



Meeting of East Renfrewshire Health and Social Care Partnership	Integration Joint Board
Held on	26 June 2024
Agenda Item	11
Title	The National Neurodevelopmental Specification
Summary	
To provide an update to the Integration Joint Board on the development of the National Neurodevelopmental Specification in East Renfrewshire.	
Presented by	Raymond Prior, Head of Children's Services (Chief Social Work Officer)
Action Required	
The Integration Joint Board is asked to: <ul style="list-style-type: none"> • Note the progress being made in implementation. • Note the development of the service and the challenges therein. 	
Directions	Implications
<input checked="" type="checkbox"/> No Directions Required <input type="checkbox"/> Directions to East Renfrewshire Council (ERC) <input type="checkbox"/> Directions to NHS Greater Glasgow and Clyde (NHSGGC) <input type="checkbox"/> Directions to both ERC and NHSGGC	<input type="checkbox"/> Finance <input type="checkbox"/> Policy <input type="checkbox"/> Workforce <input type="checkbox"/> Equalities <input type="checkbox"/> Risk <input type="checkbox"/> Legal <input type="checkbox"/> Infrastructure <input type="checkbox"/> Fairer Scotland Duty

EAST RENFREWSHIRE INTEGRATION JOINT BOARD

26 June 2024

Report by Chief Social Work Officer

THE NATIONAL NEURODEVELOPMENTAL SPECIFICATION

PURPOSE OF REPORT

1. The purpose of this report is to outline the progress in implementing the neurodevelopmental specification for children and adult services in East Renfrewshire.

RECOMMENDATION

2. The Integration Joint Board is asked to:
 - Note the progress being made in implementation.
 - Note the development of the service and the challenges therein.

BACKGROUND

3. In 2019, the Children and Young People's Mental Health and Wellbeing Taskforce recommended that Scottish Government and partners should develop a neurodevelopmental service specification for use across services in Scotland. This [specification](#) was published in 2021, and is for children and young people who have neurodevelopmental profiles with support needs that require more support than currently available.
4. The neurodevelopmental service specification outlines the principles and seven minimum service standards that all boards should follow. It is a whole system approach to meet the needs of children and young people and their families who have neurodevelopmental profiles.
5. The Neurodevelopmental pathway within specialist children's services (SCS) has the remit to provide a diagnostic service to children, young people and their families where the child or young person may be displaying signs and symptoms of the following conditions;
 - Autism Spectrum Disorder
 - Attention Deficit Hyperactivity Disorder
 - Foetal Alcohol Spectrum Disorder.
 - Developmental Coordination Disorder
 - Developmental Language Disorder
 - Intellectual Disabilities as appropriate
6. In the Scottish Government's 'National Neurodevelopmental Specification for Children and Young People: Principles and Standards of Care', standards were detailed as the fundamental components on which any neurodevelopmental pathway be based and are linked to the principles of Getting it Right for Every Child (GIRFEC). They are;

- Standard 1: High Quality Care and Support that Is Right for Me
- Standard 2: I am fully involved In the Decisions about my Care
- Standard 3: I will receive High Quality Assessment, Formulation and Recommendations that are right for me
- Standard 4: My Rights are acknowledged, Respected and Delivered
- Standard 5: I am fully involved in Planning and Agreeing my transitions
- Standard 6: We fully involve Children, Young People and their Families and Carers
- Standard 7: I have confidence in the Staff who support Me

7. These standards will underpin the philosophy of the SCS Neurodevelopmental Pathway Specification. Primarily the two conditions most referred to or highlighted as being of concern are Attention Deficit Hyperactivity Disorder (ADHD) and Autistic Spectrum Disorder (ASD).
8. This approach is being developed within a system that is experiencing increasing levels of demand. It is estimated that around 25% of mainstream pupils in Scotland have additional support needs and it is now understood that neurodevelopmental differences leading to additional support needs are more common than previously understood.
9. 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 functions which lie at the extreme of, or outwith the typical range. Neurocognitive functions are selective aspects of brain function – the ability to learn and use language, the ability to regulate attention, emotions, impulses, social behaviour and process sensory stimuli. Like height, these traits may be significantly genetically influenced, and are present from birth. The statistical normal range changes, dependant on age.

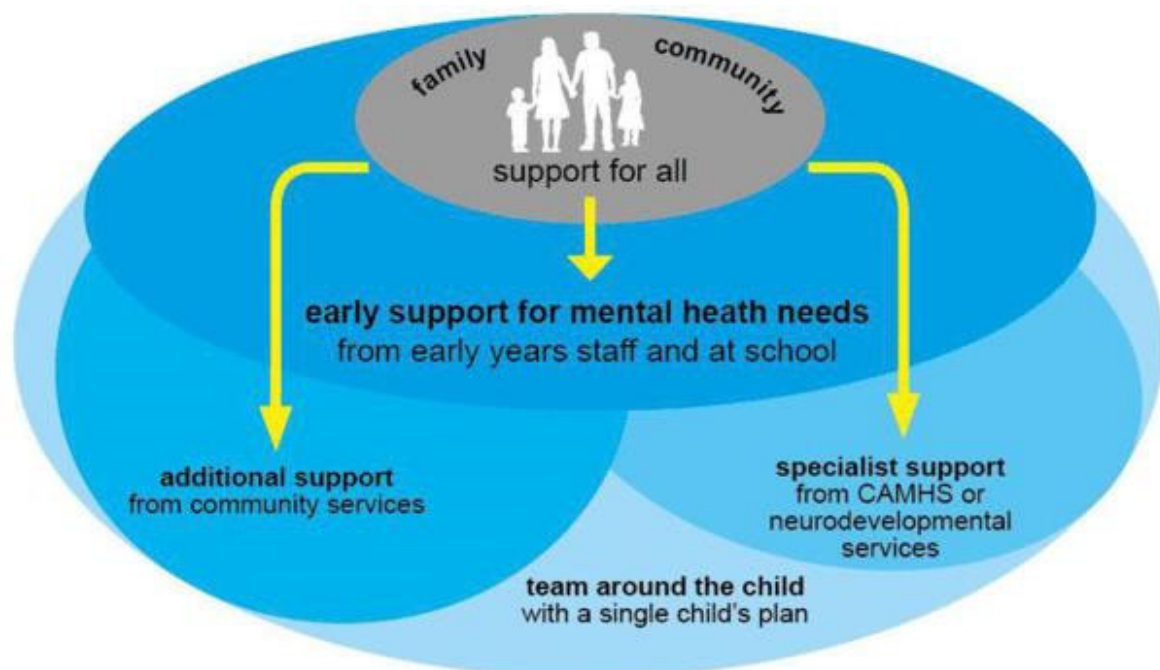
REPORT

10. The Neurodevelopmental Service Specification is a whole system approach to meeting the needs of children with neurodevelopmental profiles and their families. Whilst it is referred to as a 'service' the Standards recognise that it will be delivered by a combination of services and the neurodevelopmental specification is noted as "involv(ing) health, education, social services and third sector". It sits within the GIRFEC approach and principles of United Nations Convention on the Rights of the Child (UNCRC). Key elements include;
 11. Early identification and early support which does not wait for diagnosis, with further assessment as needs arise.
 12. Effective support from the appropriate service for needs, e.g. universal services, community based mental health and wellbeing supports and services, or specialist children's services. Delivery of services should be as close to home as possible and supports include those for parents. Where needs are best met elsewhere there should be support and 'personalised, meaningful signposting'.
 13. Close working between services, including training and advice. This close working includes involvement of the child/young person and their families/carers in care planning. A single child's or young person's plan would be used by all services and the child/young person and their family.

14. The service includes young adults aged 18-24 (and 26 for care experienced young people) and the need for support with transitions is highlighted.
15. It is recognised that diagnosis can enhance the understanding of support needs but that the provision of support should not wait for diagnosis. It also recognises that children and young people may have neurodevelopmental support needs whilst not meeting criteria for diagnosis.
16. Other principles included in the service specification and associated standards include ensuring that workforce planning and service development is informed by local assessment of neurodevelopmental needs, and, that services undertake the best standards of engagement in both redesign and in monitoring and improving services.
17. Implementation of the neurodevelopmental service specification has been progressing across NHSGGC although significant work is still required and particular areas of activity require focus. A number of these areas also have implications for workforce planning.
18. Similar to other partnerships, East Renfrewshire requires to understand demand for neurodevelopmental services. This includes both current demand, changing patterns of developmental concerns, and potential unmet need. Our partnership must also ensure that preventative work is strengthened. This includes developing a better understanding of what factors are amenable to intervention. National and local trends are towards increasing developmental concerns at the 27-30 month health visitor assessment with the most significant increase seen in terms of speech, language and communication.
19. Locally we also need to understand what the barriers are to accessing supports without a neurodevelopmental diagnosis and progressing GIRFEC approaches. This may include; parental advice and support, additional needs support in schools and financial supports. An assessment of what community supports best meet the needs of children, young people and their families will also be helpful. This would include sharing practice, evidence review, consultation and evaluation. There may also be a need to communicate the benefits of these supports to families and professionals so that their value is recognised. Community supports include the actions of the team around the child at early stages through to post-diagnostic supports. As such this is a key aspect of developing the neuro developmental service specification.
20. Local service planning needs to achieve a balance between capacity for diagnostic services and capacity for effective therapies. One example where further consideration may be required is around ADHD supports. There is a need to formalise responsibilities across partners for the delivery of the neuro developmental service specification, including core offer and the timeframes that the service will work towards. There is also a need to 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.
21. East Renfrewshire Health and Social Care partnership has responsibility for the local delivery of the neurodevelopmental service specification. To achieve this a multi-disciplinary neurodevelopmental team is being created. The core team will be led by a team lead and comprise of Nursing, Occupational Therapy and Speech and Language Therapy with access to sessions from Psychiatry, Paediatricians and Clinical Psychology. Different hub models are being progressed across GGC and the opportunity exists to take account of the

learning across the board area to ensure our model is as effective as possible. Within the HSCP all activity will be informed by our developing focus on neuro-affirming practice.

22. The Promise Whole Family Wellbeing fund has been utilised in East Renfrewshire to fund several posts, in a variety of settings, to provide neurodevelopmental support. These posts are located in the Healthier Minds service, health visiting, social work and early intervention teams. The GIRFEC approach is embedded within the service specification ensuring that a partnership approach is at the core of our delivery model. There is an expectation that professional staff supporting the implementation will include registered children's professionals with additional training in the identification and formulation of neurodevelopmental conditions including Speech and Language Therapists, General Practitioners, Paediatricians, Occupational Therapists, Physiotherapists, Peripatetic Teachers, Educational Psychologists, Nurses, Clinical Psychologists, Social Workers and Children and Adolescent Psychiatrists.
23. Clinical guidelines for the major neurodevelopmental conditions have or are in process of being written. Staff input has and continues to support both the development, sharing and implementation of guidelines. The new pathway will require a robust communication system. Referral guidance and an updated referral form and information leaflet have been produced and will form part of the service roll out.
24. The overall strategic aims of this approach are 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.
25. The services to be provided are defined within the specification. The pathways to appropriate services have been agreed and our communication system will allow children and young people and their families to understand this.



26. The local neurodevelopmental team will provide a single point of access for access into neurodevelopmental services and will be able to support the management of waiting lists. The waiting list will be dynamic with the neurodevelopmental services responding to team around the child requests. The services provided will depend on the needs identified and will be rooted in the provisions that already exist with children's services.
27. As of May 2024 there were 7560 children and young people awaiting neuro developmental assessment in NHSGGC. For East Renfrewshire there are 590 children and young people awaiting assessment with the longest wait for assessment 161 weeks. There is 0.5 wte (whole time equivalent) Speech and Language Therapy time given to neurodevelopmental diagnostic assessment work in East Renfrewshire and an agreement to recruit a further 1.0 wte post to pathway for 23 month fixed term period. Demand is significantly higher than capacity can match in terms of diagnostic assessment. Furthermore where a neurodevelopmental diagnosis is made and if this requires ongoing medication management for Attention Deficit Hyperactivity Disorder this is managed through the CAMHS team with no ability to step down to primary care colleagues further placing demand on limited secondary care resource.
28. There has been an increase in private assessment for Neurodevelopmental conditions with then a request for NHS services to provide ongoing medication support specifically in relation to ADHD medication. There has been a recently developed policy in relation to how this can be managed to ensure both that assessments are in line with clinical guidelines and then how to manage demand for support for young people in the context of those with an established diagnosis and those who have not yet received an assessment.
29. Neurodevelopmental conditions often present with more than one diagnosis, for example, ASD and ADHD. It is agreed that support should not be predicated on the basis of diagnosis but rather that children's planning should consider a child's presenting needs and the supports to help them manage in everyday environments.
30. 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. 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. Both children's and adult services are working together using the guidance to develop transition protocols and mechanisms which will ensure effective transitions for children and young people with neurodevelopmental conditions.
31. While there is currently no single adult neurodevelopmental pathway or associated single service in East Renfrewshire or Greater Glasgow and Clyde, there is ongoing activity to explore how this might be achieved across all of NHSGGC and is subject to senior level discussions.
32. There is clear evidence demand for neurodevelopment assessment, advice and post diagnostic support is rapidly increasing across all age groups. East Renfrewshire is the lead partnership for the board wide adult autism service and has, in recent years, seen 500% increase in demand. As a result we have amended our delivery model in an effort to better meet this demand however, this remains challenging.

33. The neurodevelopmental pathway does not readily align with adult services however locally work is being carried out to better identify young people transitioning from children's to adult services. Our Transitions team are making good progress in working collegiately with education, families and wider partners to ensure we are able to plan ahead for all young people with additional support needs. As the neurodevelopment pathway embeds we will ensure close working across the spectrum of Children / Transition / Adult Services.
34. From an adult perspective we are largely in a position where we are working hard to keep up with demand for neurodevelopment assessment however recognise a need to work on a whole family basis. The small nature of the HSCP places us in a good position to encourage cross system working however this will be strengthened as a new pathway is implemented.
35. In response to the increasing demand in adults we developed an ADHD assessment service embedded in the Community Mental Health Team. The team consists of two occupational therapists with expertise in assessment, diagnosis and post diagnostic support. This small resource is working closely with primary and secondary care colleagues including developing links with third sector providers.
36. While there is currently no discrete adult neurodevelopmental pathway or associated single service in East Renfrewshire or GGC, there is ongoing activity to progress this. The neurodevelopmental pathway does not readily align with adult services however locally work is being carried out to better co-ordinate transitions to appropriate services. East Renfrewshire is served by the Adult Autism Team and has an ADHD assessment service embedded in the Community Mental Health Team. Locally we also benefit from a good foundation of supports available in the community.

IMPLICATIONS

37. There are no implications arising from this report.

DIRECTIONS

38. There are no implications arising from this report.

CONCLUSIONS

39. East Renfrewshire HSCP is committed to delivering the Neurodevelopmental Pathway Specification. This paper highlights the strengths in our partnership and that we have the ingredients needed across Children's services, Transitions and Adults to achieve this aim. An equal number of challenges exist but we are aware of those gaps and recognise East Renfrewshire is in a similar situation to other partnerships across the board. There will require strong commitment and partnership working with SCS to monitor demand and resource implication across the workforce.

RECOMMENDATIONS

40. The Integration Joint Board is asked to:

- Note the progress being made in implementation.
- Note the development of the service and the challenges therein.

REPORT AUTHOR AND PERSON TO CONTACT

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BACKGROUND PAPERS

<https://www.gov.scot/publications/national-neurodevelopmental-specification-children-young-people-principles-standards-care/>