

# ND Subgroup Newsletter

Edition 1  
December 2023

Edition 2 due  
April 2024

Welcome to the first newsletter of the Neurodevelopmental (ND) Subgroup which aims to share how our work is moving us towards our aims, in a way that is informative and accessible for families, young people, staff and stakeholders.

*There is a link to give us feedback at the end so please use this to help make sure future communication works for you.*

## A quick introduction

In case you are reading this and haven't been part of discussions so far, we are the Neurodevelopmental Subgroup of the D&G Children's Services Plan 2023-2026. I am Joanne Service and I am chair of the subgroup with Sharron Harper vice chair. Our subgroup will be working on shared aims over the three years of the plan, to improve the provision in Dumfries and Galloway for children and young people with Neurodevelopmental differences and their families.

Our group includes people from NHS D&G, the Council, Education, Social Work, Quarriers and the Carers Centre. We also have a newly formed family engagement group who will help make sure everything we do has children, young people and families at the centre, designed with them for them.

Our group has three broad ambitions.

1

Neurodivergent children and young people will have their educational entitlement provided in settings skilled and equipped to support them to achieve their potential

2

Children and young people with Neurodevelopmental Disorders will have access to diagnostic assessment to enable them and their families to have a secure understanding of the differences of their brain, their strengths and their support needs.

3

Children, young people and their families will feel supported in Dumfries and Galloway as part of a system with the child and family at the centre.

We have a working group for each of these aims and you will find out more about what we have been doing on the next pages.

Thank you for reading. **Joanne Service, ND Subgroup Chair**

## At a glance:



- ✓ ND Subgroup has formed
- ✓ ND working groups have also formed
- ✓ Family Engagement Group had their 1<sup>st</sup> meeting
- ✓ Highlight report shared with the Children's Services Plan Leads
- ✓ Workshop with Teachers at their "Sharing Practice Festival" at the Bridge
- ✓ Family engagement event hosted at the Bridge
- ✓ All feedback collated into a report
- ✓ NDAS progress and waiting times reported to NHS Board
- ✓ ND Subgroup chair and vice chair contributing to plans for Education Consultation with families
- ✓ Support Working Group meeting to create proposed actions from family feedback
- ✓ NDAS progressing self referral route
- ✓ National ND Affirming Community of Practice joined.

Joanne



# Family Engagement Group

We put out an offer to families to join our family engagement group. This group will be the eyes, ears, hearts and minds of the ND Subgroup and bring the family and young people perspective into the actions and activity of the working groups.



The group met for the first time in August 2023 with 4 members. Feedback was really positive and the group began planning how to form and grow to be inclusive and representative of families across D&G.

Our families told us:



The group attended the Family engagement session and did a fantastic job of recruiting some new members. **Alison Telfer, CAMHS Participation Lead** will facilitate this group with a Closed Facebook Page as their virtual "home". All families who expressed an interest, will be invited to join this closed group and plans will be made from there.



## ND Affirming Practice

One of our priorities is that the knowledge, skills, vision and ambitions we bring to this work reflects current best practice. This will see a move for providers of services and support to model a culture that is ND affirming. This brings important changes in thinking and practice and brings us in line with National groups who are advocating for change in the way Neurodevelopmental differences are understood, reported and supported. To help make sure we are well informed, the leads of each working party have joined the National ND Affirming Community of Practice and will join their first session in December in Glasgow to hear more.



For more information about becoming neuro-affirming, see NAIT's November 23 newsletter. [NAITNewsletter \(thirdspace.scot\)](https://thirdspace.scot/NAITNewsletter)

# Education Working Group

The working group has been formed with group members representing early years, primary, secondary, additional support for learning and Autism Outreach. This group are helping us work towards ambition 1.

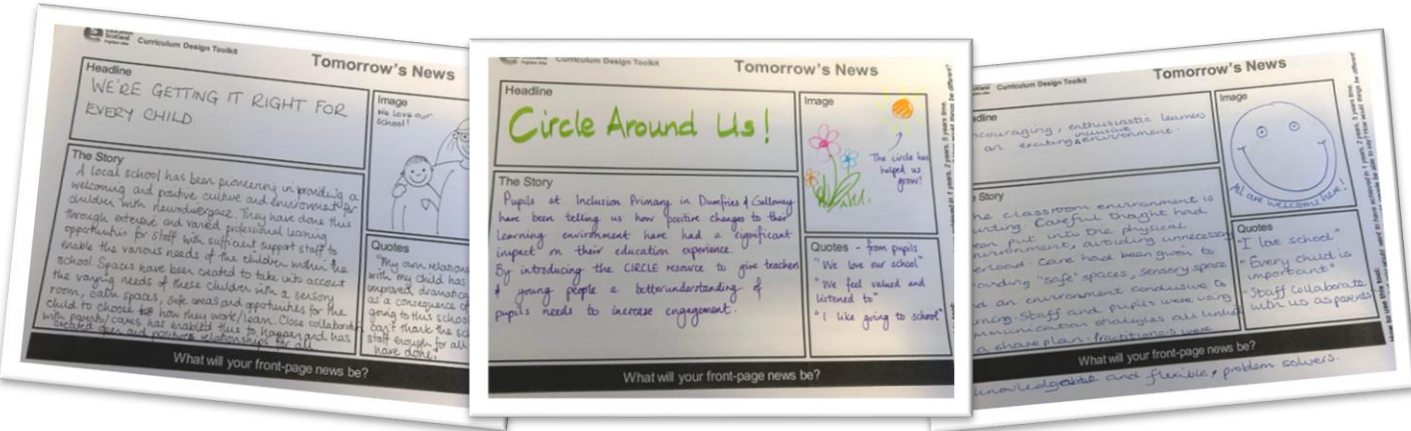


1

Neurodivergent children and young people will have their educational entitlement provided in settings skilled and equipped to support them to achieve their potential

The group is chaired by **Sharron Harper, Depute Principal Educational Psychologist**

We presented to over 60 teachers at their Sharing Practice Festival at the bridge and asked them to write their news headline for a year's time. The aim of this activity was to pull out the things that are important to teachers before we start planning how to support our schools on their Improvement Journey. Staff shared some beautiful headlines and highlighted the importance of children and young people feeling included and accepted, enjoying coming to school and school environments feeling knowledgeable and supporting for our young people with Neurodevelopmental differences.



We contributed to plans that are under way in Education to undertake a wide consultation around Education Provision for young people, specifically Autistic Young People. Although this consultation sits within Education, by working together we will be able to benefit from the themes that come from this from families and young people and include them in our improvement work.

## Exciting areas for development:

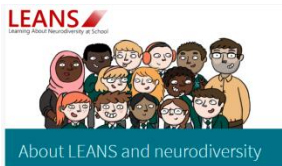
Scerts was promoted by the Scottish National Autism Implementation Team (NAIT) in 2021 with teams across Scotland trained in this framework. Dumfries and Galloway have a Team trained in Scerts and planning how to develop and scale up this framework in D&G will be an area of priority.

[SCERTS description copy](#)



LEANS (Learning About Neurodiversity at School) is a ready made, free programme available from The University of Edinburgh Salvesen Mindroom Research Centre. NWCC have a LEANS Champion so developing the use of this programme across schools will also be explored.

[Learning About Neurodiversity at School \(LEANS\) | Salvesen Mindroom Research Centre \(ed.ac.uk\)](#)





The Neurodevelopmental Assessment Service was developed as part of the 2018-2021 Autism Strategy but has carried over into this plan so we can continue to improve and monitor the progress of the service. **Dr Fiona McCrohan** chairs this group and is the NDAS Clinical Lead Psychologist. This group are helping us keep working towards ambition 2.

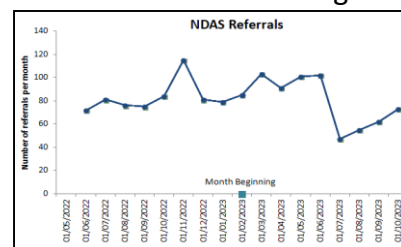
2

Children and young people with Neurodevelopmental Disorders will have access to diagnostic assessment to enable them and their families to have a secure understanding of the differences of their brain, their strengths and their support needs.

While the NDAS pathway has been approved for some time, it has taken time for the team to form but we have recently completed recruitment and new team members are currently completing their induction and additional specialist training. The service currently has 30 days per week of protected time (6.0WTE) from an NDAS Clinical Team of 11 clinicians.

A really important part of our journey to NDAS was keeping the door to assessment open while we got the service ready. This aimed to stop children “slipping through the net” and help the team by having a clear idea of the number of referrals we would get each month. This has shown us that we get an average of 81 referrals every month and gives us a clear idea of the demand for NDAS.

All referrals begin with screening to check that the NDAS pathway is recommended for the child or young person. Families provide information to allow the team to screen and when complete, a letter is sent to the family and referrer confirming next steps.



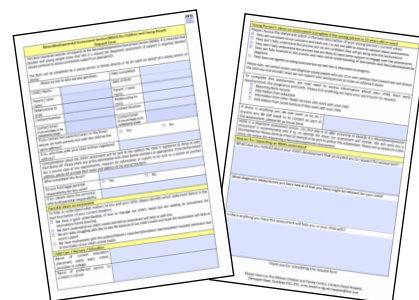
For children and young people added to the waiting list, waiting time this is currently around 85 weeks. We know that waiting causes worry, frustration and presents risks for some young people so we will keep working to reduce our waiting time.



In April 2023, we moved towards an **open referral system** for NDAS. We were clear from families that old processes caused barriers to accessing diagnostic assessment for families and young people. We moved to a standard request system that is the same, whoever completes the request. So whether a family go to the GP, speak to school, attend a clinical appointment, mention is to a professional they are seeing or self refer directly – all options take them to the same place, our NDAS request form.

This has been tested with families to make it as easy to fill in as possible while making sure the NDAS team get all the information they need to complete screening.

Finding a way to make this form accessible online is a priority for both improving access and efficiency but for now, it can be requested by emailing [dg.nd-requests@nhs.scot](mailto:dg.nd-requests@nhs.scot)



We have asked families who have chosen to self refer, to give us feedback. So far 22% have responded and overall, they rate the self referral process 7.5 out of 10 although 1 person rated it 1 out of 10 and 5 people rated it a 4 or 5 so we definitely have room for improvement.

**Families gave us some very useful ideas for improving it which we will keep working on.**

7.5  
10

We have been fortunate to have the help of a private company called Healios who are working with us until March 2024 to complete some of our NDAS assessments. Young people are offered Healios in referral date order if they meet Healios criteria. Healios offer Autism specific assessments by video appointment so this option is not suitable for everyone. Families are given the choice if we think their child meets Healios criteria and are not disadvantaged in any way if they decline this offer as they remain on the NDAS waiting list by their referral date.

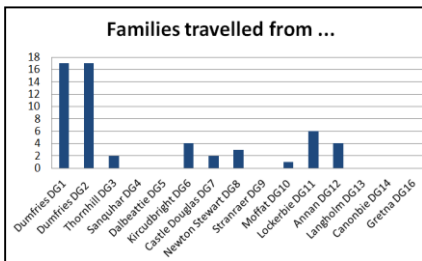


# Family Engagement Session

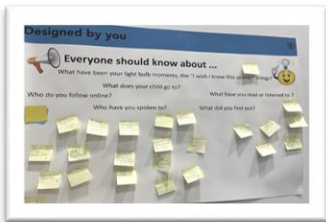


One of the priorities for our work is that families can access support when they need it, before during or after a diagnosis. Our support working group have been finding out more about what “good” support would look like for families. We held a family engagement event at the Bridge in October 23 and welcomed 56 people across two sessions.

While most people came from Dumfries, we had a small number of families from across the region.



Through a series of activities and poster questions, families shared with us their experiences, their thoughts, what works and what needs to get better.



A full report of the information gathered is available on request. Key themes from the day will be turned into an action plan by each of the three working groups.

**"I feel like I have been listened to! Have found out about support groups I would like to access."**

## Families told us ...

**“Thank You I  
felt heard.”**

**“Staff listened and took on board what we said.”**

**“I came not knowing what to expect, it has been enlightening.”**



**“Very Good Networking event. I feel like I got a lot of the event and I would love to come along to more”.**

**“Didn’t know there was such a wide range of things available / people willing to help! Nice to see we have that!”**

**“So friendly and inclusive -  
wasn’t awkward / didn’t feel  
out of place.”**

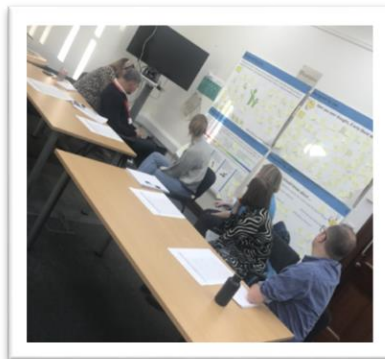
# Family Support Working Group

The family support working group has formed with representation from across children's health teams, social work, Quarriers, Carers Centre and Autism Outreach. Our role is to work with families to develop and test improvements in the way support is offered to families and young people in Dumfries and Galloway. This group are helping us work towards ambition 3.

3

Children, young people and their families will feel supported in Dumfries and Galloway as part of a system with the child and family at the centre.

We met in November after the family engagement event to reflect on the information families had given us and to identify potential short term goals as well as longer term improvements.



There were three clear areas that stood out for us as themes. We will work with our family engagement group to turn these themes into actions and plan how we take these forward over the next few months. We will keep coming back to this information as our plans progress.

## Somewhere to go for help

Families are very clear when they have a problem and need some support but are much less clear about who to go to for help. They shared common stories of feeling passed between services and not getting answers to questions or having to wait a long time to speak to someone who can help. We heard that having a single place to go to talk to someone who understands, could make finding the right support much easier.

## Understanding ND brains

Families share common experiences of the challenges that bringing up a neurodevelopmentally different child can cause. A core barrier to this is the lack of meaningful information about Neurodevelopmental differences to support families to make sense of their child, their behaviour and their role as a parent. Information currently available is online and relates to diagnostic labels. This means families have to either guess which labels they think apply or wait until the diagnosis is complete to begin understanding their child.

## ND knowledgeable workforce

Families meet lots of staff on their journey through health, social care, education and third sector services and knowing that staff are well informed about Neurodevelopmental differences is really important to them. Strong themes emerged with feeling listened to, respected and valued as the expert of their child, being things that matter to families.

# Looking Forward



The full report of information gathered from the family engagement session will be shared with attendees from the session and session organisers.



Each working group will set their aims and actions for January 2024 to April 2024.



Our family engagement group will become established and will support with these initial aims and actions.



We will start trialling improvements and will collect information to tell us what works and what needs to get better.



Our ND Subgroup will meet again in January 2024 to review these actions and offer support to the working groups as needed.



In March 2024 our groups will make plans for year 2 – April 2024-March 2025



We will contribute to end of year reporting on the Children's Services Plan.

Thank you for your interest, contribution and support towards this important work. Please use this link to tell us how we are doing – anytime! You can use it as often as you like as new thoughts or ideas come to mind.

Joanne

ND Subgroup - How are we doing?

