National Neurodevelopmental Specification for Children and Young People: Principles and Standards of Care

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Introduction

The Children and Young People's Mental Health and Wellbeing Taskforce reported in 2019 and recommended that Scottish Government and Partners should: *"Develop a Neurodevelopmental Service Specification for use across services in Scotland"*. The Children and Young People's Mental Health and Wellbeing Programme Board and the subsequent Joint Delivery Board took responsibility for developing these principles and standards of care.

The National Neurodevelopmental Specification ("the Specification") is for children and young people who have neurodevelopmental profiles with support needs and require more support than currently available. These children are often referred to Child and Adolescent Mental Health Services (CAMHS) but do not always meet the mental health criterial described in the CAMHS national service specification criteria.

The Specification complements, and sits within, the Getting It Right for Every Child approach. It reflects the principles of UNCRC, the Universal Health Visiting Pathway, and Ready to Act for Allied Health Professionals.

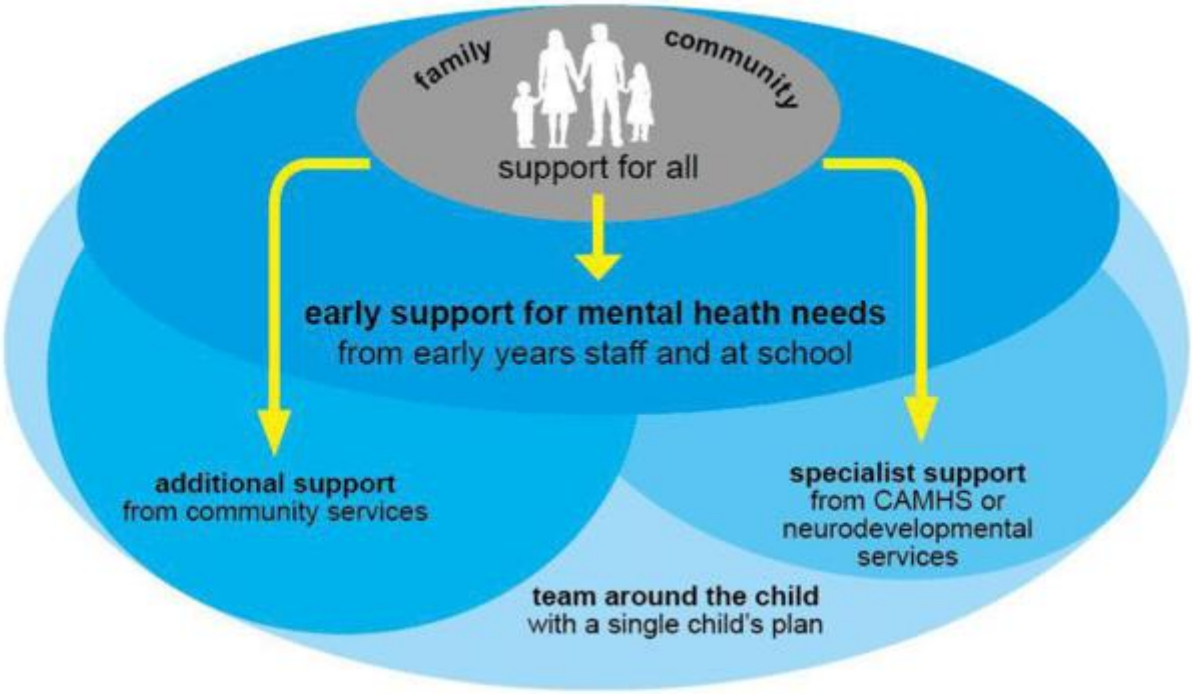
The Specification aims to ensure that children and families receive the supports and access to services that meet their needs at the earliest opportunity, based on the GIRFEC approach. For many children and young people, such support is likely to be community based, and should be quickly and easily accessible.

Children, young people and their families will be able to access additional support, appropriate for their neurodevelopmental needs, through universal services, such as via the named person, and community based mental health and wellbeing supports and services. Universal services should work closely with professionals working in neurodevelopmental services, relevant health and social care and education services. These professionals should be linked with CAMHS so that children and young people with both neurodevelopmental and mental health support needs can get the additional support they require.

Professionals providing support in neurodevelopmental services will support both universal and additional children and young people's services, including new and enhanced Community Mental Health and Wellbeing Supports. They should do this by providing consultation, advice and training and, where appropriate, supervision of those staff supporting children and young people who have neurodevelopmental needs. These services should be available for all children and young people who are aged 0 – 18 years, and young adults aged 18-24 (and up to age 26 for care experienced people).

Professionals providing support will also provide assessment, formulation, recommendations, and where appropriate and helpful, diagnostic assessment for those children and young people to help them understand their neurodevelopmental differences and support needs. Understanding of support needs can be enhanced by diagnosis but should not wait for diagnosis.

Diagram 1: Neurodevelopmental Services within the agreed Children and Young People's Mental Health and Wellbeing model:



*CAMHS and / or neurodevelopmental service

The National Neurodevelopmental Specification sits along the NHS Scotland National Service Specification for Child and Adolescent Mental Health Services (CAMHS) and the same principles underpin both specifications.

Standards 1 to 7 below provide the minimum standard of care expected in neurodevelopmental services. These standards will be reviewed regularly. Appendix 1 section 6 provides further information about the delivery of the Neurodevelopmental Specification.

The following statements should be read with the preface "Neurodevelopmental Services in Scotland will":

Standard 1: High Quality Care and Support that Is Right for Me

1.1 Publish information in a clear, accessible format about who the neurodevelopmental services are for and how children, young people and their parents/carers can access them.

1.2 Offer a first appointment to all children and young people who have been identified (e.g. by a GP, a Named Person or a Children's Planning meeting) as needing a neurodevelopmental assessment. This first appointment should be as soon as possible and no later than 4 weeks from identification of need.

1.3 Provide support and personalised, meaningful signposting to the child/young person and their family/carers, with informed consent, to access other services within the children and young people's service network, in cases where families' needs are best met elsewhere.

1.4 Conduct a full initial multi-disciplinary community-based assessment, based on the information within the request for assistance, and on the child's plan where completed and available.

1.5 Assure that the member of staff undertaking the initial assessment is appropriately trained, supervised and experienced for the purpose, including identifying strengths, as well as difficulties.

Standard 2: I am fully involved In the Decisions about my Care

Getting It Right for Every Child (GIRFEC) stresses the importance of care planning and collaboration between professionals as the required standard for delivery of children's services in Scotland. All services delivering the Neurodevelopmental Specification should work to the GIRFEC principles on a multi-professional and agency basis.

2.1 Ensure that initial and continuous care planning includes everyone involved in the child or young person's care, e.g. the child/young person and their families/carers.

2.2 Ensure that a single child's or young person's plan is in place for all children and young people receiving support from all services delivering the Neurodevelopmental Specification.

2.3 Ensure the child or young person's plans: are coordinated across agencies, teams and disciplines (using the GIRFEC principles); are clearly written; identify the case holder/care coordinator; and are developed in collaboration with children/young people and families and carers (e.g. The Triangle of Care).

2.4 Provide copies of the child or young person's plan to the child or young person and their families/carers, and, with informed consent, those professionals in other agencies working with the child, young person and families/carers such as social work, schools, children's services providers and primary care (e.g. GPs).

2.5 Build on and contribute to other parts of agreed multi-agency care pathways, including health, education and social work.

2.6 Agree, through a process of shared decision making, the goals of the child, young person and family, and regularly review those interventions and progress towards the goals.

2.7 Respond as early as possible to any indications that children, young people and their families/carers may need support, based on the principle that early intervention can happen at any age.

2.8 Ensure that the rationale for formulation and diagnosis, evidence considered, and decisions made will be fully documented. This should be shared with the child/young person and family/carer in writing as appropriate. Services should consult the child/young person and family/carers on the information to be shared with other agencies e.g. that the assessment has taken place and recommendations within the child or young person's plan.

Standard 3: I will receive High Quality Assessment, Formulation and Recommendations that are right for me

Children, young people and their families may require further neurodevelopmental assessment when they present with additional support needs arising from environmental barriers to participation in daily life and differences in:

- Communication and interaction, and broad social functioning;
- Emotional regulation, and attention;
- Development and intellect;
- Co-ordination and movement.

This further assessment, formulation, recommendations and diagnosis, if appropriate and helpful, will be provided by a range of professionals delivering the Neurodevelopmental Specification (see Appendix 1 for further detail).

Standard 4: My Rights are acknowledged, Respected and Delivered

Services delivering the Neurodevelopmental Specification will take a rights-based approach. Due to the impact of inequality and discrimination on development, physical and mental health, it's important that children, young people and their families know the actions taken to ensure their rights are respected. Children's services organisations are reminded of their duties under the Equality Act 2010 and the Equality Act 2010 (Specific Duties) Regulations (Scotland) to assess the impact on persons who share a protected characteristic in the delivery of this service.

4.1 Be available to all children and young people, taking into account all protected characteristics. Where it is deemed clinically appropriate, alternative services may be established that meet the specific needs of one or more groups within a community. Such services will enhance rather than detract from the minimum standards.

4.2 Deliver the service in timely, age-appropriate, accessible, and comfortable settings, as close to home as possible, meeting the needs of children and young people.

4.3 Ensure that informed consent issues around both sharing of information within the family, with other agencies and around interventions/treatment are clearly explained and documented.

4.4 Ensure that all service developments and/or redesigns are undertaken using the best standards of engagement, including involvement and development with children, young people and their families/carers.

4.5 Provide and act upon a risk assessment for all those children/young people who did not attend/were not brought to their appointment, including implementation of local 'unseen child' protocols and standards. (NB: services delivering the Neurodevelopmental Specification should not close a case due to non-attendance/engagement without discussion with the referrer that the child/young person has not attended/was not brought. See Child Protection Guidance for Health Professionals SG 2013)

4.6 Publish clear re-engagement policies and make them available to referrers, children/young people and families/carers.

4.7 Offer creative and acceptable alternatives to face to face work where the children/young people live at a distance from staff locations e.g. the use of approved technology like Attend Anywhere, or advice to a local professional who is working with the child, young person and their family/carer. This is particularly relevant during the Covid-19 pandemic, however families who struggle to access digital services should not be disadvantaged.

Standard 5: I am fully involved in Planning and Agreeing my transitions

Transitions for children and young people are known to increase risks, particularly for the most vulnerable. The Scottish Government published the Transition Care Planning Guidance in 2018 and this describes the standards required in the planning of good transitions for young people moving to Adult Mental Services. The Principles of Transition guidance is relevant in planning and supporting all transitions for children and young people, including those who have been supported by services delivering the Neurodevelopmental Specification.

5.1 Implement the Scottish Government's Transition Care Planning Guidance. Ensure protocols are in place so that transitions between children and young people's services and other services are robust and that, wherever possible, services work together with the young person and families/carers to plan in advance for transition (this is especially critical in the transfer from children and young people's services to adult services and primary care or other services, e.g. voluntary/third sector).

5.2 Ensure that Transition Care Plans provide children and young people with continuity of care. Ensure that any risks, and any child and adult support and protection concerns, are clearly identified and documented.

Groups of children and young people who are more at risk to adversity during transitions and require robust transition plans include:

- Looked after children;
- Care leavers;

- Young people entering or leaving inpatient care;
- Young people entering or leaving prison;
- Young people in the youth justice system;
- Children and young people with learning disabilities;
- Children and young people with neurodevelopmental disorders;
- Unaccompanied asylum-seeking minors;
- Children and young people with caring responsibilities;
- Children and young people not in education, employment or training;
- Children supported under the Additional Support for Learning Act in particular taking in account the guidance of the review of the Additional Support for Learning Implementation published in June 2020;
- Young parents;
- Young people entering college or university study and, in particular, those moving health board area;
- Children and young people with risk to their mental health and/or comorbidity.

Standard 6: We fully involve Children, Young People and their Families and Carers

The Children and Young People's Mental Health and Wellbeing Model (Diagram 1) has been built on, and informed, by significant involvement of children, young people and their families/carers. In particular, but not limited to, the Audit of Rejected Referrals Report, The Youth Commission on Mental Health and the Children and Young People's Mental Health and Wellbeing Taskforce. Services delivering the Neurodevelopmental Specification will work in partnership with children, young people and their families/carers in all aspects of service design and delivery.

6.1 Provide clear and simple ways for children, young people and families/carers to provide regular feedback or to complain. This feedback should be used to improve the support offered.

6.2 Ensure independent advocacy and support services to the whole system are well signposted and children, young people and families/carers are supported to access the help available.

6.3 Seek feedback from children, young people and families/carers, and other professionals involved with the child or young person with agreement, each time they are supported, and are involved in reviewing progress, goals and outcomes.

6.4 Involve children, young people and families/carers in all decisions/plans that affect them. This includes the design, planning, delivery and review of services.

6.5 Develop leaflets, websites, social media and other communications aimed at children, young people and families/carers in partnership with them, taking into account any barriers to communication and/or accessibility.

Standard 7: I have confidence in the Staff who support Me

No public service can provide quality of care without a commitment to develop and sustain a high quality workforce. The lack of available information about workforce levels, professional mix, skill mix, activity, productivity and outcomes in many children and young people's services, especially those delivering the Neurodevelopmental Specification, was noted in both the Audit of Rejected Referrals report and the Audit Scotland report. Workforce development for services delivering the Neurodevelopmental Specification is a critical element of the delivery of high quality and consistent care across Scotland.

7.1 Provide sufficient staff resources to meet the recommended standards for:

(i) a minimum critical mass for services delivering the Neurodevelopmental Specification, taking into account specific local circumstances;

(ii) demand and capacity model for services delivering the Neurodevelopmental Specification, taking into account wider provision of children and young people's services, ensuring Fair Work standards, and quality of care standards, are met;

(iii) an assessment of neurodevelopmental needs at a local population level.

[NB: Further guidance will follow on Scottish Government's recommended capacity and workforce model for services delivering the Neurodevelopmental Specification, which will include Fair Work Standards, and the Health and Care (Staffing) Scotland Act.]

7.2 Involve, and take into account the views of, children, young people and their families/carers in recruitment and appointment of staff.

7.3 Involve children, young people and families/carers in the design, delivery and/or evaluation of staff training.

7.4 Provide opportunities for team/service away days to build team relationships, facilitate learning and service development. This should be done on a multi-professional /agency basis wherever possible.

7.5 Develop effective relationships and pathways with key local organisations to ensure the holistic needs of children, young people and families/carers are met in a timely and appropriate manner, in line with the GIRFEC National Practice Model and the child or young person's plan (where completed).

7.6 Clearly describe the roles of professionals in services delivering the Neurodevelopmental Specification, and make this information available to a range of audiences in accessible formats. Including the capacity for supporting children, young people and their families/carers, and including administration support, team meetings and supervision.

7.7 Ensure sufficient resources are available for professional, clinical and managerial supervision, including supervision regarding the arrangements for the safety of children and young people.

7.8 Provide opportunities for professionals working in services delivering the Neurodevelopmental Specification to participate in small group case discussions about case goals and outcomes, and on a multi-agency basis where possible. This should also include consultation, where appropriate.

7.9 Include children, young people and families/carers' views and experiences in professional appraisals for staff working in services that deliver the Neurodevelopment Specification, and provide systems and process to gather views appropriately, with consent for this purpose.

7.10 Ensure systems and processes are in place (IT and others) to monitor, report on, analyse and respond to: fluctuations in the local planned capacity calculations; and to report on outcomes of interventions.

7.11 Ensure staff working in services which deliver the Neurodevelopmental Specification are supported to grow and develop the necessary compassion, values and behaviours to provide person-centred, integrated care. Ensure staff are supported to enhance the quality of experience through education, training and regular continued personal and professional development that instils respect for children/young people and families/carers.

7.12 Ensure the multi-disciplinary workforce capacity, current and future, is sufficient ensuring an appropriate skill mix and scope of practice to deliver a range of recommended evidence-based interventions within the recommended delivery and capacity model.

Appendix 1

National Neurodevelopmental Specification for Children and Young People: Principles and Standards of Care (Neurodevelopmental Specification)

1 Neurodiversity: Definitions and our Approach

"In my career, I cannot remember coming across a completely normal or typical child (or adult for that matter)" Professor Chris Gillberg.

1. Terminology:

- **Neurocognitive functions** are selective aspects of brain functions - the ability to learn and use language, the ability to regulate attention, emotions, impulses (including movements and spontaneous utterances), social behaviours, and process sensory stimuli. Like height, these traits may be significantly genetically influenced, and are present from birth. Like height, the statistical normal range changes, dependant on age. The societal norm for a selective neurocognitive function is defined by the general population and may be variably and narrowly defined.

- **A Neurodevelopmental disorder** is a term reserved for those who present with a 'functional' impairment in day to day life due to difference in one or more neurocognitive function which lie at the extreme of, or out with the normal range

- **Neurodiversity** is the statistical normal range of a function in a population at a particular age. Diversity is a trait of the whole group, not a specific individual.

- **Neurotypical** describes individuals where a selective neurocognitive function falls within the prevalent societal norm.

- **Neurodivergent** describes individuals where a selective neurocognitive function falls out with the prevalent range.

1.2 In addition we know that the child or young person's presentation is heavily influenced by their current and past social and physical environment. Although this affects all children, there are adaptations that are particularly recommended for those with Neurodevelopmental disorders. The following terminology requires explanation:

- Naturally occurring environments are: home, early years establishments, school and community settings where the child and family spend day to day life

- The Physical Environment is the physical properties of the buildings, room or spaces and the resources within each

- The Social Environment is the actions and attitudes of the people around the individual and family

Wider determinants of health which can increase the risk of inequality are referred to here as poverty, equality characteristics and adverse childhood experiences.

2 Assessment, Formulation and Recommendations

2.1 Children, Young people and Young adults may require neurodevelopmental assessment when they present with additional support needs arising from environmental barriers to participation in daily life and differences in:

- Communication, interaction and broad social functioning
- Emotional Regulation, and Attention
- Development and Intellect
- Co-ordination and movement

2.2 These problem areas often overlap. Some children will have a combination of these problems at lower levels and this may impact more than children with a single higher level of problem. In order to achieve a whole system approach the neurodevelopmental specification needs to be cross sector and involve health, education, social services and third sector.

3 Roles

Children's Services Providers are responsible for providing the range of activities and supports described in the Neurodevelopmental Specification, including:

- Deliver and co-ordinate neurodevelopmentally focussed parent supports and interventions.
- Develop training/ key messages and lead joint health and education training team.
- Provide coaching and mentoring for health and education professionals at 'enhanced' and 'skilled' level.
- Triage requests for assistance, identifying complex and core presentations and relevant pathway.
- Deliver multi-disciplinary complex assessment and interventions and advise on complex cases
- Advise on strategic planning and undertake cycles of evaluation
- Review scientific evidence for practice and lead innovation

3.1 This paper starts from the premise that neurodiversity exists across society. At each developmental stage there are 'neurotypical' or more commonly occurring presentations and 'neurodivergent' or less commonly occurring presentations across a range of developmental skills.

3.2 The differences that are seen may or may not lead to impairments or deficits depending on a range of factors, many of which relate to the social and physical environment.

3.3 There is increasing support in the literature for taking a 'Neurodevelopmental' approach to understanding the range of ways children, young people and adults present.

3.4 The presence of neurodivergent traits, together with environmental factors may lead to impairments in a child or young person's daily functioning.

3.5 Wider determinants of health may also increase vulnerability for children (e.g. poverty, equality characteristics, and adverse childhood experiences) and significantly increase the risk of poor outcomes of children and young people in this profile group.

3.6 Factors increasing the risks of neurodevelopmental disorder arising are wide ranging and include: fetal alcohol/substance exposure, in utero-trauma and/or infections to birth mother, prematurity, family history of neurodevelopmental disorder(s) chronic physical and/or mental health conditions. In many cases there are no identified 'causes' for neurodevelopmental disorders.

3.7 Additionally there is potentially increased risk of functional impairment in children and young people with neurodevelopmental disorders linked to poor attachment and/or neglect in early months, high levels of parent stress associated with chronic physical and/or mental health conditions and the experience of environments at home, school and in the community which do not match the individual's needs/ capacity.

3.8 Children and young people and their families may require support when there is evidence that development in the following areas is impacting on functioning in day to day life (e.g. play, learning and daily routines):

- General development
- Learning and cognition
- Motor development
- Sensory processing and reactions
- Speech, Language and Communication
- Social Interaction/ reciprocity
- Emotional regulation
- Activity or impulsivity
- Attention and concentration
- Imagination and interests
- Stereotypic, insistence on sameness, tics, obsessive routines
- Sleep – disrupted sleep-wake cycle, sleep onset problems, night waking problems
- Feeding – food fads, selective or consistent food refusal.
- Psychological adapt

These problem areas often overlap. Some children with a combination of those problems at lower levels, might be more impacted than those with a single higher level of problem.

3.9 Behaviour is not, in itself, a neurodevelopmental feature. It is influenced by all of the above 'within child' factors together with 'environmental' factors. It is a means of communicating a wide range of responses, emotions and needs. Distressed, passive or unexpected behaviour might be interpreted as 'challenging'. It is important to understand why it occurs.

3.10 Around 25% of mainstream pupils in Scotland have additional support needs. It is now understood that, neurodevelopmental differences leading to additional support needs are more common than previously understood, affecting around 10% of pupils in schools.

The Research Advisory Group of The Children and Young People's Mental Health and Wellbeing Taskforce advised:

- Many of these children will have more than one area of difficulty
- Although neurodevelopmental disorders are lifelong, the individual profile and support needs will change over time, as will the adaptations required
- Early identification and support to the child and family will be of benefit
- Wider determinants of health such as poverty, social exclusion and parental stressors, will cumulatively impact upon individual need.

3.11 The prevalence of neurodevelopmental profiles linked to impairment in functioning (see 3.5) has been estimated (by Gillberg and others) to be at least 10% of school age children. Research has shown:

- The Research Advisory Group advised that most of these children could be identified by age 6 years;
- Comorbidity /co-existence of a range of neurodevelopmental needs is common;
- Neurodevelopmental disorders in girls and women are less well recognised or recognised at an older age. Missed or misdiagnosis is also reported (e.g. where there is an eating disorders or severe anxiety);
- Unmet needs or missed diagnosis can lead to persistent problems in adult life (e.g. long term mental ill health, involvement with the criminal justice system);

3.12 Ultimately, all children and families should experience joined up support, based on the single child's plan, with professionals from different agencies working together on a single plan. (GIRFEC Practice Guidance)

4 The importance of Early Identification and the GIRFEC National Practice Model

4.1 The universal Health Visiting Service and GIRFEC National Practice Model provide important cross sector opportunities (across health, education, social services and third sector), to:

- Identify children with neurodevelopmental profiles who are at risk, at the earliest stage
- Contribute to the creation of a relevant individual child's plan
- Identify those children requiring targeted or specialist support through staged intervention
- Identify those children requiring further assessment, formulation, recommendations, and diagnosis where this would be helpful and appropriate
- Provide support through the team around the child to adapt daily routines in naturally occurring environments to reduce the negative impact of neurodevelopmental differences
- Provide adaptations for parents where required (e.g. advocacy, peer support, translation and interpreter support where English is not the first language or where there might be cultural barriers, 'plain English' adapted supports for parents with a learning difficulty)

- Provide adaptations to support such as respite and/or periods of substitute parental care, which take account of the need for carers to understand individual support needs and strategies arising as a result of a neurodevelopmental profile
- Support for income maximisation/financial inclusion
- Signpost to relevant resources and supports

4.2 The 27-30 month review and in particular, screening for language development at that stage, is an opportunity to identify children and families requiring further support in the early years.

4.3 For children and young people of all ages, the GIRFEC Wellbeing Indicators can be used to guide discussions about how an individual is doing at a particular point in time and if there is a need for support.

4.4 In the early years:

- Additional support needs, such as speech, language and communication needs and sensory processing differences or motor development needs, may be identified by professionals or parents/carers.
- The team around the child might include the Health Visitor, Allied Health Professionals, General Practitioner parents/carers and other health, education, social care and third sector professionals.
- Specialist support to make sense of behaviour and to adapt strategies to be developmentally appropriate is also an essential part of the early intervention approach.
- Speech and Language Therapists, and Occupational Therapists and other professionals (using Ready to Act guidance) bring specialist knowledge of neurodevelopment to the provision of Universal, Targeted and Specialist support.
- Good practice involves collaboration and information sharing with consent across the team around the child, including early learning and childcare staff.

4.5 Some children's needs will be affected by:

- Within-family and wider determinants of health (e.g. the impact of poverty and adverse childhood experiences)
- The degree of adaptation provided in naturally occurring environments (at home, school or in the community) and expectations which fit with the child's developmental stage and neurodevelopmental needs.

Where these issues can be addressed, we can be optimistic that the child will respond positively, reducing negative impact and improving development.

4.6 Developmentally appropriate, neurodevelopmental parent supports should be offered, may need to be repeated, and may need to be ongoing as child's needs change. This knowledge should be taken into consideration when undertaking strategic planning (e.g. within the Community Plan, and Children's Services Plan).

4.7 Many children will have their needs met through universal supports in naturally occurring environments (e.g. school and home).

4.8 Some children and young people will require more targeted and specialist support provided by the team around the child and planned and implemented through staged intervention.

4.9 Understanding of support needs can be enhanced by diagnosis but should not wait for diagnosis. For example, children and young people with neurodevelopmental support needs may not meet a have a single area of need that meets criteria for diagnosis but may have a number of areas of need which combined would be more impactful.

4.10 Specialist assessment, formulation and contribution to the child's plan at Lead Professional level can influence support required for the child, young person and family. These children may also meet diagnostic criteria for Neurodevelopmental disorders such as:

- Intellectual Disabilities
- Autism Spectrum Disorder
- Attention Deficit Hyperactivity Disorder
- Fetal Alcohol Spectrum Disorder.
- Developmental Coordination Disorder
- Developmental Language Disorder

4.11 A functional assessment, formulation and outcome can support parents in understanding their child's needs and the reasons for their child's difficulties. Creating shared understandings with parents, children and young people can support the fulfilment of their potential. It can inform:

- targeted environmental adaptations within home and school
- identification of relevant parent and family supports (e.g. financial supports, parent education and training)

4.12 The neurodevelopmental specification, specified below, is built on and complementary to the GIRFEC approach.

4.13 Young adults aged 18-24 (and 26 for care experienced young people) may require both neurodevelopmental diagnostic assessment and a range of universal, targeted and specialist supports in naturally occurring environments of higher education and employment. Transitions from child and young people's services into adult services require individualised planning and easy access to sustained support, which reflects the principles of UNCRC.

5 Responding to Neurodevelopmental Support Needs

The following are evidence based approaches known to be effective in supporting children, young people and their families (See Appendix 2 for references). An individualised approach is essential to take account of individual developmental stage and daily environments. There is no intervention or approach recommended for all children all of the time. The intervention should be required to be discussed fully with all contributors at the Child Planning Meeting, identified clearly within the child's plan and informed by the team around the child (maybe inclusive of health, education, social services and third sector).

There should be a cross sector commitment to developing the use of digital platforms on a national level to ensure effective communication is prioritised.

5.1 Approaches informed by evidence base, to support children and young people with Additional Support Needs as a result of a neurodevelopmental profile, and their families:

5.2 Getting it right for Every Child

GIRFEC is a way for families to work in partnership with people who can support them such as health, education, social work and third sector professionals.

- There should be regular communication between health, education, social workers and third sector professionals to promote understanding of support needs to ensure a consistent approach to the individual across settings and to monitor effectiveness of intervention
- Collaborative working across health, education, social work and third sector professionals is expected, to make adjustments to the Early Learning and Childcare environment, school environment and curriculum to meet additional support needs
- Regular assessment of need and planning as needs change, within the Getting it right approach
- Early identification of neurodevelopmental needs, formulation and diagnosis, working collaboratively with the team around the child to contribute to the child's plan

5.3 Formulation and Diagnosis

- Understanding of support needs can be enhanced by formal formulation and diagnosis but should not wait for diagnosis
- Neurodevelopmental Disorders are diagnosed following assessment by a multi-disciplinary team, with appropriate training, skills and skill mix. Assessment findings and evidence from both report and observation are 'mapped' to DSM 5 or ICD 11 diagnostic criteria
- Neurodevelopmental assessment may result in overlapping diagnoses, including: Autism, ADHD, Intellectual Disability, Fetal Alcohol Spectrum Disorder, Developmental Language Disorder or Developmental Co-ordination Disorder

5.4 Evidence based parent and family focussed interventions targeted for children with neurodevelopmental needs are recommended including:

- Parent/ family support to access relevant financial supports and welfare benefits
- Parent/ family should be provided with timely and relevant information about their child's neurodevelopmental profile and local supports
- Parent mediated interventions are particularly recommended for children in their pre-school years (specific to the needs of children and young people with neurodevelopmental profiles)
- Parent/ family education and training specific to the needs of children and young people with neurodevelopmental profiles (pre-school, primary school and secondary stage)

- Group and family work can improve family capacity to cope, increase family functioning and reduce family stress, along with or preceded by good child planning and support
- Access to respite breaks, substitute parents care and family support for families where children and young people have a need in this area

5.5 School and Early Learning and Childcare (ELC) based support and intervention

- An individualised educational programme is recommended
- Universal inclusive classroom and school/ ELC based strategies are usually put in place by school/ ELC staff and may be informed by health professionals working in education settings
- Recommended targeted and specialist adaptations in school include modifications to the social and physical environment
- Health and education professionals should work collaboratively (alongside parents and carers and the young person) to create a shared understanding of the individual's developmental stage and specific support needs and how they can be met in daily environments of home and school

5.6 Higher education and employment support for young adults

- Take a person centred approach and include the individuals' views and preferences
- Ensure adjustments are anticipatory (Equality Act, 2010)
- Provide access to employment supports (e.g. Fairstart, other employment supports focussed on those with neurodevelopmental needs)
- Prepare for transitions and any change in the environment or tasks
- Identify a "key link person"
- Consider adaptations to the physical environments (e.g. providing a quiet space or spaces with reduced distractions)
- Provide predictable routines and create certainty in role expectations
- Create opportunities for activities with low social demands
- Provide pivotal information in clear lists or through visual supports
- Consider advocacy needs

5.7 Environmental Interventions are recommended including:

- Developmentally relevant speech, language and communication adaptations at the universal, targeted and specialist level, through key language partners in naturally occurring environments
- Provision of predictability, routine and structure and consider motivation to support participation and learning in ELC and school settings
- Good inclusive practice in schools supporting impulse control difficulties (e.g. planned movement breaks, seating adaptations)
- Targeted communication interventions (e.g. use of parent mediated interventions supporting communication, use of visual supports and adapted communication and supports for social communication

- Targeted interventions to support independence in self-care, daily routines at home and school/ELC and leisure activities
- Sleep interventions, advice and training for parents and carers opportunities for and encouragement to engage in motivating physical, naturally occurring activities, with tailored adaptations to support motor skills

5.8 Interventions to support emotional regulation

- It is important to view 'perceived difficult' behaviour as distressed behaviour and to consider underlying reasons, related to the neurodevelopmental presentation and the environment – not just seeking 'within child' solutions
- Emotional regulation support should be developmentally relevant and should include environmental strategies, taking account of the range of factors influencing regulation for individuals with neurodevelopmental disorders
- Interventions for some verbal, able individuals may involve elements of CBT or adaptations to CBT interventions

5.9 Medical

- Immediate access to relevant medical treatment if required (e.g. vision, hearing, immunisation gaps, vitamin deficits)
- Medication can sometimes help (e.g. melatonin for sleep, or ADHD medication depending on age)
- Comorbidities requiring acute paediatric care, for example neurological conditions and neurodisabilities

6 Summary

6.1 The **National Neurodevelopmental Specification for Children and Young People: Principles and Standards** (Neurodevelopmental Specification) will:

- Be based on and embedded within the wider practice and principles of GIRFEC and the GIRFEC National Practice Model.

- Be within a whole system, with a single point of access, whereby health, education, social services and third sector professionals actively seek to understand each other's unique contributions and respect each other's areas of expertise. A stepped and matched care pathway is needed so additional supports from e.g. CAMHS can be accessed as needed.

- Focus on early identification and early intervention, and in particular, early indicators that children, young people and their parents and carers may need support. Early intervention can happen at any age including for young adults, who have left school.

- Work collaboratively as part of the team around the child (which may include health, education, social services and third sector professionals), across the life course through universal, targeted and specialist support.

- Where the team around the child (health, education, social services and third sector) professionals identifies that children and young people require additional help, contribute specialist knowledge to the child's plan and to achieving the targets set.

- Provide modelling, consultation, advice and training and assistance to adopt and implement environmental adaptations described in the Ready to Act guidance (Universal, Targeted and Specialist approaches).
- Provide clear guidance and a single point of access for requests for assistance from health professionals.

- Provide diagnostic assessment and formulation. Share outcomes with family and as appropriate share these with the wider team around the child (with consent).

- Professional staff supporting the implementation of the neurodevelopmental specification will include registered children's professionals with additional training in the identification, assessment and formulation of neurodevelopmental conditions, including:

    - Speech and Language Therapists
    - General Practitioners
    - Paediatricians
    - Occupational Therapists
    - Peripatetic Teachers
    - Educational Psychologists
    - Nurses
    - Clinical Psychologists
    - Social Workers
    - Children and Adolescent Psychiatrists
    - Physiotherapists

- Professionals working in adult services with additional training in the identification, assessment, formulation and diagnosis of neurodevelopmental conditions will support the implementation of the neurodevelopmental specification for young adults who have left school, including:

    - Speech and Language Therapists
    - General Practitioners
    - Occupational Therapists
    - Nurse
    - Clinical Psychologists
    - Social Workers
    - Psychiatrists
    - Further education staff
    - Employment support staff

- Support all parts of the children's and young adults' services system to identify and support individuals with neurodevelopmental profiles and support needs.

- Respond as soon as possible where requests for assistance are made (initially, within 4 weeks), and provide help within 18 weeks (defined as the start of the process of assessment, formulation and completion of child's plan and diagnostic outcome where appropriate).

6.2 The implementation of the neurodevelopmental specification will be systematic, consistent and comprehensive and identify the neurodevelopmental profiles and needs of children and young people at the earliest possible stage, following receipt of requests for assistance from professionals already involved, and also from families and carers.

6.3 A timely response to requests from families and carers who have concerns about their children's neurodevelopmental profiles and needs can reduce family and carer stress, improve confidence in adopting positive and supporting parenting approaches, and receive support, guidance and interventions that are tailored to the needs of their children, increasing the prospects of early improvements in outcomes.

6.4 The neurodevelopmental specification when implemented will also reduce the numbers of children and young people referred to CAMHS, and rejected, as they do not meet the CAMHS referral mental health and risk/impact criteria.

[NB: children and young people treated in CAMHS will have their Neurodevelopmental needs met within CAMHS to the same standards.]

Stephen McLeod

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Chair of the Neurodevelopmental Service Specification Task and Finish Group.

Appendix 2

Clinical Guidelines

There is no single SIGN or NICE guideline for neurodevelopmental disorders. The following are useful reference points:

- SIGN 145 (2016) Assessment, Diagnosis and Interventions for Autism Spectrum Disorder
- SIGN 112 (2009) Management of ADHD in Children and Young People
- NICE Attention deficit hyperactivity disorder: diagnosis and management https://www.nice.org.uk/guidance/cg72
- SIGN 156 (2019) Children exposed prenatally to alcohol
- https://www.acamh.org/topic/developmental-language-disorder/
- https://www.sign.ac.uk/assets/neurodevelopmental_areas_of_assessment_criteria.pdf
- DCD https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4467929/
- DLD – https://www.speech-language-therapy.com/index.php?option=com_content&view=article&id=183
- Intellectual Disability : https://www.bps.org.uk/sites/www.bps.org.uk/files/Member%20Networks/Faculties/Intellectual%20Disabilities/Learning%20Disability%20Definitions%20and%20Contexts%20%282000%29.pdf
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