

Cross-Party Group on Autism

25th April 2022, 14:00-16:00, via 'Zoom'

Minutes

Attendees:

MSP:

Alexander Burnett, MSP (Convener)
Stephanie Callaghan, MSP
Karen Adam, MSP
Daniel Johnson, MSP

Invited Guest / Speaker:

Lorna Johnston
Marion Rutherford
Dr. Shirley Moore
Lyndsay Macadam
Angela Stapleford
Dr. Fiona McCrohan

Secretariat

Rob Holland – National Autistic Society Scotland
Charlene Tait – Scottish Autism
Stephen Caulfield – National Autistic Society Scotland

Non-MSP Group Members:

Katie Sutherland	Jay Brownlee	Lorna Johnston
Shirley Moore	Callum McCrosson	Charlie McKenzie
Edward Fowler	Michelle Graham	Susan Chambers
Annie Humphrey	Aileen Shrimpton	Gina Appleton
Kabie Brook	Gordon Barlow	David Nicholson
Simon Stephen	Henna Cundill	Richard Ibbotson
Kirsten Mutch	Lorraine Harris	Carolyn Kennedy
Margaret Smith	Cath Purdie	Chris Griffiths
Clare Kennedy	Kate Monahan	Maria Chan
Maurice Frank	Rachael Grant	Hayley McMurray
Louise Moth	Catherine Steedman	Jean Foggarty-English
Ruth Young	Anna Nicholson	Lavinia Dowling
Isabella Williams	Rory Paterson	Tom Wightman
Fiona Clarke	Linda Singer	Dorry McLaughlin
Belinda Hook	Fiona Culbert	Rodger Watt
Fran Foreman	Susan Fullerton	William Rae
Lisa Moir	Jacqueline Campbell	Patsy Devlin
Karen Priestley	Jamie Kirk	Rachel Birch
Jacqueline Campbell	David Anderson	Catriona Stewart

Apologies:

Oliver Mundell, MSP
Annie Wells, MSP
Jeremy Balfour, MSP

Convener's Welcome

Alex Burnett MSP welcomed everyone to the meeting and introduced the theme of Diagnosis. AB highlighted the long-standing issue over the length of time it can take to receive a diagnosis.

Agenda Item 1: Feedback from 4th April Accessibility Meeting

Rob Holland, Acting Director – National Autistic Society Scotland, summarised the note from the recent Accessibility Meeting which took place on 4th April 2022.

This was the second Accessibility Meeting and was attended by various members, the Secretariat and the Convener.

The following were agreed by in the Accessibility Meeting as further steps that might improve accessibility of the online CPG meetings:

- A 10-minute mid-way break
- A Guide to the CPG for new members.
- The secretariat would provide an opportunity for pre-/ post-meeting questions to guest speakers.
- The Convener would provide an Agenda 'run-through': explaining the CPG running order at the beginning of the meeting.
- The Secretariat would update CPG webpage on the Parliament website.

RH commented that there were further things that could be done to aid accessibility which will be looked at future Accessibility Meetings.

AB asked if there are any further reflections then please let the secretariat know.

RH reminded the meeting that the Zoom 'Chat' function can be overwhelming so attendees should try to concentrate the subject that is being discussed and try and refrain on commenting too much when the speakers are presenting.

AB reiterated that post meeting questions could be submitted but that it would take time for a response.

Agenda Item 2: National Autism Implementation Team ('NAIT') - Diagnostic Pathways for Children

Lorna Johnston & Marion Rutherford from the National Autism Implementation Team (NAIT)

LJ and MR gave a presentation on neurodevelopmental diagnostic pathways for children.

The NAIT Team are professionals from Education, Speech and Language Therapy, Occupational Therapy and Psychiatry, who have considerable experience and expertise in working with autistic individuals of all ages, their families and others who support them. NAIT provide practitioner to practitioner advice.

They explained that timely diagnosis reduces stress and increases access to relevant support & information. Diagnosis matters is one of their key messages.

Post diagnostic support should be thought about before, during and after diagnosis for people waiting for and undergoing assessments and this support can definitely be less stressful if these needs are being met.

COVID has had a huge impact with highlighting the need for diagnostic assessment and reducing availability of appointments.

MR commented that the issues are really important but need to look for solutions to improve the pathway to diagnosis as well as pre and post support.

- MR highlighted how they had worked with autistic people and professionals to develop key messages and principles that applies across the board.
- Many conversations have taken place where they can support and challenge each other as they strive to improve on how things work – networks & relationships are key to make this work.
- We need to ensure using existing resources effectively.
- There are opportunities to now use blended approaches and some teams are looking at digital solutions and how well these work alongside face to face approaches.
- More professionals are needed and NAIT have a key role in developing professional learning and resources.
- Collecting the right data is key to understanding how things are improving and lets us think more about what we are measuring and how this impacts the quality of the experience.
- Successes need to be celebrated and find ways to highlight on 'what goes well'.
- Our ongoing structured professional networks are key to support the work we are doing.
- All health boards in Scotland have a children's autism assessment pathway and most are developing this into a neurodevelopmental pathway.

As a follow on the NAIT speakers highlighted the GIRFEC model (Getting it right for every child); meaning that no support should be diagnosis dependent.

NAIT also highlighted their work across four pilot site areas currently over the next few months to trial some of the recommendations in the feasibility study and looking at alternative ways to think about how we meet the needs and fill some of the gaps.

Agenda Item 3 - A Clinician's Perspective

Dr. Fiona McCrohan consultant based in Dumfries & Galloway works in Neurodevelopmental Assessment in Child NHS services.

FM shared her views and assessments in Scotland with three key themes: 1. Assessments 2. Structures & Supports in place 3. Times when things work and when the don't.

Assessments – FM has been involved with assessments for many years and seen the move to a neurodevelopmental model emerge over time which is more holistic recognises the overlap with ADHD, learning disability and other impairments/conditions among the autistic population.

Singular pathways can cause frustration and cause delays with families and that is the reason they moved to offering broader neurodevelopmental assessments.

Diagnosis allows us to find understanding and find similarities of our experiences with others which is key. FM is heavily involved in trying to develop this service in her local area but this is still under-resourced and struggles under huge demand with too little capacity. There is lack of early diagnosis particularly with autistic women & girls. She also highlighted the difficulties that autistic people face moving through this world which isn't autism friendly, which in turn may lead to them being victimised. We all need to feel a sense of belonging of having a place and being understood and accepted.

In Scotland our support and services should have all the needs of the child at heart at all time and should not be relying on a diagnosis.

Due to cuts to councils and education funding, understaffed, undertrained and overly stretched school staff and this trend has continued. Since the beginning of COVID there has been an increase in referrals to their service. Some young people have not been to school for 2 years and won't manage to get back into mainstream school.

FM felt that the education system is not supporting these young people equally and greater flexibility, humanity and support is needed. They need community, understanding, care and support and we as a society need Third Sector supports e.g. playgroups, coffee groups, garden clubs and walking groups plus many more.

AB thanked FM for her contribution and commented on a remark in the 'chat' re home schooling, often there are some anomalies in for example meal vouchers – if you are home schooling then you won't receive these. If you can send these examples into your MSP or the secretariat they can take these up with the local authorities as they are not being applied in the spirit as it's being intended.

Agenda Item 4 - Women & Girls

Lyndsey Macadam, CEO Scottish Women's Autism Network (SWAN)

LM gave some background on SWAN which is an autistic-led charity for women which includes a network of 600 women. LM explained that access to a diagnosis is one of the main issues that they are contacted about due to lack of services and lack of expertise and understanding of autistic women.

There has also been feedback from members that they have been told that they can't be autistic because they don't fulfil stereo types or ideas of what an autistic adult will look like or they seem fine and don't need any support or diagnosis which would only add pressure on an already stretched services.

Accessing the diagnosis is very important understanding on who we are and our identities and seeking support where we need it. We shouldn't be having to fight for the right to do that!

Dr. Shirley Moore is an Autistic Online Councillor working for SWAN

SM spoke about her own experience and was diagnosed 7 years ago. Since she has started counselling (for other autistic women) she has had numerous encounters with patients of mis-diagnosis.

SM explained that positive experiences are less frequent and they usually have to refer themselves privately due to bad experiences with the NHS.

Some of the work that SM has carried out with SWAN clients is to support women who have been unheard. SM clients have shared their diagnostic reports with her which have been brief and they have been denied diagnosis due to the absence of typical behaviours which are due to falling below the cut off of diagnostic tools. In research, many autistic people have difficulty filling in forms so answers are not meaningful.

The assessments that miss autistic women are done by individuals who have experience working with children, those with learning disabilities or are a forensic service but no experience working with autistic women.

Where a diagnosis is disputed these should be referred to more specialised colleagues which doesn't always happen. There is excellent training available and being developed but this is not reaching everyone.

A formal diagnosis gives a positive impact and there is a change that occurs but when this is rejected or refused or mis-diagnosed.

Angela Stapleford – SWAN Member

AS talked about her experience getting an Autism Assessment in Scotland and the issue of miss-diagnosis in women due to a lack of autism understanding.

AS highlighted that in parts of Scotland there is no diagnostic pathway for adults. Indeed, this was the case for herself where she was told by her GP that there was no adult assessments available and her only option would be to go private which would cost £2-£3k. This was out of her reach.

The process of trying to get an NHS assessment was long, exhausting and traumatising and one. AS spent her savings and got a non-clinical assessment carried out by an autistic woman and she concluded she was autistic which helped her move on and understand more about herself. These non-clinical assessments won't be recognised by some organisations but in her case made a huge difference to her wellbeing.

AB thanked the SWAN team and particular AS for sharing her experience which mirrors the experiences of people that has come to AB as a case work.

Agenda Item 5: Q&A / Discussion

Question – Private diagnosis

AB pulled together some questions from the Zoom 'chat' regarding diagnosis taking place within the private sector. In some areas diagnostic assessments have been outsourced to a company called Helios. Private assessments have not been recognised by the NHS Scotland and AB asked the NAIT team for comment.

The NAIT team explained that they don't have a particular stance or approach regarding private companies delivering diagnostic assessments but highlighted how they aren't regulated in the same way and that it is difficult to know what guidelines they are adhering to.

Where outsourcing occurs, the process should be linked up with those in health and education so they are working together. Some health boards choose to send all assessments for private diagnosis and only 50% of people get a diagnosis which is a wasteful approach.

The NAIT team highlighted a good practice example with Autism Initiatives working with a shared Governance approach within the NHS.

On the issue of private assessments not being recognised by the NHS there is an immediate need to ensure that any assessment takes place within a robust and recognised framework.

Question – training for diagnosticians

Q Catriona Stewart highlighted that those carrying out diagnosis do themselves not always have the relevant training and experience and that we should start looking at training people with lived experience and bring in insider knowledge to the process.

In addition, those who have received a diagnosis might be supported by autistic peers as the process itself can be traumatic and difficult particularly with the use of deficit language.

The NAIT team agreed professionals need the appropriate level of skill and experience and that robust succession planning needs to be in place to ensure that staff coming through are trained to the appropriate level otherwise they are continuingly playing 'catch up'.

They went on to highlight how one of the local areas piloting adult neurodevelopmental pathways are looking at how to do things differently. Ultimately there is a challenge with diagnosis often sitting within Tier 2 Adult Mental Health Services where they aren't resourced and prioritised appropriately.

Question – diagnosis waiting times

Q. Michelle Graham explained that she is a support worker working with children under 18 years old and asked what the current policy is to tackle diagnostic waiting times and support in light of delays brought about by COVID. She highlighted how many families are in crisis and the services don't have the capacity to support at this moment in time. Good family support workers are being lost as they feel they can't do their job properly because there are not the signposted services for them.

A. The NAIT team talked about how they recognised that systems and services were struggling but that work was going on across the country with a range of people at different levels in education and their health partners to look at COVID recovery.

Funding has been provided for the recovery process to each of the local areas and there was a children & young people's taskforce that worked prior to the pandemic and the outcome of that was that there was a set of standard for the neurodevelopmental specification for health services, but that funding should now be used in a more holistic way.

FM agreed with the above and it's part of an incredibly complex and much bigger picture. She reiterated that there is massive pressure on the system and the issues are much greater due to COVID. The link with the broader communities are also really important.

Question – diagnosis waiting times and private diagnosis

Q. Susan Chambers described how she had been campaigning for 30 years on subjects such as diagnosis waiting times and there has been little action particularly for older adults. How do we move forward on this and what role might the CPG play?

Q. Kabie Brook asked that with diagnostic assessments taking up to 5 years, some people feel forced to go private – this is not a choice, it's desperation and causes financial hardship and then as above sometimes the private diagnosis gets rejected from the NHS – what can we do to resolve this with the local authorities?

A The NAIT team acknowledged the challenges she was describing and reiterated that this is not just about recruiting the people but it's about having the right people with passion, knowledge, information and of course having the appropriate funding in place.

Question – 'Positive Behaviour Support'

Q. Fiona Clarke asked why Positive Behaviour Support was being promoted by Scottish Government and local authorities without sufficient evidence. In particular she said that Positive Behaviour Support was not suitable for autistic adults.

The NAIT team responded that they had developed training for education professionals which had been hugely oversubscribed (they have delivered to over 500 professionals to date). The training is focused on improving the environment and support offered to autistic learners and is intended to bring about a shift in mindset.

Question – diagnosis and early years

Q. David Anderson described how he was diagnosed at the age of 52 and the journey to get there was horrendous. Eventually after 10 weeks and many obstacles he received a diagnosis through the NHS. He commented that Autism runs in the family. He said that autism is life long and what is being done to identify children and a young age?

A NAIT representatives agreed that more could be done to identify those within early years settings although there are challenges in doing so.

Question – diagnosis and women and girls

Q Eddie Fowler described how he feels it's more difficult more so for girls to get a diagnosis. Because boys can present in a more challenging way and so can be put forward for a diagnosis more quickly.

A NAIT representatives responded that they agree with the points SWAN and others have made around the challenges facing women and girls and diagnosis.

More broadly they flagged how there are differing views among professionals around whether or not diagnosis is a high priority. It's NAIT position that diagnosis is important and for many forms an important part of their identity. Furthermore, a timely diagnosis can prevent mental health difficulties later in life.

Convener's Response

AB thanked the speakers and everyone for attending. AB commented that there has been a very extensive debate on diagnosis.

In answer to Susan's question about the role of CPG in moving this agenda forward, AB responded that the CPG doesn't have a budget or legislative powers rather it is a forum for discussion and to inform members and MSPs as to what the issues and solutions are.

However, he encouraged members to engage with MSPs on the issues so that they can raise it with Government ministers. In addition, he will look at potential questions he can ask in the Chamber.

AB thanked the Secretariat for their support organising the meeting and to the speakers for their excellent contributions. AB commented that there were 75 people on the call which was an excellent turn out. The next meeting will be in early Autumn.

AOB

No other items were raised by those present.

Written Contributions Made in the 'Zoom' Chat Function

Each of the entries below are verbatim lifts from the 'chat transcript', as provided by Zoom.

Only those contributions marked with a 'C' at the time have been included in these Minutes, in line with what the Secretariat set out in the pre-meet papers.

Consequently, the entries below may not 'flow' as a conversation; however, many are effective as stand-alone remarks.

Kate Monahan: C: Agree so much about the problems in schools. There is surely no other disability where the main context of diagnosis, referral, assessment and delivery of services to meet need and manage disability is school? this remains problematic, even harmful. Schools have no appropriate expertise, insufficient resource and offer inadequate support. Great presentation. thank you.

Carolyn Kennedy: C: Very well said Fiona - as CEO of Better Lives Partnership, a Third Sector Transition Provider in D&G we welcome progress in the support of alternative options for young people with autism and additional barriers to enable them to be the best they can be. We need revenue funding and recognition to enable us to be sustainable. Referrals to our programme are growing at a pace.

David Anderson NASUWT: C. Being told by the medical profession that you don't need to be assessed, despite the request of the patient who wants to know if they are and this is clearly being said by the Swan rep. Is this access being denied for financial reasons or pastoral as the medial professional thinks it would be detrimental for the person in front of them?

Gordon Barlow: C. People with subtler presentations of autism, often referred to as 'mild' or 'high functioning' autism, are more and more facing a double edge sword. Smart and capable, often able to be the best actors of all but without recognition and understanding of hidden difficulties it can all fall flat.

There is a need for a multi-dimensional perspective, recognising that strengths and difficulties coexist, and can often be quite pronounced - thereby leading to a complex picture. And let's not forget, that the seeming outwardly pretence of coping can mask tremendous hidden strain and pain.

Kabie (they/them) ARGH: C: AMASE have written a very good paper on PBS, see here: <https://amase.org.uk/pbs/>

Dr Catriona Stewart OBE: C: That was so good, Lyndsay, Shirley and Angela, spot on, beautifully articulated x

Michelle Graham: C: What is the current recovery process to tackle diagnosis waiting times and support, given many families are in crisis; many kids out of school. Myself and many other support workers are so frustrated that families are being signposted around many services that just don't have capacity to support at the moment.

Gina Appleton ND Parent Carer: C: Note that behind every child waiting for diagnosis is a parent carer and a family/siblings. If a child's needs are not being met, then there is huge stress for the child and their family. I know of many children that are not in school post covid because of anxiety with or without a formal diagnosis of autism.

Angela Stapleford (she/they): C: There is also the issue that if you have had to go for a private assessment - clinical or non-clinical this may not be recognised by local authorities, and does not lead to any support from services. The only support I have received has been from my own research, small independent autistic led groups and SWAN.

Fiona Culbert: C: Isn't the issue regarding the place of private diagnosing organisations within the wider framework is actually money. The contract that the likes of Helios will have is negotiated by a local authority/NHS/IJB procurement framework. If follow on post diagnostic support is required that also requires funding. It is all however moot in that the ten year Scottish Autism Strategy made it very clear that by year ten that all areas of Scotland would have systems in place that would support autists holistically "through the lifespan". It is not the private providers nor third sectors responsibility that the outcomes of the Strategy are still to be met. This has been highlighted going forward with the four strands - A healthy life, Choice and control, Independence and Active Citizenship. Bottom line autists should have choice in who they wish to diagnose them and how their support looks.

Charlene Tait: C: I think it's important to hang onto the "before, during and after" principle. This requires infrastructure - a great deal of which has been dismantled or, as in the case of much of the Third sector provision, is plagued by short termism in terms of funding and vision. Fiona mentioned walking groups, peer support etc, these are all relatively low cost yet are really challenging to sustain. The "No wrong door" approach is one I really welcome but has to include third sector and community settings.

Shirley Moore (she/her): C Perhaps the multi-disciplinary team should always include an autistic individual? There could be a pool to choose from perhaps, in the same way that panel members are recruited and employed.

Gina Appleton ND Parent Carer: C: My experience of my child's diagnosis in 2017 was good in that CAMHS did an assessment promptly and the process worked well for my child and myself. But if he hadn't presented with an anxiety breakdown he would have been put on a long waiting list.

Gordon Barlow: C: No intervention is without cost but the costs of inaction will be far higher, all the more so in human suffering. Smart, proactive support can make the world of difference and it needn't cost the earth.

Angela Stapleford (she/they): C: Please can you take that forward with NHS Dumfries & Galloway too.

Susan: C: I'm possibly being naive but why can't we be seeing private service as supporting the high demand and taking pressure off the NHS. Why does it have to be seen in an almost competitive way? I am in this situation personally at the moment and we have chosen to go private as I am not prepared to see my child damaged by the system without the right support (and possibly medication) to support him to achieve his best. It is so frustrating that the private diagnosis can be rejected. Can evidence of the diagnosis and assessments undertaken not be provided? Surely the assessments being undertaken are the same as within the NHS? And those diagnosing in the private sector are also qualified professions with a requirement to work under the requirements of their HPC Body?

Susan: C: (Kirsten Mitch) I'm sure they will often have the same qualifications as their peers who work in the NHS.

Kabie (they/them) ARGH: C: Many private clinicians are ex NHS who have left frustrated with the system.

Maurice Frank ELAS: C: the idea of needing parental/youth info existed in Cambridge's diagnoses around 2000, but seemed to have disappeared by the time I was diagnosed in 2003 without that being required at all: talking about my own youth sufficed. So how can that out of date requirement have come back ??

Simon Stephen - parent / carer: C: As a parent attending for the first time, I'm more than slightly concerned that this is nothing more than a very wide ranging discussion. There don't appear to be any objectives and a defined strategy to achieve those objectives. I've heard "we welcome those views" and similar such statements. As Kabie said "we are we are and where we are 20 years ago" My fear is we'll be here in another 20 years

Fiona Clarke/AMASE: C: It is an issue when diagnosis is only given once there has been a significant negative impact in your life.

ENDS.