ND Subgroup Newsletter

Edition 2
Summer 2024

Edition 3 due
January 2025

Welcome to our 2nd Newsletter which will update you on where we have got to since our last newsletter in December 2023. I must confess this newsletter was promised for April but it's been a busy time so here is our "Summer" edition.

A quick reminder

In case you are reading this and haven't been part of discussions so far and haven't seen our first Newsletter from December 2023, 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 who are Neurodivergent and their families.

We are a multiagency group with representation from NHS D&G, the Council, Social Work, Quarriers, the Carers Centre and our 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.

Joanne

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

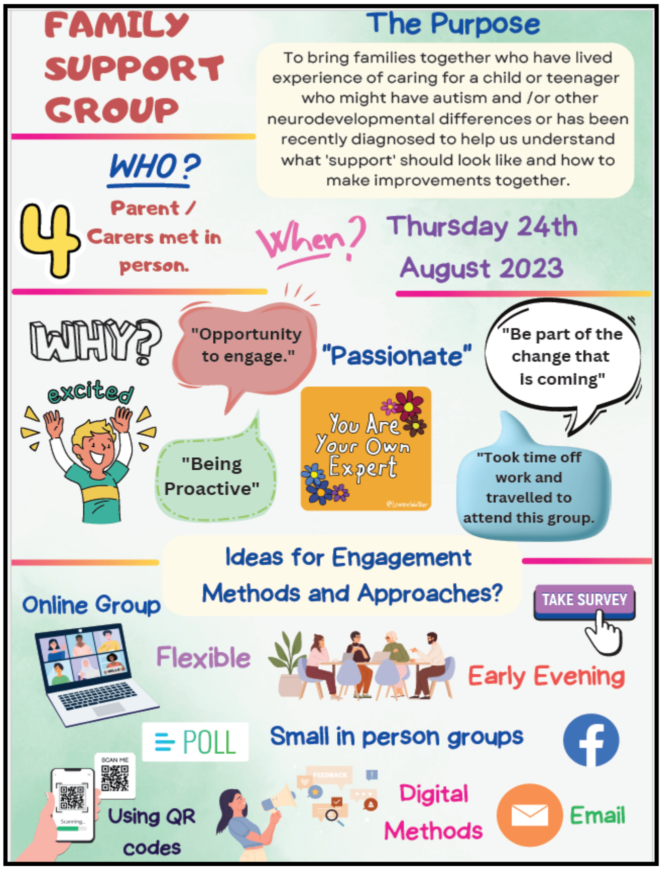
At a glance:

- ✓ Family engagement group goes from strength to strength
- ✓ SNAP review is planned
- ✓ We've joined the West of Scotland Neuroaffirming Community of Practice
- ✓ Autism – Level Up is being introduced into schools
- ✓ SCERTS is developing in D&G
- ✓ Whole School Autism Professional Learning for Primary Schools – first pilot session planned
- ✓ NDAS are gathering feedback from families
- ✓ NDAS are improving communication with families on the waiting list
- ✓ We are working to understand what community support could look like for families
- ✓ We are finding out what families what to know about Neurodivergent brains
- ✓ We have plans to skill up the workforce, 1 step at a time!

Family Engagement Group

Our family engagement group are integral to everything we do. We are learning more about participation and engagement and how to meaningfully include our families in the work we are doing. Our group of 4 has grown to a group of 55 showing the interest of families across D&G to be part of this work.

Then



FAMILY SUPPORT GROUP

The Purpose

To bring families together who have lived experience of caring for a child or teenager who might have autism and /or other neurodevelopmental differences or has been recently diagnosed to help us understand what 'support' should look like and how to make improvements together.

WHO?

4 Parent / Carers met in person.

When? Thursday 24th August 2023

WHY?

"Opportunity to engage."

"Passionate"

"Be part of the change that is coming"

excited

"Being Proactive"

You Are Your Own Expert

"Took time off work and travelled to attend this group."

Ideas for Engagement Methods and Approaches?

TAKE SURVEY

Online Group

Flexible

Early Evening

POLL

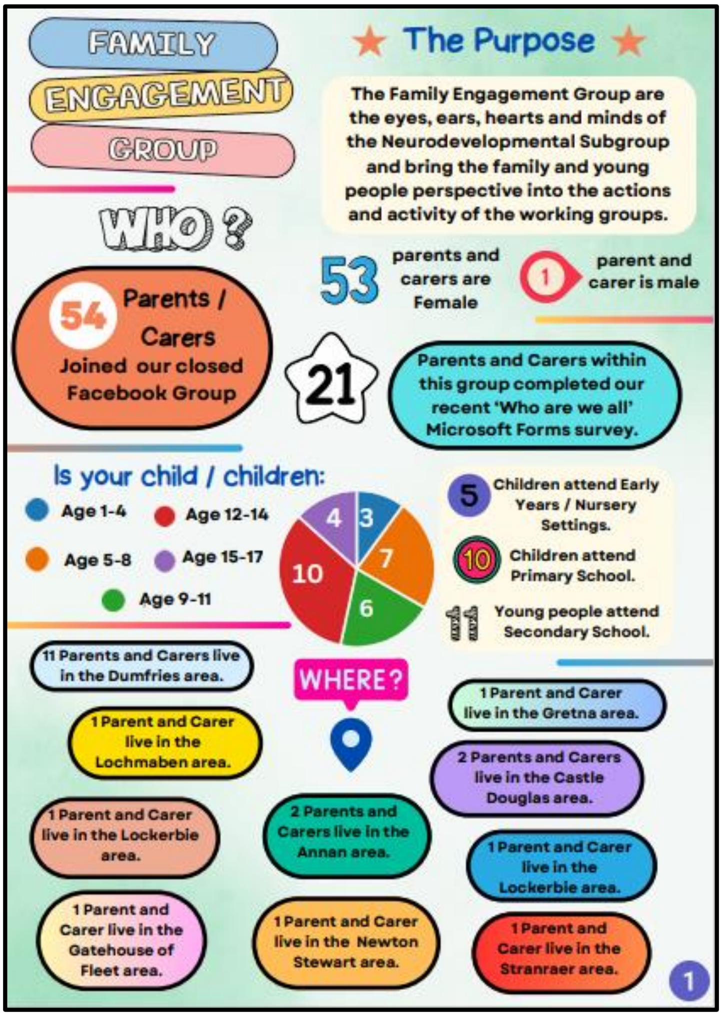
Small in person groups

Using QR codes

Digital Methods

Email

Now



FAMILY ENGAGEMENT GROUP

The Purpose

The Family Engagement Group are the eyes, ears, hearts and minds of the Neurodevelopmental Subgroup and bring the family and young people perspective into the actions and activity of the working groups.

WHO?

54 Parents / Carers Joined our closed Facebook Group

53 parents and carers are Female

1 parent and carer is male

21 Parents and Carers within this group completed our recent 'Who are we all' Microsoft Forms survey.

Is your child / children:

- ● Age 1-4: 3
- ● Age 5-8: 7
- ● Age 9-11: 6
- ● Age 12-14: 10
- ● Age 15-17: 4

5 Children attend Early Years / Nursery Settings.

10 Children attend Primary School.

11 Young people attend Secondary School.

WHERE?

11 Parents and Carers live in the Dumfries area.

1 Parent and Carer live in the Lochmaben area.

1 Parent and Carer live in the Lockerbie area.

2 Parents and Carers live in the Annan area.

1 Parent and Carer live in the Gatehouse of Fleet area.

1 Parent and Carer live in the Newton Stewart area.

1 Parent and Carer live in the Gretna area.

2 Parents and Carers live in the Castle Douglas area.

1 Parent and Carer live in the Lockerbie area.

1 Parent and Carer live in the Stranraer area.

1

Alison Telfer, CAMHS Participation Lead has evaluated the group membership so far to consider how representative it is of our rural area and to ensure we understand why this work matters to families.

See what our families have told us so far ...

In a few words, why would you like to be part of this group?

"To see what is planned and to join in discussions putting forward my ideas and suggestions if possible."

"Because something needs to get better and as a team with different views, we can try and find a solution."

"To enrich our journey and be able to help with what we find helps."

"To inform from experience and assist in finding ways to support and fill gaps in services for children and young people and their families with Neurodiversity related additional needs."

"Would like to provide feedback, daughter was diagnosed during NDAS pilot scheme."

"To speak to other parents who are going through same situations."

"To know I'm not alone."

"Because there's always a desperate need for improvement."

"Would like to provide feedback, daughter was diagnosed during NDAS pilot scheme."

"To contribute experiences that may help others with an autistic child and gain insights from others."

"I feel that help for ND children in the area is extremely poor and parents are often just left to their own devises with no help what so ever. I'd love to be part of the discussions on this changing to support our ND children."

"I've been through the lengthy process twice and it's always nice to find new ways to speed things up to help others."

"To help others in the area using my experience of living with an autistic teenager."

In a few words, why would you like to be part of this group?

"I am still relatively new to the area and I'm still trying to navigate my way through processes however I have come across a lot of bumps in the way and would like to help others that experience this"

"Help, support"

"To help provide help and support from a parent of a ND child and I also work in early learning and childcare setting."

"To contribute towards planning support for families in my local area."

"To help provide help and support from a parent of a ND child and I also work in early learning and childcare setting."

"To speak to other parents who are going through same situations."

"To have a group that can give advice and maybe support."

"As parent would like to be involved in improving services in D and G."

"My son started at Dumfries college in September 2023 he has Tuberous sclerosis, autism, epilepsy, sensory Integration and social skills difficulties And there are a number of good elements to celebrate about this, but also areas that could be improved for the benefit of him and many ND others. Any opportunity to be involved in greater understanding, education and improvement to better outcomes and opportunities then I'd love to be involved."

"To get information and advice for what support I can offer my child."

"Last year I attended the family engagement session at the Bridge. I put my name down for the Parents Focus Group and as my child is only in nursery. I would like to be involved in helping my sons and other children's experience with additional needs at schools and with services better and more supported."

Why do you think it is important that services are listening, involving and learning from parents and carers experiences?

"It's important for you to understand the children and their parents journey, see things from their eyes, see simple things that can be helpful and what may cause frustration. It helps people feel involved in their service, and that decisions are being made by a group of people with lived experience rather than managers who may not have as much experience. It shows respect to people who have all these skills and management techniques and specialist knowledge through years of trial and error."

"To help improve the ND services, having our voices heard."

"To hopefully one day not have all services feel so far out of reach, for GPs to be understanding for CAMHS actually listen and not refuse children when they are clearly in great need, and for NDAS not to be a complete and utter shambles and for us parents not to have to fight and beg!!"

"It's important because parents are 'experts by experience'."

"To improve services and engagement with families to help the children concerned."

"A Dr A said to me, never to forgot that I am the only expert on my child, you live with him every day and know more about him than anyone else. Therefore parent and career experience is invaluable to expanding our knowledge of ND."

"It's important for the best interest of our child's health"

"Those who have experienced things can help develop services for others as they know what is required."

"Being listened to"

"Because improvements can't be made if parents aren't able to express where things are going wrong."

How would you like to engage?

17 People said they would like to comment on a question, poll or topic on the closed Facebook Group.

17 People said they would like to comment on a question or topic anonymously within a Microsoft Form

12 People said for Alison our Participation Lead to email them directly and you can email her back regarding thoughts and feelings on a particular question or topics?

11 People said they would attend an online group meetings in the evening.

7 People said they would attend an online group meetings during the day.

7 People said they would attend an in person group meetings during the day.

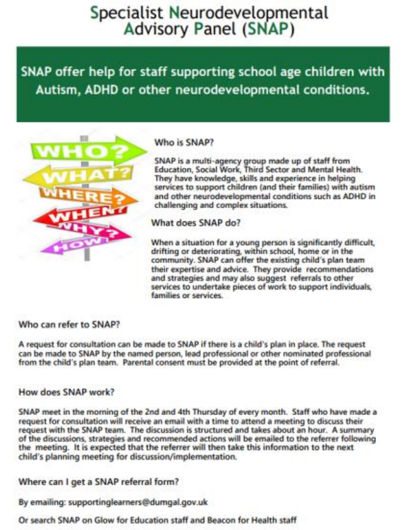
6 People said they would attend an in person group meetings in the evening

★ THANK YOU! ★

Produced by Alison Telfer Participation Lead - 26th February 24

SNAP

We are going to undertake a review of the last 12 months of SNAP referrals to better understand what is working well and what needs to get better. We will share information about any recommendations that come from this review in the next newsletter. In the meantime, SNAP will continue to meet from August to December 2024.



Specialist Neurodevelopmental Advisory Panel (SNAP)

SNAP offer help for staff supporting school age children with Autism, ADHD or other neurodevelopmental conditions.

Who is SNAP?

SNAP is a multi-agency group made up of staff from Education, Social Work, Third Sector and Mental Health. They have knowledge, skills and experience in helping services to support children (and their families) with autism and other neurodevelopmental conditions such as ADHD in challenging and complex situations.

What does SNAP do?

When a situation for a young person is significantly difficult, drifting or deteriorating, within school, home or in the community. SNAP can offer the existing child's plan team their expertise and advice. They provide recommendations and strategies and may also suggest referrals to other services to undertake pieces of work to support individuals, families or services.

Who can refer to SNAP?

A request for consultation can be made to SNAP if there is a child's plan in place. The request can be made to SNAP by the named person, lead professional or other nominated professional from the child's plan team. Parental consent must be provided at the point of referral.

How does SNAP work?

SNAP meet in the morning of the 2nd and 4th Thursday of every month. Staff who have made a request for consultation will receive an email with a time to attend a meeting to discuss their request with the SNAP team. The discussion is structured and takes about an hour. A summary of the discussions, strategies and recommended actions will be emailed to the referrer following the meeting. It is expected that the referrer will then take this information to the next child's planning meeting for discussion/implementation.

Where can I get a SNAP referral form?

By emailing: supportinglearners@dumgal.gov.uk

Or search SNAP on Glow for Education staff and Beacon for Health staff

Neuro-affirming Practice

national autism implementation team

Top 5 Values

In group discussions at our events, participants reviewed and prioritized the following values:

1. **Nothing about us without us**
2. **Difference not deficit**
3. **Support people to be their authentic self**
4. **Listen without judgement**
5. **Universal 'neuro-affirming practice'**

While minor rewording was suggested, these top five values remained largely consistent.

In our first newsletter, we shared with you that the leads from each working group of the ND Subgroup had joined the West of Scotland neuro-affirming community of practice, run by the National Autism Implementation Team (NAIT). Sharron and Joanne went along to the first meeting in December and contributed to discussions about key values.

The event organisers shared these "take away" messages from participants...

Thinking about shifting from the social model to neurodiversity paradigm and what this will mean for my practice.

I like the no blame culture - I feel less frightened to get it wrong and more accepting that neuro-affirming practice is a journey we are all on.

Enable people to be their authentic self and to celebrate and embrace it throughout life and at all stages.

New way of thinking, switching my perspective.

The power that professionals hold regarding outcomes for the social model. This has made me think on my practice.

That just because something is evidence based does not mean we should do it.

Small changes can be easily achieved to make practice more neuro-affirming.

Thinking about levelling up and what this means for each of us.

Education Working Group

The working group has continued to grow with group members representing early years, primary, secondary, additional support for learning and Autism Outreach. This group continue to 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** and vice chair of the ND Subgroup

A key part of the aim of the Education Working group is ensuring that education staff who work with children and young people are highly skilled and confident in supporting neurodivergent pupils.

Autism – Level Up!

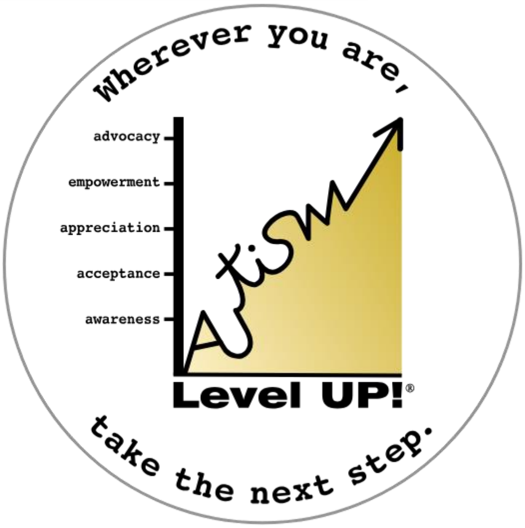
Autism Level UP!®

Levelling Up Framework and Intervention

The Education Outcome group arranged for ten Education colleagues - representing all stages of education, including Learning Centre and Inclusion Support staff - to attended funded NAIT training called Individualised Goals - A Leveled Up! Framework in January 2024. This training not only complements SCERTS knowledge but also has the potential to inform our goal of ND friendly schools across D&G. The focus of the input was:

- creating meaningful goals for educational and support plans.
- gathering and incorporating information that ensures:
  - affirmation of identities,
  - personal priorities are addressed,
  - personal preferences and neurodevelopmental differences are considered when designing supports.
- how partners provide support and facilitate attainment of the individualised objectives by the person they are supporting.

In agreeing to a place on this training, there was an expectation that our colleagues would join a D&G Levelling Up Community of Practice (CoP) and that they would commit to a fully evaluated Level Up implementation project in their place of work. At the first CoP following the training, more detail was shared about the intervention and its applicability in our schools. Level Up is based around matching energy levels to help support regulation in neurodivergent young people and an acknowledgement that coping mechanisms for some may be triggers for others.

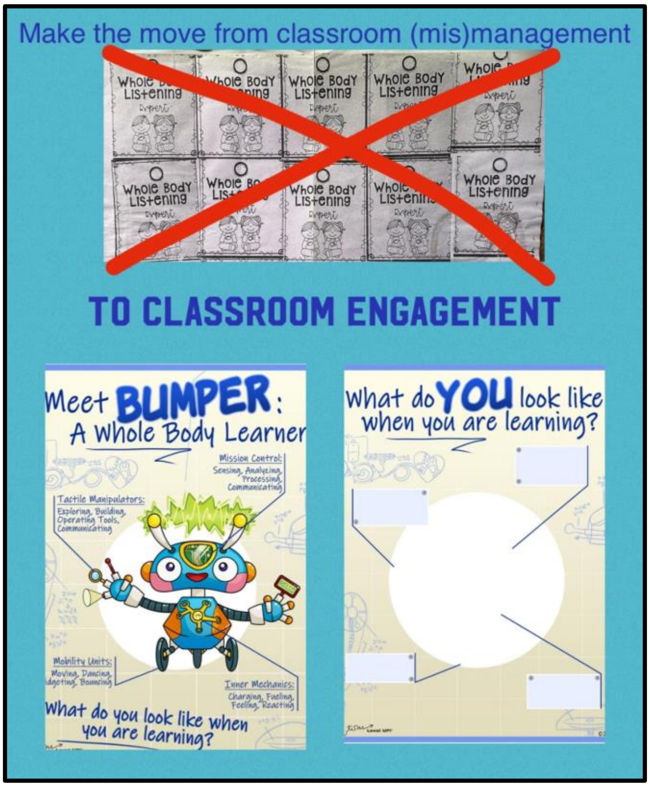


Education Working Group

Autism – Level Up! Continued …

This involves:

- Use of non-judgemental language like ‘power up’/’power down’
- The notion of energy as neutral (i.e. what energy levels do I need for this activity?)
- Helpful visuals to aid the intervention
- Access to the website as useful in planning the approach
- Clear steps connected to target setting
- The ‘3 columns regulator’
- Useful robot resource
- Now and next with timings attached
- Instruction around use of the word ‘when’



The group agreed that the learning was valuable enough that they would try a few different approaches in their various settings, and would feedback outcomes in regular meetings of our Community of Practice. The CoPs so far have been well-attended, energetic sessions and further termly meetings are arranged for session 2024-25. Chair Sharron Harper has encouraged practitioners to use the ND project template when sharing implementation updates. This helps us to do various things:

- chart the implementation journey
- share the project at the ND Education Outcome Strategy Group
- support others to design and establish their projects
- communicate our progress to others (like here in the newsletter!)
- design the next stage of the plan to develop ND friendly schools across D&G

Wherever you are, take the next step.
Autism Level UP!®

In the next newsletter, we will share details of some of the interventions, and an update on the evaluation of their impact. In the meantime, if you would like more information, please search the excellent **NAIT website**, follow the brilliant **Autism Level Up Facebook** page (which is full of brilliant classroom ideas for including neurodivergent young people) and/or contact Sharron who will be happy to support ideas for implementation in your setting, alongside other CoP members.

Education Working Group

In our last newsletter, we introduced you to SCERTS and shared that Dumfries and Galloway were putting together a group of Teaching staff to plan and develop this across schools in D&G. Since then, Esther Papworth, Principal Teacher of ASN with Supporting Learners has taken on the oversight of this group. Here is Esther's update on this work so far.

SCERTS®

The acronym "SCERTS" refers to the focus on:

"SC" – Social Communication – the development of spontaneous, functional communication, emotional expression and secure and trusting relationships with children and adults.

"ER" – Emotional Regulation – the development of the ability to maintain a well-regulated emotional state to cope with everyday stress, and to be most available for learning and interacting.

"TS" – Transactional Support – the development of supports to help partners respond to the person's needs and interests, modify the environment and provide tools to enhance learning. Specific plans are developed to provide educational and emotional support to families and to foster teamwork among professionals

21 members of staff from a variety of settings, including mainstream secondary and primary schools, learning centres and nursery settings, recently took part in three days of SCERTS training provided by NAIT. This training gave great insight into the most up-to-date research and good practice relating to autism. We learnt about neuroscience in relation to childhood development, and how to carefully assess and then plan for the educational needs of autistic pupils.

We are working together to share our findings and support each other, building a community of practice to enhance understanding and continuously improve our support. The young person is at the centre of the SCERTS model, and families are integral to planning. Practitioners were extremely positive about the training, with one commenting that she couldn't wait to put it into practice, as it gave her new tools which she felt were going to be very helpful.

The next step is for each practitioner to consider how to run the SCERTS programme in their setting – each person will be concentrating on how best to use SCERTS to support children in their nursery, school or learning centre and will run a small pilot project to build knowledge and skills.

Lorraine Harris, Autism Team Lead (Education) and ND Subgroup Member, attended a "Train the Trainer" Session with four of the Autism Officers from Autism Outreach.

We were expecting you!
Whole School Autism Professional Learning
for Primary Schools

Wednesday 19th June 2024
16:00-17:00
Online Train the Trainer Session

This session is for public sector health and education professionals working in and with primary schools in Scotland, who...

- deliver professional learning about meeting the needs of autistic learners at the primary stage.
- are trainers with enhanced knowledge about this topic.

During the session we will:

- share an overview of the resources (scripted PowerPoints with learning outcomes, Key Messages, activities, films and participant and trainer packs).
- explain the copyright and fair use agreement for those who wish to use the materials.

To request a place please use the booking link or QR code:
https://buytickets.at/nationalautismimplementationteam/1263689

national autism implementation team

The session was on Whole School Autism Professional Learning for Primary Schools. The team are offering this session as a Pilot during the August Inservice days and will bring her learning from this session to the Education Working Group to consider how it could support the group with their overall aims.

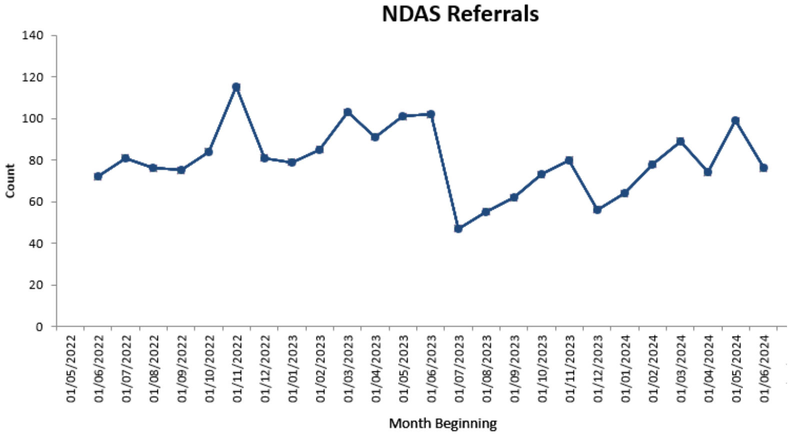
NDAS Working Group

The Neurodevelopmental Assessment Service has been open to new referrals since May 2022 and we 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.

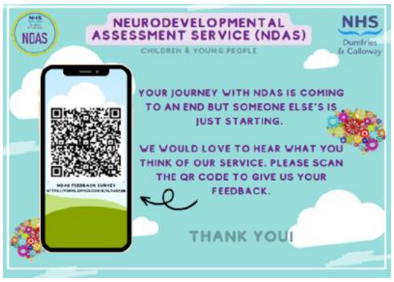
2 Children and young people with Neurodevelopmental Disorders will have access to diagnostic assessment to enable them and their families to have a secure understanding of the differences of their brain, their strengths and their support needs.

There remains significant demand for NDAS from across the region with children as young as 18 months right through to young people about to have their 18th birthday. The team currently receive an average of 76 referrals per month which represents an overall reduction from initial service referral figures of 83 per month. Referral numbers do however fluctuate during the year and a recent steady increase has returned monthly referrals to those seen in 2022-2023.

Unfortunately, this means the current waiting time for NDAS assessment is just over 100 weeks.



While our children, young people and families have a long wait for NDAS allocation, those who have been through the service are asked to provide feedback so we understand what we are doing well and what needs to improve.



NEURODEVELOPMENTAL ASSESSMENT SERVICE (NDAS)
CHILDREN & YOUNG PEOPLE

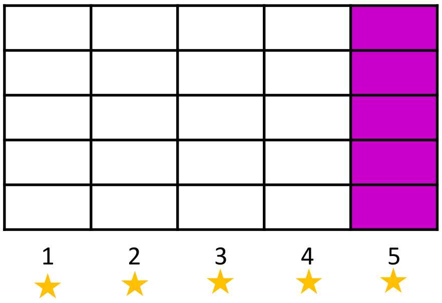
YOUR JOURNEY WITH NDAS IS COMING TO AN END BUT SOMEONE ELSE'S IS JUST STARTING.

WE WOULD LOVE TO HEAR WHAT YOU THINK OF OUR SERVICE. PLEASE SCAN THE QR CODE TO GIVE US YOUR FEEDBACK.

THANK YOU!

See what our families have told us so far …

How would you rate the service provided by NDAS?



What did we do well?

The team were very engaging and knew how to get the answers from my son

They were amazing with my little boy, took the time to find out everything about him, explained his diagnosis so well, nothing was a problem.

It was a very thorough assessment, my daughter and myself were listened to for the first time in years. Very kind staff and very approachable.

What could we do better?

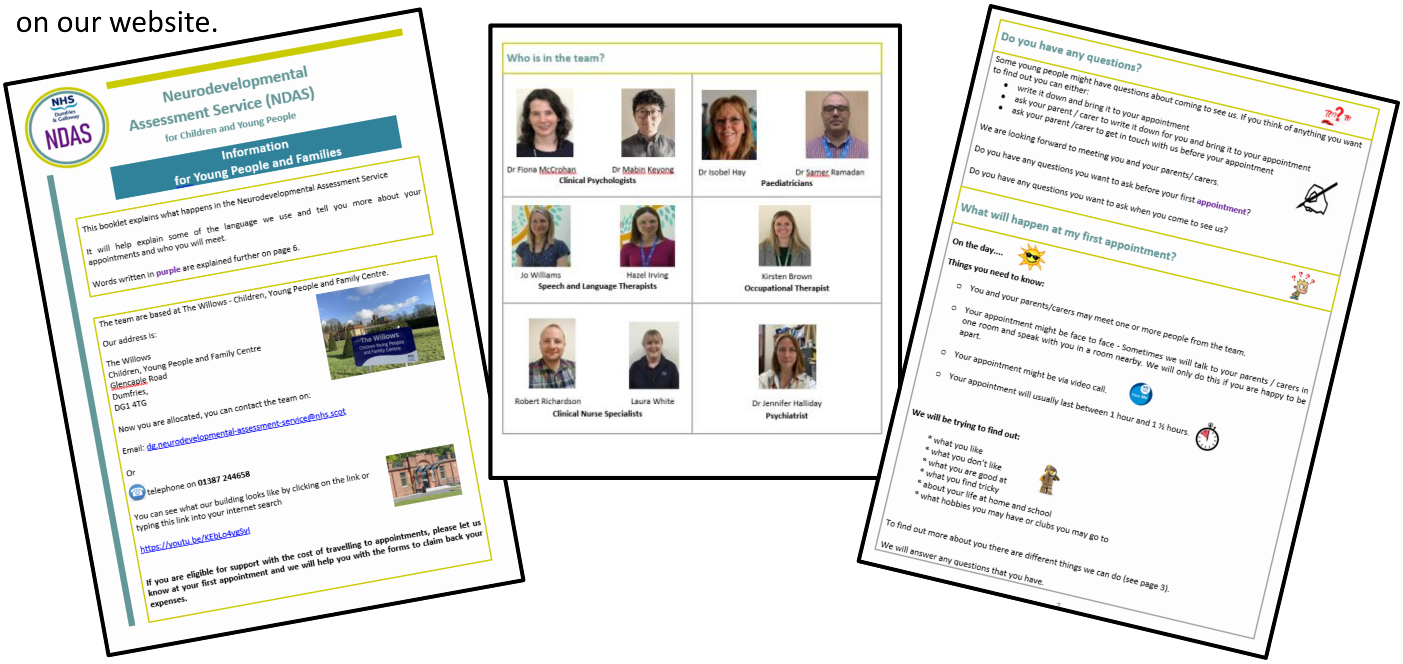
Waiting times

Whilst on the waiting list, communication with people so they know they have not been forgotten.

Communicating with families

NDAS now sends out all appointments by text message for families who can access this system. This cuts down on paper and lets families access their appointment information and receive reminders straight to their phone. Any families who don't respond to their text appointment get sent their appointment letter by post so no one misses out.

We have introduced a booklet to help children, young people and families prepare for their NDAS assessment journey and to make sure they have all the information they need. This will soon be available on our website.



Neurodevelopmental Assessment Service (NDAS)
for Children and Young People

Information
for Young People and Families

This booklet explains what happens in the Neurodevelopmental Assessment Service

It will help explain some of the language we use and tell you more about your appointments and who you will meet.

Words written in **purple** are explained further on page 6.

The team are based at The Willows - Children, Young People and Family Centre.

Our address is:

The Willows
Children, Young People and Family Centre
Glencaple Road
Dumfries,
DG1 4TG

Now you are allocated, you can contact the team on:

Email: dg.neurodevelopmental-assessment-service@nhs.scot

Or

☎ telephone on **01387 244658**

You can see what our building looks like by clicking on the link or typing this link into your internet search

https://youtu.be/KEbLo4ygSyI

If you are eligible for support with the cost of travelling to appointments, please let us know at your first appointment and we will help you with the forms to claim back your expenses.

Who is in the team?

Dr Fiona McCrohan Dr Mabin Keyong **Clinical Psychologists**	Dr Isobel Hay Dr Samer Ramadan **Paediatricians**
Jo Williams Hazel Irving **Speech and Language Therapists**	Kirsten Brown **Occupational Therapist**
Robert Richardson Laura White **Clinical Nurse Specialists**	Dr Jennifer Halliday **Psychiatrist**

Do you have any questions?

Some young people might have questions about coming to see us. If you think of anything you want to find out you can either:

- write it down and bring it to your appointment
- ask your parent / carer to write it down for you and bring it to your appointment
- ask your parent /carer to get in touch with us before your appointment

We are looking forward to meeting you and your parents/ carers.

Do you have any questions you want to ask before your first appointment?

Do you have any questions you want to ask when you come to see us?

What will happen at my first appointment?

On the day….

Things you need to know:

- ○ You and your parents/carers may meet one or more people from the team.
- ○ Your appointment might be face to face - Sometimes we will talk to your parents / carers in one room and speak with you in a room nearby. We will only do this if you are happy to be apart.
- ○ Your appointment might be via video call.
- ○ Your appointment will usually last between 1 hour and 1 ½ hours.

We will be trying to find out:

* what you like
* what you don't like
* what you are good at
* what you find tricky
* about your life at home and school
* what hobbies you may have or clubs you may go to

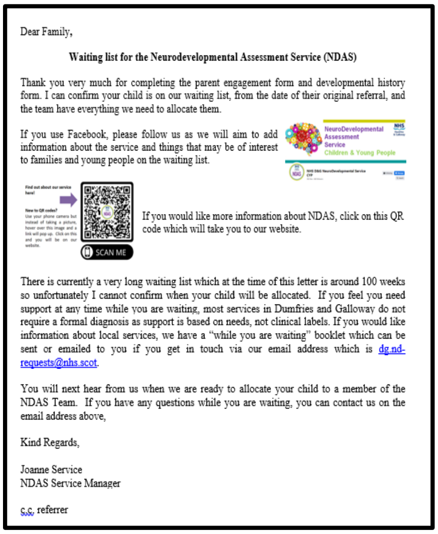
To find out more about you there are different things we can do (see page 3).

We will answer any questions that you have.

7

While you are waiting …

We are aware that waiting for allocation on the NDAS waiting list is an anxious time for some young people and families. We heard from our families at the engagement event that it would be good to hear from us to know they have not been forgotten. NDAS now send all families an acknowledgement letter following screening when a child is added to the waiting list and send a follow up letter after 52 weeks to confirm that we know they are still waiting and update on the current expected waiting time.



Dear Family,

Waiting list for the Neurodevelopmental Assessment Service (NDAS)

Thank you very much for completing the parent engagement form and developmental history form. I can confirm your child is on our waiting list, from the date of their original referral, and the team have everything we need to allocate them.

If you use Facebook, please follow us as we will aim to add information about the service and things that may be of interest to families and young people on the waiting list.

If you would like more information about NDAS, click on this QR code which will take you to our website.

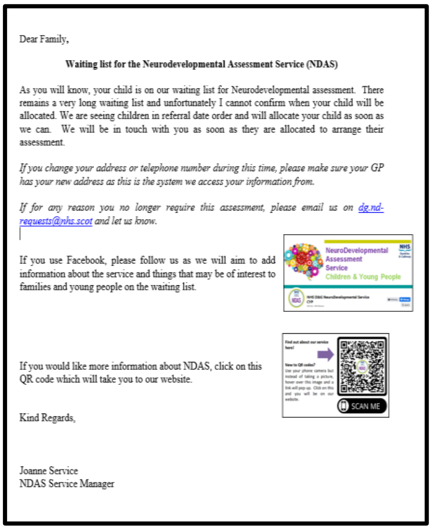
There is currently a very long waiting list which at the time of this letter is around 100 weeks so unfortunately I cannot confirm when your child will be allocated. If you feel you need support at any time while you are waiting, most services in Dumfries and Galloway do not require a formal diagnosis as support is based on needs, not clinical labels. If you would like information about local services, we have a "while you are waiting" booklet which can be sent or emailed to you if you get in touch via our email address which is dg.nd-requests@nhs.scot.

You will next hear from us when we are ready to allocate your child to a member of the NDAS Team. If you have any questions while you are waiting, you can contact us on the email address above,

Kind Regards,

Joanne Service
NDAS Service Manager

c.c. referrer



Dear Family,

Waiting list for the Neurodevelopmental Assessment Service (NDAS)

As you will know, your child is on our waiting list for Neurodevelopmental assessment. There remains a very long waiting list and unfortunately I cannot confirm when your child will be allocated. We are seeing children in referral date order and will allocate your child as soon as we can. We will be in touch with you as soon as they are allocated to arrange their assessment.

If you change your address or telephone number during this time, please make sure your GP has your new address as this is the system we access your information from.

If for any reason you no longer require this assessment, please email us on dg.nd-requests@nhs.scot *and let us know.*

If you use Facebook, please follow us as we will aim to add information about the service and things that may be of interest to families and young people on the waiting list.

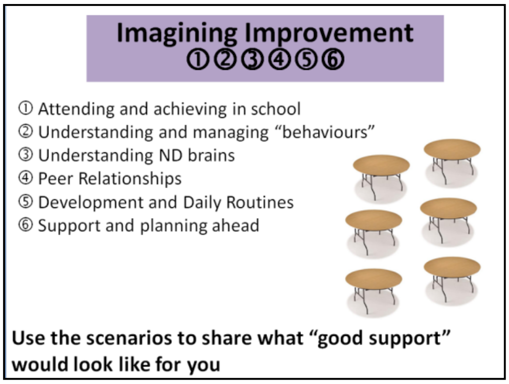
If you would like more information about NDAS, click on this QR code which will take you to our website.

Kind Regards,

Joanne Service
NDAS Service Manager

Family Support Working Group

Our ND subgroup are focusing on the key themes that came out of our family engagement event in October 2023 and more recent conversations with our family engagement group as well as the families we meet through our work. Our Family Engagement group are focusing specifically on the themes that relate to families, in their communities.



Imagining Improvement ①②③④⑤⑥

① Attending and achieving in school
② Understanding and managing "behaviours"
③ Understanding ND brains
④ Peer Relationships
⑤ Development and Daily Routines
⑥ Support and planning ahead

Use the scenarios to share what "good support" would look like for you

When we asked families "what would "better" would look like for you", we got some very clear themes

In no particular order ….

1	Accessible support – An ND expert as the first point of contact when help is needed
2	Learning opportunities - Opportunities for children and families to learn new skills
3	Peer support - Informal support/social groups for families
4	Improving education expectations / routines / environments
5	Raising awareness of ND – acceptance, understanding and differentiating
6	Accessing opportunities for ND CYP in school and their community
7	Supporting differences that impact on a child or family wellbeing – sleep, eating, friendships, sensory
8	Understanding ND – solution focused, problem solving, understanding strategies
9	Being respected and listened to – family perspectives
10	Specialist support – equitable access to clinical services for ND
11	Education resources and support
12	Anything else?

Family Support Working Group

Community Support

We are currently exploring options to develop this priority area, recognising that our families told us …

Somewhere to turn to when struggling-to get advice on how to best manage a situation

Support to bridge the gap whilst waiting on a diagnosis. Why is a referral always needed to access certain help

Cant get access to support without social services referral

Peer support to share new ideas

Information that is available needs to be more accessible. It feels like you need to really look for information and ask for referrals to made at every turn instead of them just being given

Sharing facts of how the ND brain works with parents. This would educate us to why they have certain responses and the tools are would then respond with that might be a different approach from a NT child

Our family life is unbearable. I wish I could access autism friendly advice on these behaviours

Create a parent support group to educate parents with how to deal with any behavioural issues. How to play differently

Services need to be aware that many ND children have ND parents Help lines for families and ND young people

To have somewhere outside of education system to go to for advice when you feel your child is not getting support they need. Someone to mediate/advocate

It's hard when you feel like the only one who can manage your child's behaviours. Feels like a huge responsibility on just me. Support is there but you feel like a burden especially on family etc. The guilt can be just as crushing as the responsibility

Tailored support built around the young person and their family

I wish I could have access to support to help me understand what to do when my son cant move on from things. He casts things up from days gone by and I have no idea to help him realise its no longer important. Usually its never a big issue in the first place but to him it is and he can get upset for days. Good support would be a place to call, visit, online to discuss this

It is a very lonely place as a parent. Stuck in midst the and outburst, is there capacity to organise a get together for parents to have coffee, scones and bounce ideas of one another. Could have get together with kids or an event

Family Support Working Group

Understanding ND Brains

Our family engagement group are helping us to think about what families need to know and how they would like to know this information.

We want to develop some parent information which will support families to understand their neurodivergent child's brain, development and behaviours?

What were the key things you need to know about supporting your child?

self harming behaviours, understanding this and knowing when to escalate when awaiting assessment

if they are appearing behind with language, how to support this if they dont want to communicate

how to support independence with personal care

understanding building their resiliance when sturggle with emotional regualtion

parenting strategies

Knowing when to engage with the services more than a leaflet response.

How to talk to our children about their brain differences

Jargon buster

how to use the correct language for each condition

Being trauma informed and reflective of different family circumstances

how to support sensory seeking and understand benefits of this

where to get help

who to go to when

We want to develop some parent information which will support families to understand their neurodivergent child's brain, development and behaviours?

What were the questions you needed answered?

will this get better over time

How long will it take?

how to i speak with caregivers about this

how long will it take and what can i de whilst i wait

What support is at the end?

what will an assessment bring to positively affect the child

What can I ask for? (what influence do I have in how the assessment takes place)

could I have done something different?

how do i speak with family about this

Think about what format this family information should be delivered? (In person Workshop? Booklet? Online Resource?)

When would people attend the workshop?

Producing a video

information based early stage - what to expect

important to be conscious of stigma and feelings of guilt

Online based

Easy Read Guide

Different workshops depending on where you are on your journey.

Opportunity for individual consultation on child. Not within group setting.

Problem solving session

Later workshop - more peer based, where to get support, how did you find the journey, what are the next steps

also be aware that parents may be neurodivergent

Give a pack of resources - maybe child focused?

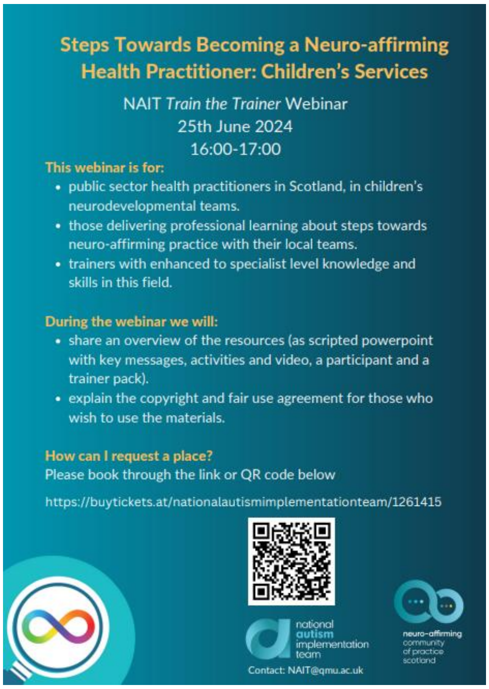
Family Support Working Group

ND Knowledgeable workforce

Our families told us it is important that they meet professionals who are knowledgeable about ND and understand the needs of Neurodivergent families and their children.

So far, we have …

… had two members of the family support working group attended this session and bring their learning back to our group.



Steps Towards Becoming a Neuro-affirming Health Practitioner: Children's Services

NAIT *Train the Trainer* Webinar
25th June 2024
16:00-17:00

This webinar is for:

- public sector health practitioners in Scotland, in children's neurodevelopmental teams.
- those delivering professional learning about steps towards neuro-affirming practice with their local teams.
- trainers with enhanced to specialist level knowledge and skills in this field.

During the webinar we will:

- share an overview of the resources (as scripted powerpoint with key messages, activities and video, a participant and a trainer pack).
- explain the copyright and fair use agreement for those who wish to use the materials.

How can I request a place?
Please book through the link or QR code below

https://buytickets.at/nationalautismimplementationteam/1261415

national autism implementation team
Contact: NAIT@qmu.ac.uk

neuro-affirming community of practice scotland

… linked up with NES to find out what is already available for staff.

NHS Education for Scotland (NES) is an education and training body and a national health board within NHS Scotland. They are responsible for developing and delivering healthcare education and training for the NHS, health and social care sector and other public bodies. They have a Scotland-wide role in undergraduate, postgraduate and continuing professional development.

Autism and neurodiversity across the lifespan

Learn home > Autism and neurodiversity across the lifespan > Support, education and evidence based interventions > General awareness and support

Our group will review this information and make recommendations for workforce training that allow all staff to access information to become informed about Neurodivergent children, young people and families. It will also allow us to map our learning resources for staff who require enhanced or specialist skills for their roles.

Thank you for your interest, contribution and support towards this important work.

ND Subgroup - How are we doing?

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

This newsletter is designed to inform all stakeholders who are interested in this work and so should be shared with any family, adult, young person, professional or organisation who might be interested.

If you feel you could offer something to the work of this subgroup, please use the survey link above to share your details and we will be in touch with you to find out more.