

Post Diagnostic Support: A National Collaboration.

Author Charlene Tait

Autism
Initiatives

Autism
Understanding
Scotland

NASS
SWAN

ARGH
AMASE

Scottish
Autism
WHERE AUTISTIC PEOPLE
ARE VALUED



Charlene Tait has worked in the field of autism for over thirty years. In that time she has been engaged in direct practice and service development. She was Lecturer and Course Director in Postgraduate Autism studies at the University of Strathclyde and has been involved in a number of national strategic initiatives. Charlene's time in autism began in 1990 with Scottish Autism (then Scottish Society for Autistic Children), she returned to the organisation in 2011 to take up the post of Director of Development and is now Deputy CEO. Her main areas of interest are in family support and enabling quality of life and quality lifestyles for people across the autism spectrum.

INTRODUCTION

The need for Post diagnostic support is frequently referenced in policy documents and consistently sought out by autistic people and their families. Good quality, effective support is however very difficult to come by and there are few models of good practice that enable access to different supports across the lifespan.

BACKGROUND

Following a commitment from the Scottish Government to address post diagnostic support for autistic people and their families, Scottish Autism submitted a proposal that resulted in seven organisations being funded to work together to pilot a range of supports for autistic people, their families, and carers. These organisations included autistic led organisations and national autism charities.

Autistic Mutual Aid Society Edinburgh (AMASE): an autistic people's organisation whose goal is to help autistic people, to make each other's lives better through community events, peer support, advocacy and education.

Autism Rights Group Highland (ARGH): a collective advocacy, lobbying and campaigning group. Run by and for autistic adults. The ARGH committee and full voting members are all autistic.

Autism Initiatives: operating in a variety of locations across the UK, offering a wide range of support for autistic people.

Autism Understanding Scotland: an autistic led charity working to reframe the narrative around autism.

National Autistic Society Scotland: Provide a range of supports for autistic people and their families. Campaign at a national and local level to help create a society that works for autistic people.

Scottish Autism: dedicated to enabling autistic people to lead happy, healthy and fulfilling lives.

Scottish Women's Autism Network (SWAN): an autistic-led charity delivering services, information and support by and for autistic women and non-binary people across Scotland.

This blend of organisations meant that there was a wide range of services that could be offered including programmes of support to families of children, peer support delivered by autistic people and support for people who have a diagnosis in adulthood, often in later life.

A critical element of the work was that an independent evaluation conducted by AT-Autism was built into the process.

CHALLENGES

The service was established at the height of the pandemic meaning all offerings were online. Whilst it was recognised this could be a barrier for some individuals, there was no viable alternative however sensitive adjustments were made to accommodate people e.g. enabling participation without having the camera on.

Routing people to the most appropriate support: there was no single point of entry to the service. Information was available on the range of organisations and offerings via a number of websites. Each organisation also has people contacting directly. This relied on organisations signposting people between the various partners. This was not always successful and risked people feeling they were being passed on rather than supported at their first point of contact.

Organisations have different infrastructure & capacity: there is wide variability between the size and scale of the various organisations. Some operate nationally others more locally, although the online nature of offerings meant that all organisations were capable of and were expected to support people from all over Scotland. Three of the organisations are large, service providing national charities whilst the remainder are autistic led organisations of varying scale, some with paid staff some run by volunteers.

LEARNING & OUTCOMES

- Collaboration between autistic led organisations and national charities that support autistic people, and their families was crucial to delivering the range of services required. Whilst there can, at times, be tensions between organisations, this project was a demonstration of collaborative and partnership working that has benefited the community across Scotland.
- Importantly, the evaluation was constructed using a Delphi process which enabled each organisation to participate and identify the data that would be useful and meaningful to them individually as well as to the project collectively.
- The project commenced on 1 December 2020. In total 966 people have benefited.
- By July 2021 468 people had completed their programme.
- A total of 335 links to the evaluation were sent at this stage.
- 149 people responded to the evaluation giving a response rate of 44.5%.

Participants reported a high degree of satisfaction with the services they used.

COMMENTS FROM PEOPLE USING THE SERVICE:

"Would have loved to have had this service at the time of diagnosis. Instead, we were given a page of links to useful websites."

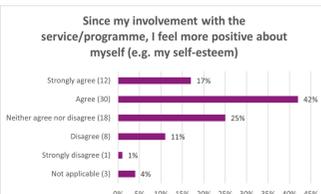
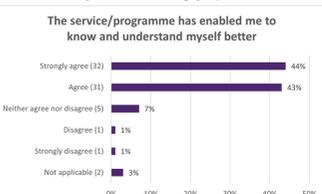
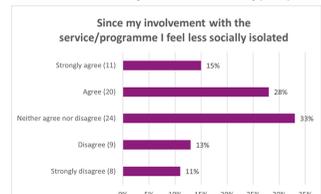
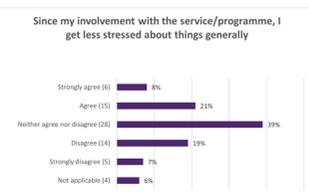
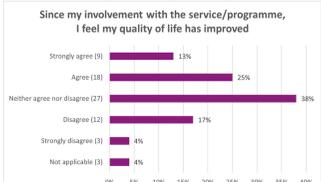
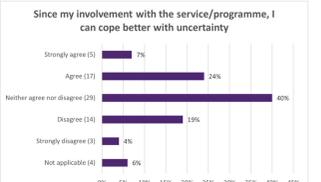
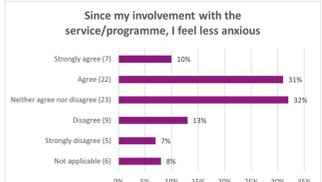
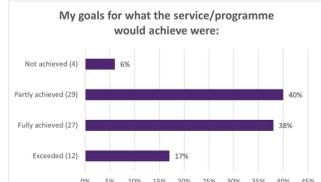
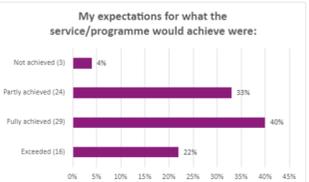
"I have found the post-diagnostic service to be a lifeline. I feel much more confident, and brave and can live life on my own terms in this world."

"The (post-diagnostic) support has been life changing. Don't feel alone anymore and really benefited."

"Some of the professionals I met before the final diagnostic meetings had very outdated information about autism. Particularly about women and girls. There were a lot of stereotypes. I was asked repeatedly why I wanted to be diagnosed and as I am able to mask well in public, I found this really upsetting."

"The service was brilliant throughout. Has improved my understanding of myself and others and my mental health has improved since attending."

RESULTS



Social isolation is a challenge for autistic people and their families in the best of times and was exacerbated by the pandemic. The social nature of some of the services and the connectivity with others was valued by participants.

It was gratifying to see a positive impact on wellbeing and reduction in anxiety of those using services, particularly at a time when society and services were in disarray and life for all was highly unpredictable.

WHAT DOES THE FUTURE HOLD?

Funding for the service has been extended until March 2023. The Scottish Government has recognised the value of this work to the community however the term "Post Diagnostic Support" is recognised to be somewhat of a misnomer in that there is no determined time period that can be recognised in this way. Rather that when a diagnosis is given, an individual or their family may need immediate information but access to support on an ongoing basis is likely to be needed and will change over time.