### Reframing Autism (Cohort 2):

# What did we offer and why?

Our plan was to develop our practice and model so that we could offer neurodivergent families across the region a longer term, relational approach that allowed them to become a part of a community of practice and advocate for other families with neurodivergence. For further insight into our earlier work with neurodivergent families, please click here:

https://youtu.be/7ykaLQhHTKc

We received £9480 from The Sir James Knott Trust to fund this provision.





When consulted, 77 % of families who accessed our earlier Reframing Autism programme said that long wait times for assessment, OT appointments and access to Play Therapy were their main barriers to improved mental health. Mental ill health within the Autistic community is disproportionately high.

After consulting with families, our provision was designed to provide the space, support and expertise that neurodivergent families are searching for, whilst enabling long term community connectedness and Identity. Our offer is a holistic service providing access to a play therapist, occupational therapist, an autistic advocate and therapeutically trained forest school practitioners. We are enabling autistic individuals to hold power and a space to embrace their

neurology, validate their strengths and create community connectedness through their Autistic identity, thereby improving overall mental health.

Funding from the Sir James Knott Trust was used to offer fortnightly sessions, using our internal team of forest school practitioners and therapeutically trained staff, alongside a multi-disciplinary team (Occupational Therapist, Play Therapist) to best meet families needs.

We offer longer term support to families as we develop our intentional community of practice and support. It is our intention to keep learning and developing this work for the long term, learning from the lived experience of neurodivergent families and evolving in response. We meet families wherever they are on the journey and then accompany them together to not only help share the load, but allow them to take power for themselves and shape what they need for their family, thereby improving outcomes not only for an autistic child but for the wider family unit.

We therefore delivered 2 sessions each fortnight, one in the morning for new families (cohort 2), and another "Reconnect" session in the afternoon for cohort 1 families to continue on their journey.

### 1. Who delivered our offer?



We worked with the following Autistic advocates and crafts people throughout the programme, who attended as 'guest speakers' and 'workshop providers'. All of our guests were autistic and ran their own organisations. Some delivered workshops on neurodivergence and others delivered skills development workshops.

The purpose of these guest speakers was to help children, young people and families see themselves as successful people in the future, by acting as role models and sharing their own neurodivergent journeys.

Our guest speakers included:

#### PANDAs online:

Nic is the owner and creator of NeuroBears the only online course for autistic children. They work internationally as an autistic trainer, consultant, and researcher. Nic is passionate about young people understanding their autistic identity at a young age and creating environments where they can feel happy, comfortable, and safe. Her areas of interest are sensory systems and burnout.

Nic has personal and expansive knowledge and experience of 'the system' that families face and works within and without it to try and help the next generation of autistic people and their families. My passions are Pandas, cats, musical theatre, and the outdoors. Nic was diagnosed autistic fairly recently in 2021 but had self-identified a long time before diagnosis, she is awaiting ADHD assessment and was diagnosed with dyslexia as a young adult.

# ZAP advocacy:

Z was diagnosed autistic in 2014, they have significant sensory needs and ADHD. They have been an autistic advocate since 2020 and have spoken at 6 international conferences, to date, delivering various training to many local sectors mainly concentrating on making sensory safe places for autistic people.

They work with various local businesses, local authorities and charities helping give young autistic perspectives on their policies and access documents. They are a young leader at

Stomping Grounds Forest School. Their passions are autism, education, musical theatre, gaming, and coding.

### Sylvan skills:

"I wasn't diagnosed as being on the autistic spectrum until I was 49 years old. I work with willow and hazel coppice, making structures and sculptures. A lot of my work is with community projects and groups, 'though I also have some commissions by individuals. I am aware that willow weaving can be therapeutic for myself and others who are neurodiverse.



I have a lot of support from 'This is Me' an employment agency in Consett, through the Department of work and pensions 'access to work' programme. I get help with coping with sensory overload and also help with processing information, for instance paperwork, also with executive function. This help has made me more able to run a business and have more confidence in my abilities. I do work quite a lot with other people who are volunteers or whom I employ.

I find it easier to work with a team on large practical projects. I have had four trainees who were all on the spectrum, through access to work. They have all gone on to self-employment, one as a gardener, one as a leather worker as a Greenwood bowl Turner, and one as a manager of a community garden project. Because I am self-employed, I am in charge of my own diary, so I build in time to rest and recover"

#### **Spectrum Gaming:**

"I'm an autistic adult and the founder of Spectrum Gaming, a charity that supports over 1,600 autistic young people across the UK. Spectrum Gaming was created to provide a space where autistic young people from across the UK could develop friendships in a safe community, in response to the loneliness and isolation that many experience.

As well as running the online social community, I lead a forest school for members, frequently deliver autism training and I am passionate about advocacy work with autistic <u>young people</u>. 2023 saw the launch of our co-produced website <a href="https://autismunderstood.co.uk">https://autismunderstood.co.uk</a>, a resource about autism created especially for autistic young people. I'm really excited to meet you all!"

### **Unite Club:**

Katie Toner is an autistic/ADHD advocate and owner of UNITE CLUB. Katie lives in Northumberland and was featured as part of the BBC folk North East Project - with the song "A dream for you" written about her life as a neurodivergent person. Her passion is creating

inclusive spaces and supporting the community to embrace and understand neurodivergence. She loves all things sensory regulation and can often be found under her weighted blanket watching RuPauls drag race for the 1739373th time, eating her safe food. (Sound familiar anyone...)

Katie will be running a workshop discussing life experience as a late-diagnosed autistic person, understanding the 8 senses and communicating our sensory needs. She will also run a hands-on sensory exploration activity.



### **North East Autism Society:**

NEAS is a local charity, "Recognised for our innovation and excellence, everything we do stems from an unswerving belief in providing bespoke person-centred support. It's at the heart of who we are to recognise the uniqueness of every human being, and to understand that no two autistic people, or in fact any humans within an understanding of neurodiversity, will have the same needs or wants."

# **Shannon Berry**

"I'm Shannon, a green woodworker based in the North East. I work in the worlds of heritage crafts and woodland management, continually developing my skills and engaging with a wide range of people along the way.

Being recently diagnosed with Dyslexia, Dyspraxia, Autism and ADHD (I know, deep breaths!), I now realise I am a part of a world where neurodivergent people need support and recognition. I want to help change the narrative; to promote acceptance and understanding towards how people like me process information and be a voice for that community through my business and as a maker.

As a maker I want to have fun, explore, learn and above all... create. It has taken me a long time to give myself permission to be creative and explore craft. I hope to inspire others to have a go and have fun while doing so."

In addition to the offer in person at the woods, we pursued sustainability of this support by establishing a WhatsApp group for the purpose of connecting families when not in sessions. This group was for parent/carers to ask questions about sessions of others who had attended previously, to connect with one another outside of the session, and to potentially foster longer term friendships across families and enable support for one another.

### 2. Who attended?

**21 families** (**70** parent/carers and young people) were given a space at Reframing Autism for this round of funding. We offered **10 sessions between March and July 2024**. Attendance at each session was variable, with a maximum of 48 people and a minimum of 18 attending a session. 2 families (8 people) withdrew from the group.







## 3. Evaluating our offer

Stomping Grounds North East distributed an online survey after this cohort had completed 10 sessions to gather parent/carer perspectives on our offer, to reflect on our model of delivery, methods of communication and the impact of our sessions upon participants. 8 parent/carers responded and their contributions are shared below.



### 3.1. Specialist support

All 8 respondents confirmed they had benefited from the support of an Occupational Therapist and Play Therapist. Specifically, gaining practical guidance to action with their child, an understanding of autism and their caring approach was noted.

"We got so much advice from all the professionals that we could take away and put into practice. It was also just great to have someone there to listen to us and understand what we were going through."

"Having people who completely understood autistic kids was so refreshing as you could tell they really cared and weren't just reading

from a script / text book. Some of the advice has worked so well for our family and has given us a different insight into things we do and how we can help our son."

"We had so many great conversations and got some fantastic tips and information relevant to our child and family."

"...they seem really knowledgeable and are genuinely lovely people."

Some respondents identified difficulties around receiving the support they wanted whilst also caring for their child in session; for example:

"I would have liked the opportunity to speak more with both therapists than I did, but it was tricky trying to talk to them whilst also seeing to my son's needs."

7 of our respondents said they had benefited from the sessions where we invited a guest to run a workshop. This included: Pandas Online, Zapp Advocacy, Sylvan Skills, Spectrum Gaming, Unite Club, North East Autism Society, and Shannon Berry.

Overall workshop guests were highly valued by respondents, specifically when they had lived experience:

"Katie Toner (Unite Club) was great at showing how an AuDHD adult can create a life and job they enjoy that works for them. Z was a brilliant role model to show you don't have to let neurodivergence hold you back."

"It was great to see autistic adults leading sessions and doing what they love - great role models for the children but also gave us parents hope for the future for our kids."

"...it was great for my son to meet neurodivergent adults who are happily following their passions."

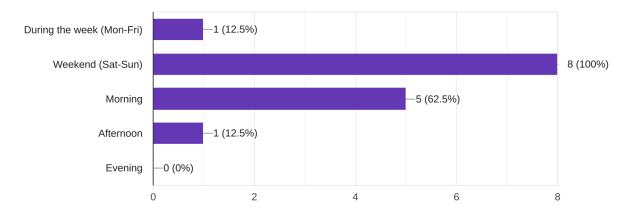


Only 1 respondent commented on the benefit of workshops to them as an individual, perhaps due to the earlier note about participants needing to care for their child whilst in session.

"I appreciated having the space to try new things like willow weaving"

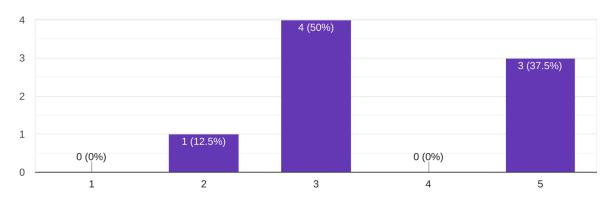
# 3.2. Session logistics

All 8 respondents said that the size of the group session was 'just right'. Most respondents preferred a fortnightly session (6), with 2 preferring a monthly session.



willingness/ability to make a financial contribution to future sessions. 6 respondents said they would consider a financial contribution; 1 said 'maybe'; 1 said 'unable to at this time'.

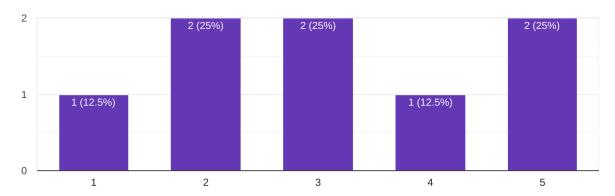
The WhatsApp group we established for the purpose of connecting families and enabling sustainable impact was rated by respondents. This group was for parent/carers to ask questions about sessions of others who had attended previously, to connect with one another outside of the session, and to potentially foster longer term friendships across families and enable support for one another. Respondents rated it 1-5, from very useful (1) to not at all useful (5).



Responses were mixed; 2 people forgot it was there, 3 had not known about it, 1 person felt it was not the right forum for them, and 2 commented it was not particularly busy. Moving forward, consideration of preferred modes of communication for each family could be offered. 2 respondents described difficulty around accessing content; for example, "I find group chats a bit overwhelming at times so I didn't join. In hindsight, it probably would have been helpful." One parent suggested a reminder about the WhatsApp group during a session would have been useful for them:

"I must've missed the info about it in the initial email. A reminder at the sessions would have been useful as I struggle to read long emails. I would have definitely been interested in using it though. Particularly the time when I turned up on the wrong week."

We asked respondents to rate the usefulness of the Young Person's Passport, from very useful (1) to not at all useful (5).



Feedback from respondents focused on forgetting the passport was available from session to session; it would be useful for participants to be reminded of the core offer and support mechanisms during each session. 2 respondents commented that it was difficult to find online. 3 respondents commented that they forgot it was there, but had found it to be a useful way to share information about their child initially. 1 respondent explained that their preference was to engage with the professionals in person in session and this is what they most benefited from, particularly when they "...don't have a lot of time to complete forms - we are constantly filling them in for assessments etc.".

# 3.3. Attendance



We found that turnout for this cohort of Reframing Autism was lower than previously experienced; when asked for feedback 7 respondents had attended 7-9 sessions and 1 respondent 4-6 sessions. Some respondents explained pre-booked commitments made attending all sessions impossible. Other respondents shared valuable insight into why attendance was not always possible for their child:

"Sometimes [our child] just didn't want to go and we didn't want to force him."

"We missed the first 2 because [our child] was in complete burnout and struggling so much with school."

"Sometimes our child just didn't want to attend that week and we didn't want to upset him by making him attend."

"My children see their dad at weekends and he doesn't live locally so it was difficult to make all sessions."

# 3.4. Expectations and suggestions moving forward

When we asked our respondents whether our Reframing Autism session met their expectations, 6 said 'yes' and 2 said 'somewhat'. Feedback largely focused on the benefit to the whole family unit; for example:

"We have absolutely loved these sessions and they have made such a difference to not only our son, but to us as a family. We don't have many places we feel we can go, and most forest schools just aren't set up in the way that meets the needs of autistic kids (or allows parents to stay over the age of 5). We were all so sad for it to end! Thank you so much for giving us a space."

"[Our child] wouldn't leave our side on the first session but by the end of it he was exploring completely independently and looked forward to the sessions each time."

Respondents also shared some ideas about how their experience could be improved. For some, finding opportunities to have confidential conversations with OT/PT would be beneficial:

"Difficulty in watching my child and also talking to the guest/therapists at times, as you don't always want your child to hear what you are asking them about."

For others, the size of the group had an impact on their overall experience:

"The first session seemed quite busy . We preferred it when the group was smaller through non attendance as it gave us more time to chat to other families and guest speakers."

Another respondent would have appreciated a clearer understanding of who could participate in workshops:

"Really disappointed with gaming person as our son got really excited then was told it was only for Manchester residents. Hard to explain he couldn't join."

Finally, one parent/carer requested a similar offer to Reframing Autism, but for families of adopted children. In response to this recognised gap in provision, we collaborated with Through The Trees CIC, on a project funded by the National Lottery Community Fund. We offered Family Forest Days as one-off events with the aim of providing families with adopted or looked after children an opportunity to get outdoors into nature together, to experience the



benefits of nature-based interventions and create connections in a supportive, accessible and safe environment.