



RCSLT NI Response to consultation to inform development of NI Autism Strategy 2023-28

Further to our contact with the Autism Strategy Delivery Team we have engaged with our members in Northern Ireland, and also with our colleagues across the UK, to inform the below comments on the relevant key areas identified in the strategy consultation. RCSLT are also currently consulting its members across the UK on updated Autism Professional Guidance which has been co-produced with national expert advisers and people with lived experience – this work has also helped to inform the comments below.

We would like to thank the Department for their work to gather the views of people with lived experience. Working in collaboration with autistic people and meaningful co-production is critical to improving services and the lives of autistic people in NI.

Speech and Language Therapists (SLTs) are a key profession in the diagnostic assessment of autism and provide crucial support to autistic people across health, education, social care and justice settings. We would be grateful if the Department can add RCSLT NI to the list of Autism Strategy stakeholders and would welcome further opportunities to engage with the team on the strategy as it progresses.

For any further information please contact Vivienne Fitzroy, Policy Adviser, RCSLT NI, Vivienne.fitroy@rcsltni.org.

Priorities for Autism Strategy 2023-28

Early development work has indicated there are 10 priority areas that the next strategy will address. We have not provided comments in all areas, only those where our members can offer significant skills, experience and expertise.

Waiting lists for autism assessment.

Q. Please provide any comments or information you wish to highlight in relation to autism assessment services, this can include any services offered, or gaps for, those on waiting lists for assessment.

- Our members have reported that families should be signposted as soon as concerns arise to supports such as evidenced based information. This should be on a regional basis so that there is equity of access to the same advice. This support should be evidenced based and neurodiversity affirming and based on what we have learned from individuals with lived experience.
- Waiting lists are long and this has an impact for families and children. When considering how best to support initiatives to reduce the length of wait it is important that the quality of the assessment is not compromised and remains NICE compliant.

- As in other jurisdictions, pressures on resources in Northern Ireland impact access to diagnosis and we welcome the identification of improving access to autism assessment as a key pillar of the next Autism Strategy. Limited resources may impact the ability to follow diagnostic guidance, as highlighted in the NICE autism guidance surveillance 2021. In response to both the complexity of diagnosis in neurodevelopmental conditions and the impact of long waiting times on neurodivergent people and their families, many are calling for multi-diagnosis assessment pathways or neurodevelopmental pathways (e.g. Male, Farr & Reddy 2021; Rutherford et al 2021; Rutherford & Johnson 2022).
- Traditionally, diagnostic pathways and guidance are centred around specific diagnoses, having separate pathways such as for autism, for ADHD and for mental health conditions. Condition-specific pathways can make it challenging to fully understand a neurodivergent person's profile and identify their support needs. It can mean that individuals seeking diagnosis may not have access to professionals with the breadth of knowledge of co-occurring conditions and at best, may experience sequential long waits on different diagnostic waiting lists.
- The assessment process and pathway models should consider the services that the child is already open to. Some of those professionals may be able to assist with providing information that could contribute towards the diagnosis or they could contribute to the diagnostic process. The information and case histories they take could be reconsidered to encapsulate the information that would help with the DSMV. For example: if they are open to SLT and there is a lot of information from assessments and intervention then this could be used to aid the assessment. SLTs should be part of the MDT discussion if they have the required competencies, which means that the child does not need to go for a separate autism assessment but might just need to see a paediatrician or a psychologist
- Scotland, through the National Autism Implementation team (NAIT) recommend a shift towards a single Neurodevelopmental pathway to diagnosis (see excerpt below) with progress being made e.g. some areas are currently testing new models aiming to roll out new Neurodevelopmental Diagnostic pathways in 2023.

Excerpt from National Autism Implementation Team (NAIT) in Scotland:

“Internationally recognised diagnostic criteria for Autism Spectrum Disorder (ASD) are provided in the Diagnostic and Statistical Manual of Mental Disorders (5th ed.; DSM–5) and the International Classification of Diseases, Eleventh Revision (ICD-11), under a newly included category of ‘neurodevelopmental disorders’, which are lifelong and not episodic mental health conditions. The behaviourally defined criteria continue to be ‘impairment’ or ‘deficit’ focused and diagnostic terms use the language of ‘disorder’, which might be considered to be at odds with social models of disability, realistic medicine and the neurodiversity paradigm.

There is clear evidence that different neurodevelopmental conditions defined as they are currently, usually co-occur and overlap and it is often the combination of individual profile or ‘neurotype’ together with environment that determines support needs rather than diagnosis. One consequence of this development in diagnostic criteria is that it supports the shift in clinical practice, away from a ‘single condition’ focus towards ‘neurodevelopmental’ pathways and a diversification of our approach to assessment, diagnosis and intervention.”

Collaboration and joint working

In NI we are aware that each Trust has a different system and so how SLT is provided to the assessment process is varied dependent on locality. For example, in SHSCT AHPs can refer directly for ASD assessment from 5 years onward. Younger children are referred by Community Paediatrics. Core SLT in SHSCT provide assessment and intervention for children pre and post diagnosis and provide reports to support the diagnostic process. Work has been ongoing to streamline this process and ensure timely accurate information is shared.

A working group has been established to develop liaison between assessment and intervention teams post diagnosis and a draft SOP for joint working between Autism Intervention and SLT has been developed and shared with staff for comment. Information regarding SLT providing services to Social Communication Classes (formerly ASCs) across the trust has been shared for ease of liaison and to support joint working.

Adult Autism Services

Q. Please provide any comments or information you wish to highlight in relation to adult autism assessment services. Views are being sought on use of private assessments by adults, services made available to adults and what type of support would be most helpful.

We would welcome further commissioning of support to autistic adults across health, social care, education and employment services from the age of 18. In particular we would welcome further consideration of services for autistic adults without a learning disability. Although an autistic adult may be able to meet their own basic needs - prepare their own meals, get dressed independently and drive – social isolation and communication needs can have a significant impact on a person's quality of life. If unsupported may result in worsening mental health and behaviour that challenges.

There is also a need to ensure that adults have effective pathways to assessments, particularly where additional vulnerabilities and risks are present. This includes effective pathways and access to services for young adults with care experience and/or in contact with the justice system. This is particularly critical as unidentified or masked needs, particularly communication needs, can have a detrimental impact on a person's ability to engage with rehabilitation services, such as anger management or substance misuse services, and mental health services.

"One young woman received a diagnosis of autism at almost 18 years old. She had many services including CAMHS, Social Work, alternative education placements prior to this (SLT assessment) and although there were concerns noted, speech, language and communication weren't considered. I think this demonstrates that these issues can be very hidden in some young people". SLT, Children and Young People's Residential Team, WHSCT

Emotional Wellbeing and Mental Health

Q. Please provide any comments or information you wish to highlight in relation to emotional health and mental health for autistic people this can include programmes or services within HSC and schools /education or third sector and what has been successful and any barriers to access.

The RCSLT working with members from across the UK has highlighted concerns that healthcare professionals are not effective in supporting autistic people with mental health problems. In addition to difficulties accessing both CAMHS and adult mental health services due to high thresholds, *specific barriers related to autism and communication needs include:*

- People are frequently required to verbally express themselves in order to access mental health services – people need to be able to express themselves in a clear, cohesive way and know what information is relevant to share. Autistic people may have difficulties expressing themselves in this way, and as a result may not get beyond the referral process – this is particularly the case for services which conduct a screening assessment over the phone.
- Differences in communication style can mean that professionals may not believe an autistic person when they say they are having suicidal thoughts, as their non-verbal communication may not reflect the distress they are feeling.
- There is a risk of diagnostic overshadowing – where signs of a mental health condition may be attributed to their autism. For example mental health services may reject referrals for autistic clients on the basis that anxiety is deemed part of the neurodevelopmental diagnosis. Conversely, communication breakdown can be wrongly interpreted as emerging psychosis.
- IAPT services may deem autistic people as being too complex for them to deal with.

The RCSLT recommends that mental health professionals should be trained in supporting the communication needs of autistic people, to include the RCSLT's [Five Good Communication Standards](#) which sets out the reasonable adjustments that autistic people can expect.

Our members in NI have highlighted that there is an ongoing need to educate and advise how to support EHWP at different ages, stages and in different presentations of autism. There are many things to consider:

- Ask what matters to the autistic person and what will aid their EHWP so they are involved in that discussion
- Presume competence when trying to involve the autistic person and give them a means to communicate and express their emotions
- Do not assume what will make them feel better.
- Value, accept and try to understand what being autistic means for the individual
- Understand the impact of masking.
- Understand and recognise that what makes an autistic person happy/sad may look different but is valid for them. For example, they may be alone but are not lonely. Others feel that they should have friends but they prefer adults, or prefer to be alone
- Understand that an autistic person may express their emotions in a different way, for example they may hand flap or jump and that this should not be suppressed or stigmatised.
- Recognise the impact of the environment on the functioning of an autistic person. It might overwhelm them and exhaust them leaving them depleted in energy. They may need quiet places and breaks.
- SCERTS is a neurodiversity affirming approach to supporting children and young people in naturally occurring environments and moving away from compliance and reward-based approaches or neurotypical goals <https://scerts.com/>.
- Improved referral opportunities via single point of entry for children with Emotional Health and wellbeing concerns. There is a need for services to be more fluid at times to respond in a timely way to the needs of an autistic person. Highly structured models of working can make joint inter-agency working challenging.

- Improved community-based commissioning to provide help and support to families.
- Incredible years training

Transitions

Q. Please provide any comments or information you wish to highlight in relation to transitions including primary to post-primary, school to college or university, moving to a new place, employment, within HSC, wider community.

Please be aware that SLT provide annual review reports and transition reports / transfer reports as children travel through the service and as part of our collaborative working with education. For a child with communication needs this is a vital aspect to supporting smooth transition and we would welcome if the new strategy recognised that communication needs should be supported during the stresses of transitions.

Q. How could transitions be improved in relation education, health and social care, employment, independent or supported living?

Our members have highlighted specific areas they feel would better support transitions:

- Clearer pathways
- Better interface/ joint working between agencies
- More flexible ways of working to meet the needs of the autistic person rather than being confined to a system that only copes with certain types of intervention.

Educational Environment

Q. Please provide any comments or information you wish to highlight in relation to the confidence and skills available within schools to support young people; barriers that could be eased through reasonable adjustments; access to additional technology or equipment in schools; the SEN framework and the changes it will introduce; services from the Middletown Centre for Autism; barriers to accessing further or higher education; what support should be in place for autistic people in education settings?

The prevalence of autism in schools is high and our members felt that it would be supportive for teachers to access training on how to support autistic pupils of all ages and abilities as part of undergraduate training. Further development of skills need to be maintained through regular CPD based on the latest evidence/best practice.

It is important to think of the autistic pupil holistically. Every autistic pupil will have different needs. While there are some generic supports such as use of visuals, a one size fits all approach is not beneficial. The increase in discussion and awareness regarding neurodiversity is welcomed and services will need to continue to develop and adapt in response to users requests and needs for intervention using particular approaches, for example, access to AAC- particularly VOCA; Child-led play based interventions following NLA approach; collaborative working with other AHP colleagues in what may have been a uni-professional intervention previously. Staff skill mix, level of experience, confidence, scope of practice and supervision will all need to be considered.

We recognise the pressures on teachers, nonetheless, it is of enormous benefit to a child if education professionals are provided with the time and resource needed to work with others who know the child. This includes their families and other professionals such as SLT to understand what supports might work for that particular child, for example access to alternative communication or sensory diet. Changing the environment to reduce sensory stimulation/ overload and adapt to the

needs of autistic children within the classroom can be achieved at low cost, for example reducing wall displays, having a clutter free classroom. Having a 'safe space' or 'sensory room' that children can access to help regulate is beneficial.

SHSCT have developed a SEN Training menu with support / advice/ resources available for use in SENU. A plan of assessment, intervention and training has been put in place and link therapists for each school have been established.

However as demand for special school places has grown exponentially and the EA has been under severe pressures to find suitable placements for children this has resulted in the opening of unplanned units without prior notice to health staff. This has placed a heavy burden of pressure on staff and potentially created unrealistic expectations for individuals and families. Many members report to us that the delivery of service to new classes has been challenging.

RCSLT NI hope that this strategy will link across to other vital workstreams including area planning, the new SEN framework and relevant health workforce planning workstreams – specifically SLT. It will be important for the next strategy to adopt a multidisciplinary and cross-sectoral approach to its key priorities to ensure that service modelling and commissioning will be sustainable and meaningful to autistic people and their families, across the entire lifespan of the new autism strategy.

Community

Q. Please provide any comments or information you wish to highlight in relation to wider community and participation for autistic people? [RCSLT NI will highlight opportunity for communication access to be adopted for businesses and facilities in the community]

While acknowledging progress in the public's general awareness of autism, speech and language therapists identified some specific issues in relation to the public's understanding of the communication of autistic people, including:

- the specific communication style of autistic people who don't have a learning disability.
- understanding the links between communication needs and behaviour that challenges.
- There is a need to develop more integrated approaches to supporting autistic children and their families from an early age in their local communities.

Early Intervention Model – working in collaboration to place the child at the centre

An example of good practice is the current Early Year Pilot project between the BHSCT SLT/OT/Paediatrician/Surestart and 2 local charities (SOLAS AND Kids Together) and the EA.

Sure Start therapists will often refer children to SLT for direct intervention – this can be community SLT or Child Development Clinics for those with more complex/ additional needs. Professionals identified a new opportunity for some partnership work in order to better support children with possible autism who were waiting. The aim was to empower and build capacity in those around the child, whilst also enabling community-based therapists to deliver direct therapy/ input as needed.

SLTs are working into the local projects to support preschool children and nursery aged children who did not gain places in special schools. They are working closely with the projects following a structured award winning programme “ The Partnership Programme” (NAS professional award 2019).

The model has been further developed to incorporate agreed referral process for children being referred to the EA, as well as a pilot on completing the assessments for Autism within the project. The pilot will be independently reviewed later this year.

- Voluntary groups do amazing work to support families and children. With increased capacity within SLT there would be more opportunities to support training on how to support the development of speech, language and social communication within a communication rich environment in their groups. The CDC SLT team have undertaken some training for local family hubs in North Belfast and once again if there was more capacity this is an area that could be further developed.
- Autism is a part of all communities but access is not equitable to support services such as Sure Start or services that work in only certain postcodes. There should be equitable access across all postcodes as all the families and children need support no matter where they live, what socio economic group they are in or cultural background they are from.
- Greater awareness and acceptance of neurodiversity in wider society.
- Changing our language and projecting a positive view of autistic people in our communities (see attachments).