIONS what will we change or introduce?	THEORY OF CHANGE why these interventions for these drivers?	OUTCOMES what will be the effect of the interventions?	IMPACT how will this affect the drivers?
People are unaware of the support they're entitled to access without a formal diagnosis.	Training provided to VCSE organisations in guiding people through e.g. right to choose, access to work etc.	Autistic people who have access to financial, emotional and practical support are less likely to reach burnout and experience mental health crises. Some Autistic people would not usually engage with VCSE organisations for well-being support, but an offer of practical support can help get them 'through the door' and linked up with wider support services. Providing orgs with financial support and training will allow them to continue the work they're already doing and mitigate some of the capacity issues they're facing. Utilising not only Autism-specific organisations will ensure we're able to reach a wider range of people.	More Autistic people able to access right to choose and reduce their waiting time.	Reduction in crises in Autistic people awaiting diagnosis and post-diagnostic support.
Autistic people are reaching crisis point before being able to access support.	Financial support for VCSE organisations.		Autistic people able to access emotional and practical support before a formal assessment takes place.	Improved capacity in the VCSE sector.
The VCSE in Sheffield are stretched beyond their capacity.	SAANS will send out paperwork at the beginning of the waiting process with signposting to VCSE organisations.		Recognition of the power VCSE organisations and the need to provide consistent investment.	Increased awareness of what support Autistic people are entitled to without a formal diagnosis.

NB: we eventually decided not to include Right to Choose in the training and overall project aims, as this project was intended to focus on the needs of those on the SAANS waiting list – not on reducing the length of the wait.

Expressions of interest were requested from members of the Sheffield Autism Partnership Network via the network newsletter and some targeted conversations with organisations who are embedded in the priority communities. 6 organisations were chosen by the project group to take part in the project:

- Autism Plus
- Darnall Well Being
- Firvale Community Hub
- Percy Street CIC
- SACMHA
- Sheffield Voices

We wanted to make sure we provided a variety of options, not just those focused on Autism. From our past experiences and conversations, we understand that individuals from marginalised communities often don't feel safe or at ease when seeking support in environments where most service users don't share their experiences or identities, so it's important to offer support in spaces where people already feel welcome and comfortable. In particular, Sheffield Voices works with many LGBTQ+ neurodivergent people, Firvale Community Hub are embedded in an area with a large proportion of South Asian people, and SACMHA's main cohort are Black people. Working with these organisations alongside those with a more generic offer allowed us to reach into the priority communities whilst ensuring that there were enough choices for nobody to feel pigeonholed based on their identity.

5 training areas were also agreed by the project group:

- Autism awareness
- The gendered experience of Autism
- Communication differences and language
- Reasonable adjustments and Access to Work
- Suicide awareness and prevention for Autistic people

All but one training piece was delivered by an Autistic or otherwise neurodivergent person with expertise in the area and experience of delivering training. The suicide awareness and prevention training was delivered by a member of the Director of Public Health's Office at Sheffield City Council, who had an existing training package for this area which was adapted with help from the Autism Partnership Lead at VAS to ensure its relevance to Autistic people.

Social media posts, physical flyers and posters were made and distributed across the city to raise awareness of the project, with a particular focus on spaces like cafes, supermarkets, pubs, salons and hobby shops in order to try and reach people who were not already connected to voluntary sector support. SAANS also sent out signposting information to those accepted onto the waiting list during the delivery period, and to 500 people who were already on the waiting list.

Organisations were given a portion of the funding as a grant to help with their capacity for supporting more people, and asked to complete a monthly monitoring form to let us know how many people they'd worked with each month, and what kinds of things people were seeking support with. They were also asked to share anonymous demographics and feedback forms with the people they worked with, so we could better understand who was seeking support and how they felt about it.

At the end of the project, we hosted an in-person learning event, which brought together our partner organisations and other members of the VCFSE sector with an interest in addressing the needs of this cohort to talk about how the project went, and what is needed to continue supporting people who are waiting for an Autism diagnostic assessment. The findings in this report are derived from the feedback from the monitoring forms and the discussions at this event.

What we found out

Funding and investment

Short-term, competitive funding rounds mean that organisations have to focus on gathering data and statistics to secure future funding instead of being able to carry out in-depth, sustainable, appropriate work. Organisations are plugging holes in support, rather than actively addressing need.

One partner organisation said '*The support we can offer is deliverable but does come at a cost*'.

Additionally, communities of colour and immigrant communities often encounter stigma both within their communities and without, making it challenging for them to trust or engage with services. This highlights the need for additional resources for VCFSE organisations to be able to foster relationships and rapport in these communities.

Most of the partner organisations found that even after the delivery period came to an end, they were still receiving queries from people about the project offer. Some of them have been able to continue supporting people using other funding pots, but this is not a sustainable or efficient way to work in the long-term.

Another partner organisation said '*Further funding would help provide capacity to support people who may need more time to engage and feel comfortable. It allows us to adapt resources. It allows for following up on signposting to ensure that needs are effectively met and that barriers can be overcome*'.

Understanding and planning

It can be difficult for people to articulate what they need or want from support services because, before a diagnosis, individuals don't always have a clear understanding of Autism, or even a framework of criteria to refer to, to help them make sense of their own experiences or needs.

One individual who accessed support said '*It is really good that I am getting this support because I never got this kind of support and understanding before*'.

People waiting for an assessment often see themselves as being in a transition stage, so it's harder for them to make a support plan with services as they don't know what their next few weeks, months or even years are going to look like.

If people don't have easy and reliable ways to find out where they are on the waiting list and how long it will be before they're assessed, this becomes even more difficult – and can potentially create a barrier for them to even seek support in the first place.

A quote from one case study said: *T's extended family understand that he has been referred for an adult assessment some time ago, but are uncertain about when the referral was made, by whom and the process*.

Autistic people often experience 'waiting mode', whereby the anticipation of an event prevents them from engaging with other tasks or activities. Whilst this is most often referencing disruption to a single day due to an appointment in the afternoon, or waiting for a phone call with no specific time window, it can easily be extrapolated to see how people may find it difficult to engage with support services whilst waiting for an assessment appointment to be assigned.

The language around assessments was also highlighted as an area for concern. Using 'waiting for an assessment' or 'waiting for a diagnostic assessment' over 'waiting for a diagnosis' may seem trivial, but it helps to set realistic expectations, and mitigate disappointment or distress for the small number of people who do not get an Autism diagnosis from their assessment.

Barriers to support

Before the project started, we noted that people of South Asian backgrounds were more likely to drop off the waiting list than any other racial background, according to SAANS demographic data. Firvale Community Hub focussed on this group as they work with a large proportion of South Asian people in the Firvale area and highlighted some key barriers for this community.

- Language and communication challenges can make it more difficult to pursue assessments and navigate available services. There is a lack of culturally appropriate resources and interpreters to assist individuals in expressing themselves effectively and comprehending the technical terms used in healthcare.
- There is distrust within the community of healthcare and education systems. A history of being overlooked or misunderstood has led to hesitation in seeking support, and a lack of confidence in the system.
- There are often cultural barriers stemming from stigma or outdated beliefs within communities. Sometimes, medical advice is overlooked in favour of prayer, or individuals may be isolated due to shame or taboos surrounding neurodivergence.

These findings were also reflected in feedback from other organisations working with other marginalised communities, proving that this is not just an issue for South Asian people, but a wider issue of the ability of healthcare and awareness projects – and traditional Autism support spaces – engage with these cohorts effectively.

Equity disparity

People have described a 'lottery system' around whether schools, universities, workplaces and healthcare providers will put adjustments in place without a formal diagnosis, and even if they do, the level of difficulty people might face in getting them to do so varies.

One person who was unable to get occupational health support without a diagnosis said of the project: '*Over the past year, I've struggled with balancing my job and life in general. Attending the sessions has been a huge help… It's something I look forward to every week, and couldn't have discovered it at a more perfect time.*'

People's ability to advocate for themselves can often be influenced by factors such as race, gender, class, first language, and education level, which in turn contributes to widening the equality gap.

VCFSE expertise

Partnering with organisations who have embedded links with the priority groups allowed us to take advantage of their existing rapport to connect people with support more easily.

When asked why they chose the organisation they did, one individual who was working with Firvale Community Hub stated '*they understand the barriers and institutional racism issues that BME families experience*'. Another individual told Autism Plus '*I have also felt comfortable because my employment coach understood my needs and neurodivergent traits*'.

Combined with findings around marginalised communities feeling distrustful and apprehensive of services, or unsafe in spaces where their identity is not represented, this highlights how critical it is to recognise the expertise of VCFSE organisations with embedded relationships.

Recommendations

This project is tackling a significant issue that has arisen over the years due to insufficient funding and resources for both diagnostic services and the voluntary sector, alongside a long-term lack of awareness and misinformation about Autism. While this work is a positive step forward, it's just a small part of a much larger solution, and the sector needs continued investment to make a lasting impact.

- The needs of people who are waiting for an assessment differ in some significant ways to those who are post-diagnosis, and a solid piece of **engagement with those currently waiting for an assessment** is necessary to better define what this group needs and wants from support services.
- An accurate and accessible **way of finding out where someone is on the waiting list from the diagnostic service** is necessary to help people better plan and prepare during this transitional period.
- **A needs-led approach from statutory services** like education, work and healthcare would combat many of the practical issues people face while waiting for an assessment. To adequately address this, a huge culture shift is required, but awareness campaigns and reviews of processes and protocols where possible can help to start this change.
- It's important for **the VCFSE to diversify the spaces where Autism support is offered**. We need to meet people where they are and ensure that all services are accessible and beneficial for everyone who might need them, rather than assuming they'll go to the places we expect.
    - This applies not only to enhancing Autism support in organizations that aren't specifically focused on Autism, but also in other areas of identity within Autism-focused organisations. For instance, majority-white organisations should have the right knowledge and training to effectively engage with communities of colour, and majority-cishet organisations need to be well-equipped to support LGBTQ+ individuals as well.
- These **challenges must be tackled creatively**, using approaches that have shown positive results within those communities—especially considering the existing distrust in healthcare services and the lack of culturally appropriate resources, which can make it particularly difficult for healthcare providers to overcome these obstacles.
- The **VCFSE sector will be an invaluable resource** in this work due to their existing relationships and extensive knowledge on how best to work with marginalised communities.