Clare Haughey, MSP
Convener, Health, Social Care and Sport Committee,
The Scottish Parliament,
Edinburgh
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29th April 2025

Dear Colleagues,

On behalf of Child Heads of Psychology Services (CHOPS) (including CAMHS) in Scotland, we are writing with recommendations to improve the experiences of children and young people with neurodiversity across Scotland; and improve timely access to equitable service provision across the country. This paper focusses on those aged under 18, however we recognise the importance of a lifespan approach.

EXECUTIVE SUMMARY

1. *The current population of children and adolescents and the world they are living in is markedly different to that of ten years ago.*
2. *For multiple reasons, requests for assessment and diagnosis of Neurodevelopmental Disorders have increased exponentially and demand currently vastly outstrips capacity.*
    - *Waiting times for specialist assessment are estimated at 6 years for those under eighteen in some Board areas, with marked geographical differences in terms of service provision.*
3. *Without whole system consideration and radical systemic change, individual's social, emotional, cognitive and developmental needs are not being adequately met, with associated systemic risks to these individuals, their families and carers, and to wider education, health and social care service provision.*
4. *A significant paradigm shift is required, including -*
    - *A move away from the historical medical model of specialist assessment and diagnosis first, followed by support and intervention.*
    - *A move to an individualised needs-based, stepped and matched care approach.*
    - *A strong focus on whole systems ownership (Multi-Agency, Community-based, Education, Applied Psychology / AHP, Social Work and Health).*
    - *Provision of tailored needs based support at the earliest stage possible, with no barriers in place to receive this.*
    - *Use of individualised formulation and bio-psycho-social frameworks to determine the professionals or services best suited to meet needs.*
    - *Led by Psychology and Allied Health Professionals (AHP's).*
        - *Delivered in a multi-agency and multi-disciplinary manner.*
    - *Prioritising understanding need and delivery of support is an accessible, compassionate, evidence-based, trauma informed, effective and timely way to meet identified needs.*
    - *Acceptance of self-identification and recognition of the need for a cultural shift to truly become a neuro-affirming society, with acknowledgement that whilst needs-based approaches are acceptable for some, the process of diagnosis is necessary for others.*
    - *A specialist assessment pathway should be an important part of a service model, but not at the heart of it, with an increased use of consensus diagnosis where appropriate.*
5. *Recommendations for key underlying principles for service models are outlined.*
6. *A review and refresh of the Scottish Government Neurodevelopmental Service Specification is required, based on the above.*
7. *A review and refresh of SIGN and NICE guidelines is required.*
8. *Psychology led research into factors underpinning the increase in demand and associated needs is required, alongside evaluation of different ways of responding to this.*

The context - recognising a different population and the need for radical changes to service models and delivery

An increasing body of evidence, both academically and empirically as well as from a clinical perspective, suggests that the current population of children and adolescents (those aged under 18) in Scotland in 2025 is now markedly different; socially, emotionally, behaviourally, cognitively, physiologically and psychologically; compared to that of ten years ago (as evidenced in the HBCS 2022 Survey[i] in Scotland).

Research is growing around the impact of rapidly evolving technology, access to smartphones and the internet on our children and young people. This exists in parallel with marked changes in terms of (i) the spaces and communities children and young people exist and live in (ii) the wider world around them; (iii) parenting styles and opinions, and (iv) societal attitudes and general expectations over the last few decades. In addition, the influence of various global and political factors continue to be of relevance, including the Covid-19 pandemic and the associated impact and consequences of this for those who lived through this as an individual aged under 18.

The scale of the change around and within children and young people in Scotland and the associated challenge in schools is outlined in the Scottish Government report, Relationships and behaviour in schools: national action plan 2024 to 2027[ii] (published August 2024). A recent Audit Scotland report[iii] (February 2025) highlighted that since legislation was put in place in 2004 around additional support for learning there has been an eight-fold increase in accessing this, with 40% of Scottish pupils receiving this at the time of the report.

Increasing public interest in and recognition of the concept of neurodivergence across the age range and associated opinions regarding how to best understand, respond to and support this are now some of the most hotly discussed topics within society at present.

Increased access to openly available information online contributes to differing views, with a plethora of differing language and narratives to navigate, including the terms Neurodiversity, Neurodivergence, Neuroconvergence, Neurodevelopmental Disorders, Neurodevelopmental Conditions and the wider inclusive terms Neurodevelopmental differences and Neuro-affirming communities.

Differing views and expectations exist within and between the general public, those who have a neurodevelopmental difference and those who live with and care for an individual with specific identified needs. Different service offerings exist from public, private and third sector services across the country; with variance in waiting times.

Requests for assessment and diagnosis of Neurodevelopmental Disorders within NHS Scotland have increased exponentially in the last five years and this demand currently vastly outstrips available capacity within Children's Services. Factors underpinning this increase in demand are multi-factorial and are not discussed here, with further multi-disciplinary research required.

The current clinical and political position

It is now accepted within specialist NHS clinical services for those aged under 18 that previous models of service delivery, based on diagnosis of single conditions, are outdated and inaccurate, with Neurodevelopmental Services moving to incorporate Autism, ADHD, Intellectual Disabilities, Fetal Alcohol Spectrum Disorder (FASD), Developmental Language Disorder (DLD) and Tourette syndrome.

Whilst definitely useful in many ways and helpful in highlighting the situation and offering some clarification as to need, the separate Scottish Government CAMHS Service[iv] and Neurodevelopmental Service[v] Specifications have, arguably, resulted in an unintended consequence of setting up silo-based working. This has created a diffusion of responsibility between Education, Community Paediatrics and CAMHS in terms of perceived responsibility for either assessment, diagnosis and / or support for those with neurodevelopmental differences. The Neurodevelopmental Specification was also predicated on the outdated position with regards diagnosis and co-morbidity.

In the context of Education, Community Paediatrics and CAMHS striving to meet other key service requirements and a lack of consensus or consistency regarding which services hold responsibility for the delivery of Neurodevelopmental assessments; multiple children and young people with reported neurodevelopmental needs and their families / carers have fallen between the gaps of these respective services; or they have been put on increasingly lengthy waiting lists for assessment and diagnosis where specialist Children's Neurodevelopmental Services do exist.

CAMHS and Psychological Therapies (PT) received an injection of funding in 2021 to support service improvement and management of mental health waiting times, which would include the completion of Neurodevelopmental assessments for children and young people who meet referral criteria for CAMHS as part of a holistic assessment and formulation of need. However Community Paediatrics, who have historically also contributed to Neurodevelopmental assessments in a range of ways across different board areas, did not; leaving the Paediatric workforce and their wider patient group even more under pressure and vulnerable with the exponential increase in demand for Neurodevelopmental diagnosis.

A very small amount of specific funding was allocated to Boards with the intention to implement the Neurodevelopmental Service Specification however it was not sufficient to provide capacity to either recover waiting lists or invest in developing an integrated whole system approach. Although various Scottish Government driven national tests of change have occurred around Neurodevelopmental Service provision for children, they have had short term funding and have failed to yield a clear and effective national direction.

A predominantly medical model of assessment, diagnosis and treatment, particularly for ADHD, continues to exist and has resulted in waiting times bottle necks for this; with limited development of first line recommended community-based holistic psycho-social and / or psychological interventions in some Board areas. This is significantly out of kilter with the current evidence base. Provision of holistic psycho-social post diagnostic follow up is highly variable across the country.

The labelling, medicalisation and pathologising of differences continues to be a topical debate. Psychologists are well positioned to lead research into the rise of requests for Neurodevelopmental assessment, exploring issues such as the impact of the covid-19 pandemic on child development and opportunities to scaffold the development of social communication, developing cognitive skills such as focused attention, learning organisational skills and managing emotions in the context of understandably uncontained adult responses; as well as the social, emotional and cognitive impact of the rapidly changing world children and young people live in.

With the Scottish Government direction to exclude assessment and diagnosis of Neurodevelopmental Disorders from CAMHS referral to treatment (RTT) reported waiting times for psychological therapies[vi]; current waits for Neurodevelopmental assessment and diagnosis in

children and young people are now not reported in most Board areas and are thus effectively hidden from the public domain.

In the absence of a nationally shared functional electronic records system it is not possible to currently adequately record or compare support offered in different Boards to those where neurodiversity is relevant either in the community or whilst a family is waiting to be seen.

There are now marked geographical differences in terms of whether or not Specialist Neurodevelopmental Service provision exists; and where it does, waits for assessment are internally projected at 6 years for those under eighteen in some Board areas, with proposals to close waiting lists in others. This means that a large proportion of children and young people will age out of Children's Services before they are ever seen. With a similar exponential increase in demand in Adult Services and even longer waits and / or an absence of availability of services, this is neither an acceptable nor sustainable position. Due to variance between child and adult services, transitions for those with Neurodevelopmental Conditions at age 18 are not accepted in some areas, with Adult Community Mental Health Teams (CMHT) and GP's each looking to the other.

There is variability regarding the threshold for specialist clinical assessment, that is who needs a structured clinical assessment, or who may benefit most from more timely abbreviated approaches that can be done in collaboration with Education, third sector or community-based services. There are also skills gaps and training needs in order to accurately identify needs and provide support for children and young people in schools and the community well; with pressures on Education meaning they struggle to release capacity for this.

Acceptance of self-identification and recognition of the need for a cultural shift to truly become a neuro-affirming society are increasingly being discussed, however both remain at odds with the traditional medical model of service delivery which focuses on diagnosis. Furthermore, whilst needs-based approaches are acceptable for some, the process of diagnosis is both validating and necessary for others. This is particularly important for those with ADHD as medication remains a recommended and beneficial treatment for some children and young people with moderate to severe / combined ADHD. Access to some adult services for people with Intellectual Disability, or for guardianship applications, also relies on formal diagnosis.

There is recognition that neuro-diverse children and young people can have significant vulnerabilities. Over a three -year period between 1st April 2019 and 31st March 2022, 35% of children and young people with Autism who died in England were categorised as dying due to suicide or deliberate self-inflicted harm, which was significantly higher than the non-autistic population (14%) (National Child Mortality Database Programme (NCMD)[vii], July 2024). A whole system stepped approach to truly understand and meet the individual needs of neuro-diverse children and young people is urgently required, using a formulative needs-based model rather than only diagnostic categorisation.

A new way forward / Recommendations.

NHS Fife have successfully managed to do things radically differently by developing an integrated whole system approach to the provision of support for children and young people with neurodiversity as outlined in Audrey Espie's paper published in October 2024. This has involved a huge paradigm shift with a brave and bold move away from the historical medical model of assessment and diagnosis first, followed by support and intervention. The model is not discussed in detail here as this is available elsewhere. This model is being reviewed and evaluated regularly to ensure it is achieving what it set out to in terms of meeting the needs of this population.

The need for whole systems planning and ownership of this complicated and complex issue is underpinned by principals from the United Nations Convention on the Rights of the Child (UNCRC)[viii] and Getting it Right for Every Child (GIRFEC)[ix] as well as multiple other interdependent policies and legislation.

Prioritising understanding need and delivery of support is an accessible, compassionate, evidence-based, trauma informed and effective way to meet identified needs. Whilst different Board areas have examples of good practice, there are a number of key underlying principles within the NHS Fife Neurodevelopmental model that should be the foundation of developments across Scotland. These are –

- A paradigm shift away from the historical medical model, to a needs-based, stepped and matched care approach.
- Use of a public health lens.
- Timely access to meaningful early intervention with needs-based support at the heart of this.
- Led by Psychology and AHP's.
    - Delivered in a multi-disciplinary and multi-agency manner.
- An individual, collaborative formulation-based approach, utilising a bio-psycho-social framework with the individual needs of a child, young person and / or family and carers determining the professionals or services best suited to supporting them.
- An approach that is inclusive, service user led and needs-based.
- A strong focus on whole systems ownership (Community-based, Education, Applied Psychology, Health and Social Care).
- Increased use of digital resources.
    - A national platform with psycho-educational materials, easy access to therapeutic interventions and groups, tailored to need and with embedded local links.
- Increased use of digital options to support assessment.
- Stepped and matched care as key underlying principles.
- A focus on supporting wider workforce development within Education (in line with the Education (Additional Support for Learning) (Scotland) Act 2004)[x]
- A clear national competency based framework for different levels of service provision.
- Interventions and supports that are evidence-based.
- A specialist assessment pathway as an important part of a service model, but not at the heart of it.
- In line with NAIT principals.
- As per NAIT principals, assessment should consider the neurodevelopmental profile of the child, including complex differential diagnosis, comorbidity and individual strengths and difficulties.
- Where appropriate, utilisation of consensus-based diagnosis.
- Recognition of the importance of the AHP workforce, particularly Speech and Language Therapy and Occupational Therapy.
- Recognition of the importance of the Educational Psychology workforce.
- Development of peer support systems for parents, carers and young people.
- Development of peer support systems for professionals.

Neurodevelopmental differences are not mental health conditions, though these can be closely linked or co-occur. Children and young people with mental health conditions require timely access to services, with a recognition that identification and treatment of mental health conditions can be more challenging for those with co-occurring neurodivergence.

A formulation-based model means that early intervention and universal provision for neurodiversity is not confounded with or built with the same workforce as responsive, specialist CAMHS services (that are inclusive of children and young people with neurodiversity). Holistic formulation led decisions should underpin escalation or braiding-in of specialist services such as CAMHS with wider provision for individuals with neurodiversity who require it, when they require it. This safely frees up the existing CAMHS workforce to respond and enhance the safety around the most distressed or mentally unwell children and young people with neurodevelopmental disorders, and ensures that not all needs are considered equivalent in terms of risk.

Applied psychology led formulation and intervention adds value at both an individual level, as well the wider system around the child / young person, working with Police, Schools and wider health and social care services to better work with children and young people promoting positive outcomes for individuals and across agencies.

The Fife model has been developed, led and is staffed at the frontline by Applied Psychology and Allied Health Professionals (AHP), with timely access to specialist needs based advice for (i) parents / carers (ii) other professionals including Education. This harnesses a readily available supply of a Psychology workforce. Alongside this, as part of a stepped care process, where diagnosis is required, more efficient multi-disciplinary and multi-agency consensus models involving Education, Social Work and Specialist Services are used. The model is more sustainable because limited specialist resource (such as Psychiatry and Paediatricians) is protected, thus using workforce capacity efficiently and effectively; freeing up specialist time where more intensive assessment and diagnostic work up is required.

Ongoing monitoring of ADHD medication requires a specialist service model set up where there is recognition that individuals will require ongoing specialist care for as long as they continue to take this medication. This requires an associated recognition that this population cannot be included in terms of considering flowing patients through and out of services. Utilisation of prescribing Pharmacists and Nurse Prescribers with appropriate supervision could support meeting this demand, particularly in light of limited and expensive Psychiatry and Paediatric workforce.

Alongside the need for radical changes to service models and delivery, other identified recommendations are –

- A review and refresh of the Neurodevelopmental Service Specification in light of the evolving evidence base and the experiences of service delivery currently. CHOPS are well positioned to contribute to this.
- Going forwards, to ensure true whole systems working, any position papers from the Scottish Government, COSLA, Education, Health or Social Work should have strategic and clinical membership and critical review from each of these respective areas to ensure cross system working.
- Any available additional funding should be considered across agencies as the issue does not only sit with Health and the solution is not to add more clinical capacity but to support the whole system in shifting to support neurodivergence.
- There is an identified need to review SIGN[xi] and NICE guidelines (ASD, ADHD, and FASD) as they suggest a gold standard assessment that services are not in a position to deliver.
- Many services are developing abbreviated assessment pathways - these would benefit from being robustly evaluated to ensure clinical pathways are fit for purpose.
- Evaluation of community-based supports offered and equitable roll out of such supports where there is proven usefulness.

- It is recognised that some areas, such as NHS Lanarkshire and NHS Lothian, have developed a bank of digital resources offered to those waiting to be seen, however this is not the case across the country and it is recommended that a Once for Scotland style approach is taken in terms of resource development.
- Consideration of a national electronic recording system which adequately records what support is being offered in different Boards either in the community or whilst a family is waiting to be seen out-with RTT times.
- Psychologists are very well positioned to lead wider research into the rise of requests in relation to neurodevelopmental need and the population-based changes in those aged under 18 and the relationship between these.

CHOPS call on the Scottish Government and NHS Services to urgently recognise the different population we are now serving and the need for radical changes to service models and delivery with respect to neurodevelopmental differences, to truly cater for everyone.

As an expert collective, CHOPS are well positioned to contribute to further discussions around this and lead local changes required, so that across the country, we can ensure that children and young people with neurodevelopmental differences thrive.

Yours Sincerely,

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[i] https://www.gla.ac.uk/media/Media_976057_smxx.pdf

[ii] https://www.gov.scot/publications/national-action-plan-relationships-behaviour-schools-2024-2027/

[iii] https://audit.scot/uploads/2025-02/briefing_250227_additional_support_for_learning.pdf

[iv] https://www.gov.scot/publications/child-adolescent-mental-health-services-camhs-nhs-scotland-national-service-specification/

[v] https://www.gov.scot/publications/national-neurodevelopmental-specification-children-young-people-principles-standards-care/

[vi] https://publichealthscotland.scot/publications/psychological-therapies-and-interventions-waiting-times-standard-definitions/psychological-therapies-and-interventions-waiting-times-standard-definitions/

[vii] https://www.ncmd.info/wp-content/uploads/2024/07/NCMD-Learning-disability-and-autism-report_FINAL.pdf

[viii] https://www.unicef.org.uk/wp-content/uploads/2016/08/unicef-convention-rights-child-uncrc.pdf

[ix] https://www.gov.scot/policies/girfec/

[x] https://www.legislation.gov.uk/asp/2004/4/contents

[xi] https://www.sign.ac.uk/