

Cross-Party Group on Autism: Diagnosis

12 May 2025, 2-4pm

Minute

Present

MSPs

Alexander Burnett – Convenor

Annie Wells MSP

Invited guests

Lyndsay Macadam (SWAN)

Stephen Caulfield (The Donaldson Trust)

Dr Joe Long (Scottish Autism)

Vicky Taylor (National Autistic Society)

Lizzy Archibald (NHS Grampian)

Kabie Brook (Autistic Rights Group Highland)

Dr Marion Rutherford (National Autism Implementation Team)

Non-MSP Group Members

NAS Scotland (Host) – Alex West

David Anderson East Ayrshire NASWUT

Marion Aurora

ARGH

Suzi Martin - NAS Scotland

Marion Aurora

Kabie (they/them) ARGH (ARGH)

dixone

Stephen Caulfield, The Donaldson Trust

Joe Long - Scottish Autism (Joe Long)

Marion Rutherford

Mark McDonald - Scottish Autism

Alex Burnett

Robyn (Alex Burnett)

Ben Adam - SPICe

Alex Burnett

Vicky T

Steve

Linda Donnelly

Angie Ferguson

kclement

Lizzy Archibald (dixone)

Jamie
Becky McGinney
Louise Storie
fiona clarke
David Anderson East Ayrshire NASWUT
Maurice Frank ELAS
Olga Dobrushina
Stephanie Bain
Rachel Birch
Annie Wells MSP - Scottish Parliament
SMC Admin
Catherine Steedman
Lorraine.Harris
Niamh Roberts (she/they)
Sofia- SEMA
LWassell
Mary Doherty
Maria Chan, Aberdeenshire HSCP
Dorry.McLaughlin
Callum McCrosson
Lyndsay Macadam
Carrie Watts
Dawn Brown - SCDC
Paulo Nunes de Moura
Dorry.McLaughlin
Carrie Watts
Steve
Maria Chan, Aberdeenshire HSCP
Rachel Birch
David Anderson Scotland President NASWUT (David Anderson East Ayrshire NASWUT)
Linda Donnelly
Sofia- SEMA
Stephanie Bain
Mary Doherty
Lorraine.Harris
Callum McCrosson
LWassell
Niamh Roberts (she/they)
David Yeoman
Kate Clement (kclement)
Becky McGinney
Louise Moth, Scottish Autism
Annie Wells MSP - Scottish Parliament
Angie Ferguson
Paulo Nunes de Moura
Jamie
Fiona Clarke (fiona clarke)
Dawn Brown (Dawn Brown - SCDC)
Louise Storie

Olga Dobrushina
Catherine Steedman
Lauren Murray (Mindroom) (SMC Admin)
Ben Adam - SPICe
Maurice Frank ELAS
M Barker
Helen Mahood
Louise Carson - HOPE for Autism
Kate's iPhone
Cuzen
Karen Sweeney-PLUS Forth Valley (Karen Sweeney-)
Trish Collins
niamh
Leo Starrs-Cunningham
niamh
Daniel Mayol
Lorraine.Harris
Ewan Carmichael (Quarriers)
Lorna
Clare
David Yeoman

Apologies

Billy Alexander
Autistic Knowledge Development
Richard Ibbotson
Cherie Morgan
Sam Nicholson

Agenda item 1 - Convenor's Welcome

The convenor welcomed members to the meeting and outlined the agenda which would be followed.

Agenda item 2 - Meet the Member (The Donaldson Trust & SWAN)

The Donaldson Trust

Stephen introduced the history and work of The Donaldson Trust. The organisation is based in Linlithgow and was previously Donaldson's School for the Deaf but has developed to become a body focused on neurodiversity with the purpose of supporting the needs of neurodivergent people and families.

The Donaldson Trust seeks to develop greater understanding of neurodivergence, envisaging a society where neurodivergent people are accepted, understood and valued.

The organisation has a number of services:

Sensational Learning Centre – which is a grant-aided special school.

Vibe – which is a well-being service for neurodivergent young people.

Adult Services – which include Treehouse, focused on developing communication skills, and Gate, which is focused on preparation for future learning, training and employment.

Policy – seeking to influence positive change.

Connect – which seeks to provide training, consultancy and advice across the public, private and third sectors.

SWAN

Lyndsay advised that SWAN was set up in 2012 and has evolved to support autistic women, girls and non-binary people. Their purpose is to ensure autistic women, girls and non-binary people in Scotland feel valued, understood and connected.

The organisation runs a range of activities, both online and in-person, online activities which were started during COVID were found to be very beneficial so have been maintained alongside a reintroduced and expanded in-person suite of activities.

SWAN has four strategic themes. Autistic identity, mental health, life stages & transitions and access & inclusion.

SWAN Spaces exist in both online and in-person groups which work across a number of themes.

Online – Autistic Identity & Wellbeing, Intersectional/Whole-life Experiences, 1-2-1 & Peer Support.

In-person – informal groups in a wide variety of locations, run by autistic volunteers and providing connections in local areas. There are also walking groups which have been established in partnership with Paths For All.

Externally, SWAN delivers a wide range of training and consultancy split across training for professionals looking to develop their knowledge and practice and workshops for allies (friends, family, colleagues) which help them to learn more about autistic people and how they can support them through allyship.

Agenda item 3 - Diagnosis Discussion

Lizzy Archibald – NHS Grampian

Lizzy outlined the work which was undertaken to develop the diagnostic pathway in Grampian and that with the ending of the autism strategy, funding has become temporary on a six-monthly basis, with Aberdeenshire exiting the approach in March 2025.

The clinicians working in the team are 'borrowed' from their substantive roles with only four hours per week working together.

People can self-refer via the website. The benefits of self-referral are that a high level of detail is provided to the assessment team, this also reduces pressure on mental health and GP services.

A pre-assessment call takes place with those contacting the team, but there is a long waiting time – more than two years for those who join the service now.

The team are trying to offer drop-ins, a newsletter and have run focus groups to work out how to support people during their wait, with a post-diagnostic booklet and signposting for people at the point of diagnosis.

The team is trying to build the skills of the wider workforce – possibly expanding the assessment process.

Majority of referrals are female, with 87% self-referral and a diagnostic rate of 84-88%

Vicky Taylor (NAS Scotland)

Vicky is a volunteer for National Autistic Society in Angus & Tayside and is herself autistic as well as being a parent of autistic children. Vicky has received support from the organisation Parent To Parent.

NHS Tayside is not meeting the standards for waiting times with widespread reporting of pathways now being closed for children unless they have a co-existing mental health condition.

NHS Tayside have stated that referrals made today would have to wait ten years and reach adulthood before being assessed. This has been claimed to be a 'temporary measure' but there is a lack of information on what any future pathway is going to look like.

Absence of diagnosis can be a barrier to access to services, with some statutory services only accepting referrals if a formal diagnosis is in place.

There has been a significant increase in the numbers of families looking for support but organisations who support these families have been hit by funding pressures and risk being overwhelmed by demand.

Kabie Brook (ARGH) & Dr Joe Long (Scottish Autism)

Kabie & Joe introduced the initial findings of the research project on experiences of autism assessment and diagnosis in Scotland, a collaborative project between ARGH, AMASE, SEMA and Scottish Autism.

The survey was undertaken in 2023, but the findings remain relevant to the current situation facing people accessing assessment and diagnosis.

The survey received feedback from 624 people across 31 local authorities. 405 autistic people and 219 family members/carers.

The survey found that 50% found it hard or very hard to get a referral for assessment with 21% having been refused a referral at some point.

A lack of information while waiting for assessment was a common theme in the survey with many people describing uncertain timescales and a 'limbo period'.

62% did not feel adequately informed about the assessment process.

64% did not feel adequately informed about support services available to them.

21% of respondents with a diagnosis had received their diagnosis from a private provider. Reasons given included:

Long NHS waiting times

Lack of confidence in frontline services or 'gatekeeping issues'

Additional support was needed quickly and a diagnosis was required

No adult assessment pathway was available locally

Those experiencing long wait times were experiencing exacerbated stress/MH issues

Young people ageing out of CAMHS and facing long waits for adult assessment

Costs of private diagnosis ranged from £200 to £4500 with the average costs being £1540.

Of those obtaining a private diagnosis, 39% stated this had caused them financial hardship.

If people do not have the means to afford a private diagnosis they have no option but to wait in distress.

Good experiences were defined by:

Clear information in advance

Regular communication throughout

Respectful, non-judgemental and understanding dialogue with diagnostic teams

Members of the diagnostic team with lived experience

A specialist neuro-affirmative environment

Clear signposting to support services

Neuro-affirming post-diagnostic support

The organisations are looking to present the report to Scottish Government and will be making a number of recommendations for action to deliver better experiences and outcomes.

Dr Marion Rutherford (NAIT)

Support should not be dependent on diagnosis, and support should be a product of needs. Sometimes diagnosis can be the support that is needed.

When considering why diagnosis matters, autistic people clearly say that it matters. NAIT do not believe that we are overdiagnosing, but rather we are catching up.

Diagnosis provides clarity, validates identity and fosters community.

Not meeting rising need. Average age for adult diagnosis is thirty, so still catching up to be done.

Need to move from single-condition pathways to joined-up neurodevelopmental pathways.

NAIT has produced a practice framework for children's neurodevelopmental pathways.

NAIT have presented a proposal to SIGN for a single autism and ADHD guideline, with support from Healthcare Improvement Scotland.

Agenda item 4 – Q&A Discussion

Q to Lizzy

Is the 2 yr wait for first appt? 12-18 months for a pre-assessment chat, further 2 years after that. Really difficult to administer a large list with small team working short length of time together.

Are you the only area that provides for self referral? Believes so for adults. Marion Rutherford said D&G accept self-referral for children's pathway.

Were autistic people involved in your materials? Yes

Q to Vicky

Drop in referral numbers due to the length of wait?

Yes, hearing regularly from parents who feel the waiting times are so long that there is no point. Also hearing that schools are discouraging engagement with the system on that basis.

Q to Kabie & Joe

Do we need to take a different approach to diagnosis and take it out of the hands of overstretched professionals.

Kabie – in the long term, yes, but needs wider change to the system as we see the challenges getting private diagnosis accepted and if we went radical with diagnosis it would need wider systemic change to ensure this was accepted.

Joe – a question of how we put this in place.

Q to Marion

The SIGN guidelines need updated, can this be pushed even if it is not multi-neurodevelopmental?

SIGN gets applications from all disciplines. They have a finite resource and must prioritise. There is a strong case as there is no ADHD adult guideline, the children's ADHD guideline is so out of date its use is actively discouraged and the autism guideline needs to be revised.

Q to Marion

What reason is given for not recognising private diagnosis?

The lack of quality control and checks on private companies. It can be set up without stringent checks to ensure that a robust process is being followed.

Agenda item 5 – A.O.B.

Response from Maree Todd on invitation to meeting to discuss LDAN Bill. Minister outlined the steps which will be taken moving forward on developing the draft provisions of the Bill.

The convenor stated that he would write to the Minister again and advise the Cross Party Group of her response.

Agenda item 6 – Closing Remarks

The Convenor thanked those in attendance and closed the meeting.