

Adult Neurodevelopmental Pathways

Report on Actions, Outcomes and Recommendations from Pathfinder Sites in Scotland

March 2023

Adult Neurodevelopmental Pathways – Pathfinder Sites

Acknowledgements

Thank you to neurodivergent people and third sector colleagues who have taken part and worked alongside us to inform professional thinking nationally and locally, often sharing challenging personal experiences. Through your involvement at every step, we hope that new ways of using resources will better meet the needs of everyone in our neurodiverse society.

Thank you to the four pathfinder sites

- NHS Borders
- NHS Fife
- NHS Highland
- NHS Lanarkshire

Multi-disciplinary teams in each area have shown a high level of commitment and provided leadership at all levels to this work. The effects of the Covid pandemic have made this a difficult context in which to introduce new thinking and practice but local teams have persisted with a determination to understand solutions and to make the changes needed.

Thank you also to NHS Education for Scotland and the members of the NAIT Adult Neurodevelopmental Pathways Professional Network from across Scotland, who continue to share practice, data and learning.

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Executive Summary

In 2021, there was a recognised need to improve experiences and outcomes for autistic adults, adults with ADHD and those with co-occurring neurodevelopmental conditions in Scotland - before, during and after diagnosis. Current provision is such that in some areas there is no service at all and where there is provision, waiting lists can be long and only accessible to people meeting particular thresholds for access.

There is a need for:

- Neurodevelopmentally informed services developed with and for neurodivergent people.
- Neurodiversity affirming, proportionate, relevant support and information across services, communities and society.
- Timely access to neurodevelopmental assessment, diagnosis and interventions or medical treatments where required.
- Better ways to understand and manage demand and capacity.
- Building workforce capacity including broadening cross sector and multi-disciplinary roles.

Although Community Mental Health Teams (CMHTs) are key leaders in this work, this need cannot and should not be met solely within CMHTs. There is a recommendation from recent review, that a Stepped Care Adult Neurodevelopmental Pathway is required in each locality.

In 2022, work has begun to break new ground, innovate and test out new ways of working towards these goals with local partnerships across 4 tiers, involving third sector and community teams, employers and employment support providers, further and higher education, new Primary Mental Health teams and CMHTs.

This report provides background and context to work of the pathfinder sites, enabled by the National Autism Implementation Team (NAIT), with practical support and mentorship as well as consideration of taking an evidence informed approach to the work.

In 2022, there has been related development work underway in other Health and Social Care Partnerships in Scotland. NAIT have led a national Professionals' Network to bring together those working with a shared focus across the country, to combine and pool learning and experiences.

This report describes the work undertaken in real world settings, outcomes, new resources developed and key learning from this first year of focussed work. Recommendations are provided that could take this work forward in the short term over the next 12-24 month and in the longer term and this report will support decisions about how to take the next steps locally and nationally.

Recommendations:

Short Term: Local work

Recommendation 1: An adult neurodevelopmental pathway strategy and planning group to be hosted in all Health and Social Care Partnerships.

Recommendation 2: Support to develop local neurodevelopmental pathway action plans.

Short Term: National work

Recommendation 3: A Neurodiversity Affirming Community of Practice.

Recommendation 4: A focus on 'Post Diagnostic Support' or 'Support before, during and after diagnosis'.

Recommendation 5: Build a Neurodevelopmentally Informed workforce in Scotland.

Longer term

Recommendation 6: Development of neurodevelopmental pathway standards and guidelines for assessment, diagnosis and support.

Recommendation 7: Understanding demand and capacity within the system, to meet the needs of neurodivergent adults.

Recommendation 8: Neuroinclusive Further Education and Employment environments.

Recommendation 9: Build a shared expectation that support should be available at any stage for people who identify as neurodivergent.

Recommendation 10: Seek to understand the changes needed to effectively meet the mental health needs of neurodivergent people.

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Introduction

This paper reports outcomes of Scottish Government Mental Health Recovery and Renewal Fund allocated to four health board areas in 2022, which has focussed on understanding the key requirements and practical steps involved in developing and implementing adult neurodevelopmental pathways. The pathfinder sites have been supported by the National Autism Implementation Team (NAIT) and a range of partners in setting aims and a 12 month action plan.

The ultimate aim of the work is to inform the delivery of sustainable, local provision across Scotland, which meets the needs of autistic adults, those with ADHD and those with other neurodevelopmental conditions. New approaches developed are intended to work towards delivering timely access to diagnostic assessment and proportionate and neuro-affirming support before, during and after diagnosis. Recommendations for next steps are based on learning from this work in real world settings.

Background

There is an identified need to improve experiences of adults with neurodevelopmental conditions in Scotland, which affect 10-15% of the population. Although mental health conditions are not inevitable, up to 70% of people with neurodevelopmental conditions seek mental health support and this group makes up a significant proportion of adults involved with mental health and criminal justice services.

Scottish Government are leading a programme of related Leadership and Engagement work with autistic people and people with intellectual disability. Work is underway to develop 'Post-diagnostic Support' for this group and to look at provision which take account of the likelihood of co-occurring conditions.

Public Health Scotland analysis on ADHD prescribing for adults in 2019, highlighted that alongside a steady and large rise in prescribing, there continues to be significant under-diagnosis of adults with ADHD, with significant variation between Health Boards and a range of 0 to 14% of the adults we would expect to have ADHD in Scotland being prescribed medication. (Publication available on request).

In particular young people and adults with untreated ADHD are more likely to develop substance misuse disorders which is particularly pertinent in Scotland where addressing drug related deaths is a national priority area.

Scoping

Scottish Government asked the National Autism Implementation Team (NAIT) to undertake scoping work in 2020-21, to better understand needs and make recommendations. This work included:

1. A Feasibility Study¹ to inform future adult ADHD pathways and to scope views around development of adult neurodevelopmental pathways. This study was carried out Nov-Jan 2021.
2. A report on the current provision of neurodevelopmental, autism and ADHD pathways (May 2021 - see Appendix).
3. A rapid systematic review and evidence summary of Mental Health in Autistic Adults² which included prevalence of co-occurring neurodevelopmental and mental health conditions.
4. Engagement with a) a neurodivergent partner network and b) a network of professionals leading on neurodevelopmental, autism and ADHD work in Health and Social Care Partnerships across Scotland.

NAIT have led related work on Practice Guidance for the Implementation of Neurodevelopmental Pathways in Children's Services³. (Rutherford et al., 2021)⁴. Although there are clear differences in the context for support and service delivery, there are also principles for practice which are relevant across the lifespan.

In 2022, NAIT have concurrently conducted a wait times review to support understanding of demand and provision for diagnostic assessment of neurodevelopmental conditions in children and adults.

Key findings

NAIT and pathfinder teams have asked neurodivergent people about their experiences and the value of knowing and having your diagnosis confirmed is a strong message. The ever increasing demand for diagnostic assessment speaks for itself and the overwhelming evidence highlights that diagnosis really makes a difference, when the process supports individuals to understand what it means for them. Living as a neurodivergent adult without a diagnosis often has a negative impact on mental health and wellbeing and participation in daily life. Adults we have spoken to describe diagnosis as 'like opening a door'. Most people describe always being aware of feeling different or wrong but not knowing why.

Although everyone has a different experience and response to diagnosis, some key benefits are:

- Understanding 'I am different not broken'
- 'Finding my people' and realising other people have similar experiences and preferences
- Understanding why mental health treatments and therapies had not worked

- Accessing neurodevelopmentally informed treatments, therapies, adjustments and peer supports that do work
- Having words to describe sensory responses and preferences, communication differences and thinking styles
- Understanding masking, autistic burnout and meltdowns and why terms like ‘anxiety’ and ‘depression’ or other mental health diagnoses have not fully explained individual experiences
- Accessing more appropriate support, knowing what reasonable adjustments to ask for and learning how to do this
- Changing how others see you – it’s not that you are being difficult, it’s that you need things to happen differently to be able to take part in naturally occurring environments of home, education, work, healthcare and in the community
- Transitions and times of change can be particularly difficult for neurodivergent people. Diagnosis helps with self understanding, knowledge and autonomy so that individuals can be involved in planning and feel in control in preparing for and living through transitions.

Co-occurrence is the norm:

- Autism and ADHD commonly co-occur. Single condition pathways waste resources and extend waits for diagnosis and support.

Current provision does not meet needs:

- In 2021, only 1/14 Scottish health boards provided both autism and ADHD assessment for adults; 1/14 provided for neither and 12/14 provided for one or the other but not both.
- No service described comprehensive provision, or proportionate pathways in place that assist with scaling of response dependent on needs.
- Existing services are in high demand, but this is not matched by capacity to meet the need. The lack of services is compounded by a lack of skills and appropriate interventions within mental health services.
- Adults seeking assessment find that there is either no local service that they meet the referral criteria for, or there are long waiting times.
- Responsibility for providing diagnostic assessment has lain within Community Mental Health Teams (CMHTs). Thresholds for access to CMHTs leads to referrals from people seeking diagnosis and support related to neurodevelopmental conditions being rejected.

- Where neurodivergent people are involved with mental health services, there is a sometimes a mindset that diagnosis of neurodevelopmental conditions is not the remit of the team and there is a focus on pharmacological solutions and psychological therapies for mental health conditions, which may or may not be neurodevelopmentally informed.
- People who seek to access healthcare and professionals have highlighted the need for updated professional learning and a more neurodevelopmentally informed workforce.

New approaches are needed:

- There is limited provision of neurodiversity or neurodivergence affirming practice, psychoeducation, peer led support, environmental modification and supports in naturally occurring environments or access to expertise of allied health professionals.
- Co-production with neurodivergent people in developing services to meet needs was not commonplace. There is consensus on the need to develop meaningful partnerships and practice in line with the principle of 'Nothing about us without us'.
- There is consensus on the need for timely access to diagnostic assessment, better ways of supporting mental health needs and up to date professional learning.
- Adult neurodevelopmental pathways are the logical way forward but this is an uncharted approach in Scotland. This work will be breaking new ground.

Managing expectations, demand and capacity:

- It is important to note that in the short and medium term, it is expected that demand will increase.
- There is significant unmet need and under-recognition of autism and ADHD in adults. As services develop to address the unmet need, demand is expected to grow.
- As services develop new ways of building capacity to meet the need, clear communication and ways of managing expectations should be built in to planning.

Scoping Recommendations

- **Neurodevelopmental Pathways:** There is a need for neurodevelopmental pathways to replace single condition approaches, with the aim of autism and ADHD assessment and support being accessible in all 14 health board areas.
- **Stepped Care:** There is a need to develop local stepped care pathway models, which will mean forming new teams and partnerships to meet a need not currently met, with leadership from:
 - **Tier 1-2:** Third sector and Community services, with access to self help, peer support, psychoeducation and a range of provision before, during and after diagnosis
 - **Tier 3:** Primary care neurodevelopmental teams, with prescribing and differential diagnosis capability as well as direct access interventions and supports
 - **Tier 4:** Secondary care neurodevelopmentally informed teams

Good links are required across all levels in the pathway to ensure a 'step up' or 'step down' to best meet individual needs. Tests of change should support the development of effective models.

- **Workforce:** New service developments should broaden the membership and roles of the multi-disciplinary team.
- **Professional learning, knowledge and skills:** A planned, and strategic approach is needed to understand professional learning needs across the range of professionals who make up a neurodevelopmental team. Neurodevelopmental assessment and diagnosis can no longer be the role of a small number of 'specialists' rather it should be 'everybody's role' within stepped care mental health teams.
- **Adult Neurodevelopmental Specification:** In keeping with realistic medicine, we recommend investing in developing a proportionate cross sector adult neurodevelopmental service specification and standards, which are strategically aligned to children and young people's neurodevelopmental service specification in these lifelong conditions. Learning from pathfinder sites should contribute to this development.

While some of the work involves adaptations to existing services and mindsets, with resources being used differently, it is also acknowledged that the creation of new services and pathways requires new resource and the recruitment of a workforce with a broad range of skills deployed with an expectation of meeting the needs of adults with neurodevelopmental conditions. Needs cannot be met through tweaking CMHTs.

The Covid-19 pandemic and recovery process is an important context. The wellbeing of staff, as well as people they support, is central to any effective service development.

Pathfinder Sites: Context

In 2022, the focus of pathfinder work has been on autistic adults and those with ADHD. The intention is to widen this going forward, to include consideration of other neurodevelopmental conditions, with the recognition that co-occurrence is the norm rather than the exception and that understanding individual profiles leads to better personalisation of support. For example, in time pathways should also meet the needs of adults with overlapping conditions: Pre-natal Alcohol Exposure, Fetal Alcohol Spectrum Disorder, Developmental Co-ordination Disorder and Developmental Language Disorder.

This current programme of work has focussed on assessment and diagnosis pathways, but these inevitably make links with developing access to proportionate, relevant, evidence informed supports before, during and after diagnosis for adults with neurodevelopmental differences, within a Stepped Care Pathway model.

Neurodevelopmental pathway status in 2021: Where did each area start?

NHS Borders

NHS Borders has a population of around 115,000 people, almost half of whom live in rural areas.

- In 2021, there was a nurse led adult autism pathway in the learning disability service but no autism pathway for all adults. The ADHD pathway was in development. Most ADHD assessments were completed by a single psychiatrist for people meeting Secondary Care (Tier 4) criteria.
- Service leads from psychology, psychiatry and nursing identified a strong will to develop a multidisciplinary approach to neurodevelopmental pathways, in which medics input, provide leadership and partnership but are not the sole providers. There was a strong drive to get the right people, with the right skills for an early and proportionate response.
- There was a local funding arrangement with Autism Initiatives about third sector support, which was due for review.
- There was no neurodevelopmental pathway strategy group or involvement of neurodivergent people in planning related services.

NHS Lanarkshire

NHS Lanarkshire is the third largest health board in Scotland with population of 655,000 across rural and urban communities in North and South Lanarkshire.

- In 2021, there was a high quality multi-disciplinary autism service for adults with learning disability but no pathway for all autistic adults. Most ADHD assessment was led by a single psychiatrist, with identified ADHD cases managed within the Adult Community Mental Health Teams (CMHTs).

- Previous training needs analysis highlighted the need for development of workforce skills and knowledge about neurodevelopmental conditions.
- A neurodevelopmental conditions strategy group had recently been established, including psychology, psychiatry, nursing and occupational therapy. The group had links with the local children's neurodevelopmental pathway. They were looking at ways to involve people with lived experience and were actively seeking funding within the health board to develop an autism pathway for all adults.
- Recent Local Authority consultation with service users and carers highlighted where it was felt services could be improved. These included:
 - Pre diagnostic support
 - Post diagnostic support
 - Employment
 - The lack of education, training and awareness raising for health and social care professionals

NHS Highland (North and West and Inner Moray Firth)

NHS Highland is the largest geographical health board area in Scotland including a large remote, rural and island population as well as urban centres. This part of NHS Highland (excluding Argyll and Bute) has a population of around 234,000 people.

- There was a longstanding adult autism service and pathway outwith the CMHT, led by 1-2 practitioners which was the hub for assessment, diagnosis and support. Demand was difficult to meet, with the small staffing allocation.
- Diagnosticians worked in close partnership with the Autism Initiatives led Highland One Stop Shop and there were links with Autism Rights Group Highland (ARGH), NAS Highland Branch and Scottish Autism post diagnosis group leads.
- There was no adult ADHD pathway for those who do or do not meet secondary care thresholds and no specific neurodevelopmental provision in primary mental health care. However, there were some skilled and interested psychiatry, advanced nurse specialists and non-medical prescriber staff interested in taking this work forward.
- A lifespan Neurodevelopmental Steering Group had been recently set up with involvement of children's services, the adult autism team, adult psychiatry, nursing, managerial staff, third sector and autistic people.

NHS Fife

Fife has a population of around 370,000 people, including a large student population, across urban and rural communities in 7 localities.

- Adult ADHD and autism pathways were managed separately.
- The adult ADHD pathway was in development and was managed within the CMHTs with a nurse specialist post supporting transitions, assessment and treatment in 3 locality areas.
- There was an established autism pathway for all adults meeting secondary care thresholds for acceptance of referrals. This was based within psychology for non complex autism assessments and within the CMHT for complex assessments. An experienced team supported clinicians making diagnoses.
- The well established Fife One Stop Shop, led by third sector partners Scottish Autism was an important resource. Recent investment from the partnership was agreed for a half time Occupational Therapist (OT) to be based within the One Stop Shop.
- Close links were established between St Andrews University and the North East Fife CMHT and efforts to work jointly with clinical staff from the university mental health team were underway to support triage and assessment (but not diagnosis or ongoing management). The university have in place an autism support group.
- A neurodevelopmental pathway strategy group had recently been set up, including psychology, psychiatry, nursing, OT and other partnership members. The group were keen to develop engagement with neurodivergent people.
- There are strong building blocks on which to develop an adult neurodevelopmental pathway though it is clear that the pathway will need to be resourced for development of self-help resources, third sector provision and the creation of the primary mental health tier.
- Discussions were in progress developing the Primary Care Mental Health vision for Fife. It was deemed important that the neurodevelopmental pathway would be aligned to these as it evolves.

Key messages underpinning neurodiversity informed services

In partnership with neurodivergent people, NAIT developed and shared key messages for supporting adults with neurodevelopmental differences which should underpin the development of future adult neurodevelopmental pathways. These key principles reflect the importance of approaching this work with a neurodiversity affirming mindset. It is acknowledged that the neurodiversity paradigm⁵ is a relatively new concept and guidance for practice is still evolving through new ways of working in equal partnerships between professionals, neurodivergent people and their allies.

Key Messages for supporting neurodevelopmental differences in adults

1. 'Nothing about us without us'

Meaningful co-production is central to developing a whole systems approach neurodevelopmental pathway that works for all people who access it.

2. Difference not deficit

Neurodiversity is a positive thing in society. A strengths based approach changes how we communicate about people, communicate with people, make adjustments and what services focus on.

3. Environment first

The basis of all effective support is having the right expectations and adjustments in the physical and social environment in every day naturally occurring settings of home, education, employment and the community.

4. Diagnosis matters

People seeking or receiving neurodevelopmental diagnoses tell us diagnosis matters in so many ways – understanding and celebrating personal identity, understanding past, present and future experiences, accessing relevant information and a community of peers, informing which supports and interventions are right for them.

5. Language matters

A range of preferences exist and one size does not fit all – we can listen and adapt the language we use to reflect individual and community preferences.

6. A neurodevelopmental lens

We can expect to meet people with neurodevelopmental differences in everyday life and in mental health services. We can approach everyone with an inclusive and positive mindset and the right lens on support we provide.

Pathfinder Sites: Mechanisms for change

The Adult Neurodevelopmental Pathways Interim Report⁶, June 2022 summarised the early work undertaken across all 4 sites.

Overall aims of the work in pathfinder sites were to:

- Prepare to introduce a single stepped care pathway for adult Autism and ADHD, with staff confident to identify, assess and diagnose both conditions.
- Develop local pathways which deliver graded and proportionate support before, during and after diagnosis with strong links between Tiers 1, 2 and 3 to avoid unnecessary blockages and waiting lists.
- Undertake work linked to four key areas summarised below: **Workforce development; Mechanisms for change; Identifying where this service will be offered and Developing support to meet needs.**

Pilot sites (Fife, Borders, Lanarkshire and Highland) are undertaking focussed work, adapted to local priorities and intended to inform future service structures and an adult neurodevelopmental pathway approach across Scotland. The areas of focus for pilot sites include:

Workforce development:

- Broadening the range of professions involved in assessment, diagnosis and support.
- Recruitment and retention.
- Development of professional learning and understanding needs.
- Demand – Capacity Modelling.
- Leadership models.
- Models of multi-disciplinary working.

Where do autism and ADHD support, assessment and diagnosis happen? Potential changes might include:

- New Primary Care mental health teams.
- Allied Health Professionals and Nurse led ND teams at primary and secondary care levels.
- New partnerships between health professionals and third sector teams.
- Third sector partnerships, with shared governance of clinical roles undertaken out with NHS teams.
- Changes in mindsets in mental health teams around the value & therapeutic importance of neurodevelopmental diagnosis.

Mechanisms for change:

- Involvement of people with lived experience in local decision making.
- Local neurodevelopmental and autism strategy groups (including neurodivergent people).
- The NAIT Adult neurodevelopmental pathways national professional's network.
- Development of professional learning to encompass a neurodiversity informed approach to practice across professions.
- Development of a Community of Practice interested in environment and participation focussed approaches.

Developing support to meet needs:

- Trial a range of evidence informed support provided before, during and after diagnosis (e.g. Psychoeducation; Group and individual information sessions; Self-help materials and guides; Signposting to peer-to-peer supports).
- Develop 'patient information' resources about neurodevelopmental assessment.
- Review of evidence for current and new practices.
- Share resources developed across Scotland.
- Liaison with Further Education establishments to develop autism informed practice.
- Exploring links with local employment support provision.

Mechanisms for change

The plans for developing neurodevelopmental pathways should be grounded in an understanding of modern change theory, which supports whole systems change and is focussed on a shared purpose rather than separate interests. There is no single or linear path to identifying a problem, solutions and outcomes but rather the complex inter-related factors should include an understanding of real world context, mechanisms and outcomes. Small teams can leverage big change at a systems level through the right mechanisms, for example, through new partnerships and networks, which challenge historical assumptions, silos and hierarchies and support people to take action because people experience connection with shared values. There was a strong sense across the pilot sites of the real desire to better meet the needs of neurodivergent people and that all involved were glad of the chance to take time to focus on this, with old and new partners and to bring their skills, passion and experience to this challenge.

In pathfinder teams, mechanisms include:

- **Passionate, informed and motivated local leaders** with influence, vision, positive relationships, persistence and understanding of local processes, are central to making this work happen. This has been strongly evident as a factor in achieving all that has happened in the first 12 months of this work.
- **Involvement of people with lived experience** in shared planning and local decision making. This means that the focus of change is more likely to feel like the right thing to do and more likely to meet the needs of neurodivergent people.
- **Establishing a local neurodevelopmental pathway strategy and planning group**, which includes cross sector and lived experience membership. All four sites now have these in place, to develop a locally relevant plan; to maintain a shared focus on implementing the plan, reviewing it and learning. The group is more than the sum of its parts and there is power in the relationships which are inter-dependent and collaborate across the whole system.
- **Writing down a shared purpose and values**, which helps team members to step outside of the operational complexity, seek solutions to the apparent barriers imposed by the system and to ask why can we not do this differently? or how can we do this differently?
- **Finding your people.** Within local areas and through the NAIT professional networks, practitioners have reported the value of finding other people who share their vision, passion, motivation, experiences, knowledge, learning, questions and who notice and understand the huge achievement of a seemingly small step or who understand when things you work really hard at seem to take forever to move forward.

- All four sites have been **open to sharing resources and practical materials** they develop, e.g. job descriptions, FAQs for referrers, local websites, patient information resources and have contributed their expertise and feedback to national NAIT Neurodevelopmental pathway resources.
- **Community of practice:** this pathfinder work has highlighted the desire for a community of practice which will be led by NAIT going forward and will underpin a national endeavour to improve experiences of neurodivergent people across Scotland, within a neurodiversity paradigm. This community brings a point of focus on evidence informed ideas and opportunities for learning and professional development.
- **Having ways to articulate the focus of change** is an important factor. This year's work has provided opportunities to have conversations about changing mindsets, stepped care, interventions which focus on environmental modification, neurodiversity affirming language and practice and neurodevelopmentally informed assessment and diagnosis. Partners have shared that they have learned from listening to different perspectives from within and outside their usual circles of contact.
- **Access to practical guidance and resources to enable professionals to feel confident** in assessment, formulation, sharing diagnoses and providing supports in line with evidence informed guidelines.
- **Engagement with and access to relevant professional learning** is another key mechanism to build the capacity in the workforce to meet the aspirational action plans set. There is an ongoing requirement from local teams, NAIT and NES to understand needs and to look for ways to meet this need.
- **Managing expectations** has also emerged as an important mechanism. There is a fear amongst teams setting up new services (from a position of there being no previous way of meeting the need) that they will be inundated and this has indeed been the case in some areas. Just as staff are developing skills and confidence, teams can feel like they are letting people down by not having the capacity to meet the demand. For neurodivergent people, clear expectations are important. People often understand about waiting when they feel informed. The pathfinder sites working with NAIT and neurodivergent people, have developed FAQs for referrers and people seeking assessment which explains a phased approach and why some people may not yet be able to access assessment.

Workforce development

NAIT have worked in partnership with pathfinder sites to provide support for sustainable change, in the following ways:

- Identification of pathfinder site areas and support to write proposals and action plans
- Hosting monthly pilot site meetings, to support ongoing monitoring
- Providing responsive support to services to address practical issues arising
- Hosting a National Adult ND Professionals Network which will continue to meet four times per year
- Hosting the NAIT Neurodivergent Partners Reference Group which meets regularly and works with us to inform the range of work underway
- Regular liaison and partnership with NES to identify shared and complementary roles in relation to Adult ND pathways and professional learning
- Engaging in discussion with a range of professional partnerships, networks and organisations (e.g., Professional bodies, FASD Hub, Inspiring Scotland, ARC Scotland and UK wide networks)
- Development of resources to support delivery of professional learning and application of a neurodevelopmental approach in pilot sites:
 - Hosting a national webinar – Supporting Adults with Neurodevelopmental Differences⁷
 - Offering three Adult Neurodevelopmental Assessment Workshops for pilot sites (April, May, December 2022)
 - Writing the Adult ND Assessment Workbook⁸ to accompany workshops, with guidance on assessment tools and processes for neurodevelopmental assessment
 - Supporting the completion of a trial version of the Fife Adult Neurodevelopmental Questionnaire (Fife Adult NDQ) developmental history assessment tool
- Adult ND Assessment Tool: NAIT Early Neurodevelopmental Questionnaire⁹
- Adult ND Assessment Tool: NAIT Assessment of Sensory Preferences¹⁰
- NAIT Sensory Preferences Checklist for Adults¹¹
- Hosting ACE+ ADHD Training
- Hosting ADOS Training for pilot sites

- Writing NAIT Guides¹² in response to issues arising in pilot sites, A full list of relevant NAIT resources is provided in the appendix - for example, guidance on:
 - Language Matters – Terminology Guide
 - ADHD Prescribing and Private Diagnosis
 - ICD-11
 - Autistic Masking
 - Using ADOS with Adults FAQs
 - Guide to Who can Diagnose ADHD
- Sharing of resources developed in pilot sites (e.g., FAQs on the new pathway; web resources, psychoeducation materials)

Impact and learning

- All four pathfinder sites have actively engaged in all of these professional learning opportunities and provided positive feedback.
- Recruitment of staff to the pathfinder funded posts took several months and in some areas is still underway (11 months on). This means that all areas are likely to require further and ongoing opportunities for workforce development.
- There is a shared understanding that attending training is not the only means of building capacity and confidence in the workforce.
- There has been a strong focus on looking for ways to embed a mentorship and partnership working approach which uses the skills of local professionals with expertise and builds a local community of practice that will continue to actively plan to meet workforce development needs and succession planning.
- Lanarkshire have had a particular focus on understanding professional learning needs and will use new funding to employ a training co-ordinator. We look forward to future updates on this work.

The NAIT Neurodevelopmentally Informed Practitioners information below highlights 7 stages of career long professional learning for neurodevelopmentally informed practitioners, which could support future workforce planning and development.

Neurodevelopmentally Informed Practitioners

Graded and career long learning opportunities:

1. Students and trainees

- Course materials and placement tasks support engagement with stages of neurodevelopment, inclusive practice and the neurodiversity paradigm.

2. Newly qualified / New to this field

- Mentoring and coaching, reflective logs
- Watch one, do one, reflect (with supervision)
- ND Informed and skilled level learning
- Online resources (e.g. Symposium, NAIT, NES, Education Scotland resources)

3. Skilled level in aspects of neurodevelopmental assessment, diagnosis and support

- Engage in local programme of professional learning and mentoring, supported by national resources.

4. Enhanced level in aspects of neurodevelopmental assessment, diagnosis and support

- Specialist training (e.g. ADOS)
- Attend and deliver local learning, coach and mentor others (using train the trainer materials).

5. Expertise level in aspects of neurodevelopmental assessment, diagnosis and support

- Lead strategic planning for workforce
- Deliver and develop training materials

6. Accredited post graduate study

- Practice focussed on PGCert, PGDip, Masters, PhD focussed on ND conditions.

7. Professional bodies accrediting institutions

- Learning accredited by professional bodies (e.g. GTCS, Royal Colleges, SIGN, NHS Scotland)

Where does assessment, diagnosis and support take place?

The NAIT recommendation was for pathfinder sites to develop stepped care approaches across all four tiers, from the baseline of there only being provision in Tier 4. There has been no previous research or guidance to refer to in decision making and the nature of pathfinder work is to break new ground and learn from this. Within the time frames, we found that local areas made pragmatic decisions about where to start.

- All four sites had a secondary care (Tier 4) CMHT which was the only team with a role in assessment, diagnosis and support of autism and ADHD. Three of the four areas opted to use the additional funding mainly at this tier, with Fife including work at all tiers.
- **Highland** have developed a new Tier 4 adult ADHD pathway in 2022. In phase 1, this is for those meeting the CMHT threshold (where there previously was no ADHD pathway). This will provide a basis for future work to develop a stepped care and neurodevelopmental pathway. They have also focussed work on professional development of CMHT staff experienced in ADHD, developing skills in neurodevelopmental and autism assessment and working alongside the autism team. And in parallel, trialled assessment of ADHD when co-occurrence is considered as part of an autism assessment, through the specialist autism diagnostic team. No third sector, community or primary care initiatives have been part of this phase of work but are all under consideration as future developments.
- **Borders** have focussed initially on addressing the waiting list of people meeting the Tier 4 CMHT threshold with separate lists for autism and ADHD assessment. They appointed an OT to lead the neurodevelopmental team and support professional learning and capacity building within the CMHT. The leadership team have also engaged with local third sector stakeholders and have reviewed the commission of work to third sector partners Autism Initiatives (AI) with whom they reached a shared governance agreement for AI to undertake autism assessments for less complex cases who do not meet CMHT thresholds alongside follow up support at Tier 2. This has led to a challenging situation where some on the waiting list do not meet thresholds set for either service and no alternative is being offered at this time. No community or primary care initiatives have been part of this phase of work but are all under consideration as future developments seek to build on this work.
- **Lanarkshire** have also focussed on Tier 4 and have taken a decision to build on separate autism and ADHD pathways. They succeeded in identifying permanent funding through the HSCP for an all adult autism pathway and recruitment to this team is underway. The focus of pathfinder funding has been to recruit a training lead and build knowledge and skills within the existing workforce for both autism and ADHD assessment and taking a neurodevelopmental approach. Separate work in Lanarkshire has led to the provision of Primary Care Mental Health Occupational Therapists linked to all GP practices. Local third sector and lived experience stakeholders are part of the neurodevelopmental strategy group. There are opportunities to build on the work and partnerships in place this year to develop stepped care provision.
- **Fife** used the funding at all tiers and have undertaken tests of change in NHS staff working in the University of St Andrews. The pathfinder funding has in part been used to appoint senior staff to co-ordinate and make links across this tiered pathway.

- Tier 1: Work has been completed to develop self help information and resources for adults with neurodevelopmental conditions, on the NHS Fife Mood Café website¹³
- Tier 2: There is a One Stop Shop in Fife, run by third sector partners Scottish Autism. An NHS OT is now working across the One Stop Shop and in the local community team to deliver collaborative support including psychoeducation groups.
- Tier 3: There is a primary care mental health team test of change underway.
- Tier 4: There is an ongoing focus on professional learning and building capacity within the CMHT.

The practicalities of setting up new ways of working at all tiers cannot be underestimated. There has been a lot of learning from the work this year and we anticipate using this to undertake further pathfinder work in the years ahead.

Summary of changes in Adult Neurodevelopmental Pathfinder Sites

We asked each of the pathfinder sites to report on 15 key areas of focus over the last 12 months (November 2021-november 2022). This is summarised in the tables below, with red indicating this factor is not in place, amber indicating that it is in progress or partially in place and green indicating that it is in place. White boxes indicate missing data at the point of publication.

This outcome is shown visually below and represents positive changes and the direction of travel for pathfinder sites. These factors could be used by other HSCPs reviewing pathways and could inform standards within a future adult neurodevelopmental pathways specification.

Figure 3

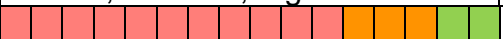



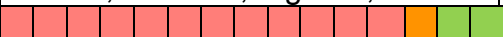

	In 2021	In 2022
Borders	11 red, 3 amber, 1 green 	3 red, 9 amber, 3 green 
Fife	10 red, 4 amber, 1 green, 	0 red, 9 amber, 6 green 
Lanarkshire	12 red, 1 amber, 2 green, 	2 red, 7 amber and 6 green 

Table 1 Summary of changes in Adult Neurodevelopmental Pathfinder sites

		Borders	Fife	Highland	Lanarkshire
A co-ordinated multi-agency group looking at Neurodevelopmental Pathways across the HSCP	2021	No	No	No	Yes
	2022	Yes in CMHT only	Yes	Yes	Yes
Neurodivergent people are partners in planning and co-production	2021	No	No		No
	2022	Yes	Yes		Yes
New staff have been recruited to a neurodevelopmental team or service	2021	No (planned)	No		No
	2022	No (skilling up CMHT)	Yes (partial)		No (planned)
There is a pathway and referral process for adults who may be autistic	2021	No	Yes in CMHT only	Yes	No
	2022	Yes in CMHT only	Yes in CMHT only. Improved links with 3rd sector, primary care and OSS	Yes	Yes
There is a pathway and referral process for people who may have ADHD	2021	No	Yes in CMHT		No
	2022	Yes in CMHT only	Yes in CMHT, Tests of change looking at provision outside CMHT		Planned
There is a single pathway for autism and ADHD	2021	No	No	No	No
	2022	No. Planning around managing co-occurrence	No but steps towards this underway	No	No
There is a process for recording demand and capacity in relation to neurodevelopmental conditions	2021	No	Partial via psychology		No
	2022	In progress	Needs development		Yes

Table 1 (continued) Summary of changes in Adult Neurodevelopmental Pathfinder sites

		Borders	Fife	Highland	Lanarkshire
There is an AHP/ Nurse led team outside of the CMHT, with knowledge and skills about neurodevelopmental conditions	2021	No (planned)	No		No
	2022	No – Skilling up CMHT	No (planned)		No (planned)
There is primary mental health care support and diagnostic assessment for people with neurodevelopmental conditions	2021	No	No	No	No
	2022	Yes – in CMHT only	Planned Current ToC will inform developments	No	No but under discussion
There are partnership arrangements with third sector in place around ND pathways	2021	No	Yes (partial)		No
	2022	Yes – in CMHT only	Yes Part of a ToC		No but could be considered
A range of support is provided before during and after diagnosis	2021	Yes, but limited	Yes for ASD Limited for ADHD	Yes but limited	No for ASD Post diagnosis follow up only for ADHD
	2022	Yes and in development	In development	In development	In development
There is a professional learning strategy to have a neurodevelopmentally informed workforce	2021	No	No		No
	2022	Yes for staff in CMHT	Under consideration by strategy group		Under consideration by strategy group
Team members engage with NAIT adult ND network	2021	No	No	No	No
	2022	Yes	Yes	Yes	Yes
We have sought or secured other local funding and resources linked to this work	2021	No	Partial		No
	2022	No	Yes. Business case approved		Yes. Business case approved
First line interventions include psycho- education, employment support and environmental modification	2021	Needs dependent	No		Unsure
	2022	Needs dependent	Yes		Unsure

Developing support to meet needs

There was a strong consensus, backed up by research evidence, that diagnosis alone is not the most helpful thing but rather the support surrounding diagnostic assessment before, during and after a decision is made is what makes a difference to people. One size clearly does not fit all and there is a need for choice and access to all of the range of supports shown below over time.

The collective work of pathfinder site teams, in partnership with neurodivergent people, third sector, NAIT, NES and the research community is required to develop, implement and evaluate supports.

- **Peer support**
- **Support surrounding diagnosis** – ‘Psychoeducation’ or ‘post diagnostic support’ which people can access before, during or after diagnosis.
- **Information about local referral process.**
- **Psychological, OT and SLT therapies** which are neurodiversity affirming and take account of neurodivergent thinking styles.
- **Practical support for particular issues** e.g. to engage in helpful routines; apply strategies in daily life; address sleep, communication and sensory needs; help to understand reasonable adjustments and how to access them in education, employment or other settings.
- **Self-help materials and guides** reflecting that knowing which diagnoses apply to you makes self help more effective.
- **Web based information and helplines.**
- **There is a need** for evidence review and a source of guidance about recommended interventions and approaches to meet different needs.
- **Support** for families and carers of neurodivergent people.
- **Prescribing** of medication and ongoing monitoring – where this is indicated, alongside shared care agreements.

Understanding demand and capacity

Understanding demand and capacity for adult autism, ADHD or neurodevelopmental assessment is complex. It becomes even more complex when trying to understand demand, need and service capacity for support at different tiers in a cross sector system. Consensus on effective and efficient data collection, which measures what matters should be a national focus as neurodevelopmental pathways develop and requires collaboration between clinicians and data scientists in Public Health Scotland.

NAIT continue to work with the national practitioners' network to collate and share information that is available. In future we recommend looking for ways to understand local and national demand and capacity across all 4 tiers of the stepped care pathway. There will be opportunities in future to learn from related work in children's services.

Demand:

- Even if we narrow the focus to assessment and diagnosis within adult mental health services, there is no national system for collecting this information.
- It is not easy to understand how to capture demand or need when there is no service, so no referral data.
- Service configuration is complex and even where services or pathways do exist, they often focus only on a subgroup of the total number of people who might be seeking assessment (e.g., CMHT ADHD referrals only or Adult LD autism assessments only).

Capacity:

- Understanding capacity includes knowing hours of clinical time from different members of the multi-disciplinary team, relevant knowledge and skills in the workforce, physical space to deliver services and many other factors.
- Services in development will use time differently to highly skilled and confident teams, working within an established stepped care service, so that capacity and what can be delivered within resource can change over time.

Given this context, we will report here on information from Scotland which add to our understanding. This is not a complete review of all health boards and we are aware there is work going on in other areas and we look forward to opportunities to share related work in future.

Public Health Scotland audit of prescribing of ADHD medication in Scotland between 2010 and 2019

- In 2019, medication was the recommended first line of intervention for ADHD and there is strong evidence that it can improve quality of life, mental health and wellbeing in a population with high rates of substance misuse, involvement with criminal justice and psychiatric illness
- There were significant increases in people receiving medication for ADHD between 2010-2019. The numbers dispensed a prescription increased by 233.2%
- Nationally, for adults at an estimated 2% prevalence level, 91% of cases with likely ADHD were not prescribed medication, and at the 4% level the figure was 96%
- When examined geographically, there were stark differences in local practices with between 85%-100% of adults with likely ADHD in a health board area not prescribed medication

Although this does not directly relate to demand and capacity, it indicates the level of unmet need and potential demand once local areas start to address neurodevelopmental assessment.

Local Area Data

Large increases in referrals for autism and ADHD assessment are reported by local services. Through the national network, we have learned about related work in other HSCPs around Scotland. Local teams have kindly shared the following:

Glasgow: Autism, ADHD and a stepped care adult neurodevelopmental pathway plan

NHS Greater Glasgow & Clyde is the largest health board area in Scotland and serves a population of 1.2 million distributed across 6 HSCPs.

- NHS GG&C had a well-established specialist multi-disciplinary adult autism team that provided diagnosis and short term support to autistic adults with a clear pathway in place.
- There was an over 1000% increase in referrals for assessment of adult ADHD to CMHTs over the past three years. These assessments were initially undertaken within CMHTs but waiting lists rapidly built up due to limited capacity within CMHTs. NHS GG&C is currently receiving over 2000 referrals for ADHD assessment per year. Over the same time frame, there has also been an over 250% increase in referrals for assessment of autism.
- A small nurse led ADHD waiting list initiative (WLI) was set up in April 2021 in Glasgow City to address waiting lists for assessment as an interim measure while work was undertaken to develop a more comprehensive pathway. Access to the WLI is through adult CMHTs with treatment provision remaining within CMHTs. As a result of the investment in the WLI, there has been an over 800% increase in recorded diagnosis of

ADHD among adults within Greater Glasgow & Clyde over the past 3 years. However, it has been challenging to maintain staffing levels in the WLI with increasing competition for trained staff from the private sector.

- A neurodevelopmental pathway development group has been set up with multi-disciplinary input and with wider stakeholder involvement from public health and primary care.
- A needs assessment of people referred for ADHD assessment using a questionnaire survey and engagement sessions with autistic adults has been undertaken.
- A new, single neurodevelopmental pathway which envisages a matched care approach with service provision at secondary care, specialist third sector and primary care level has been developed. The primary care component relies on new investment from Scottish Government within the mental health in primary care teams. Efforts are underway to identify funds for the secondary care and specialist third sector components.

Fife ADHD referrals

- In 2012 Central Fife (population 150,000) received 59 referrals for ADHD assessment in one year. In 2022 the same area received 297 referrals for the year. This reflects an increase by 500% in referrals over 10 years.

Lothian neurodevelopmental pathway

- Lothian have an established neurodevelopmental approach to adult autism and ADHD assessment in the CMHT over the last 10 years. A small multidisciplinary Neurodevelopmental Resource Team support professional learning, coaching and mentoring to build capacity across mental health, social care and primary care teams.
- Up to 30% of referrals to the CMHT have been for neurodevelopmental assessment; 70% of these individuals were previously known to the CMHT but not diagnosed and there was found to be a 40% co-occurrence rate of autism and ADHD in individuals assessed.
- Information on [RefHelp](#) supports GPs to make referrals with relevant screening information, to increase capacity through gathering information in advance of first appointments and supporting effective triage.
- The team identified that 30% of referrals to the CMHT for autism assessment were 'non-complex'. A successful governance arrangement between NHS Lothian and Autism Initiatives means that this group are offered quick assessment through (Tier 2) third sector partners along with a range of supports, thus reducing demand on the CMHT and reducing the number of people refused assessment because of Tier 4 thresholds.

- In East Lothian, the local Primary Care Mental Health Team (Tier 3) have developed a direct access service led by AHP and Nurses and many of the people accessing brief interventions and support are neurodivergent. Some seek support and others are still seeking diagnostic assessment. This team does not currently undertake diagnostic assessment but there is an opportunity in local areas to consider how such teams can meet demand at an earlier stage and before crisis hits, as well as being a maintenance support for people who have previously been engaged with the CMHT.

NHS Grampian Adult Autism Assessment Team

- Prior to 2021, there was no pathway for adults seeking autism or ADHD assessment in Grampian. The small multidisciplinary AAAT started offering assessments in April 2021, with 4 hours each a week allocated to develop a sustainable pathway with self-referral for adults seeking autism assessment in Aberdeen City and Aberdeenshire and works closely with Autism Understanding Scotland and other third sector organisations. Moray joined the team in May 2022.
- Team members all have roles in the CMHT but this service operates at Tier 3 and is not dependent on Tier 4 thresholds.
- There were 789 referrals in the first 18 months, 62% of these were female and on average 4 direct contacts were needed to complete the process agreed, with information gathered in advance to support efficiency. 31 referrals were declined and the diagnostic rate was 80-85%.
- Feedback to date from the autistic community has been hugely positive.
- The local Quality Improvement and Assurance team supported the development of a clinical data gathering system to understand demand in relation to number of referrals, time for assessment, wait times, diagnostic rate and proportion of referrals declined or advised to follow a different pathway.
- In reviewing next steps, the local team have developed a proposal with 5 levels of costed options, ranging from maintaining this service to a full stepped care adult neurodevelopmental service. There is local agreement to continue with the status quo until March 2024, with a small increase in staffing to increase capacity for assessment.

NAIT Wait Times Review 2022

NAIT undertook a national review to understand wait times in adult and child Neurodevelopmental services and to investigate key time points (measured against NAIT Child ND time standards below) and factors within the diagnostic process. Responses were provided by services around Scotland for assessments completed between October 2021 and May 2022. Outcomes will be reported fully in a separate report.

Table 2: NAIT time standards

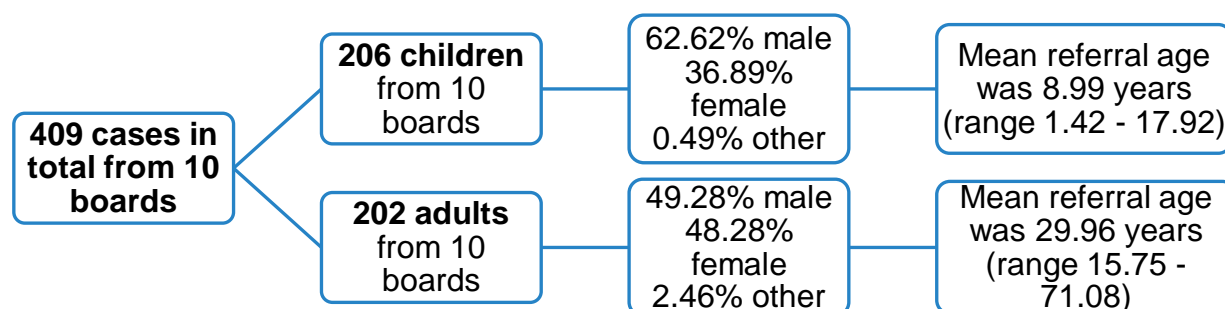
Stage in Pathway	NAIT Proposed Time Standards
Request for neurodevelopmental assessment	Time from acceptance of referral to first appointment should be no longer than 12 weeks (84 days)
Diagnostic assessment	Time from first appointment to last appointment should be no longer than 6 weeks (42 days) to 22 weeks (154 days)*
Full process	Total waiting time (from request/referral accepted to diagnosis shared) should be no longer than 19 weeks (133 days) to 36 weeks (252 days)*
Support	Follow up (meeting after diagnosis) should be within 8 weeks (56 days)

*depending on case complexity

Findings

A retrospective case note analysis of 409 individuals seeking neurodevelopmental assessment services, was used to gain an understanding of the neurodevelopmental diagnostic assessment process. Data was received from 11/14 health board areas.

Figure 5



Pathways followed were:

- Autism only n=58 (28.71%)
- Autism & Learning Disability n=10 (4.95%)
- Autism & ADHD n=47 (23.27%)
- Autism & Mental Health n=8 (3.96%)
- Learning Disability only n=17 (8.42%)
- ADHD only n=52 (25.74%)
- ADHD & Substance Misuse n=1 (0.5%)
- ADHD & Mental Health n=1 (0.5%)
- Mental Health n=9 (4.46%)

Diagnoses received were:

- Autism n=79 (38.92%),
- Attention deficit hyperactivity disorder n=92 (45.32%),
- Developmental language disorder n=2 (0.99%),
- Fetal alcohol spectrum disorder n=1 (0.49%),
- Developmental coordination disorder 1 (0.49%),
- Intellectual disability n=11 (5.42%),
- Other neurological or psychiatric diagnosis n=27 (13.30%),
- No diagnosis on completion of assessment n=28 (13.79%)

Diagnostic rate = 86.14%

This is an important figure which suggests that very few people are coming forward for assessment who do not meet diagnostic criteria.

How long is the wait for diagnosis?

Waiting for diagnosis has three parts, namely:

- wait for first appointment (from referral)
- duration of assessment (first appointment/contact to last appointment/contact)
- wait to receive diagnosis

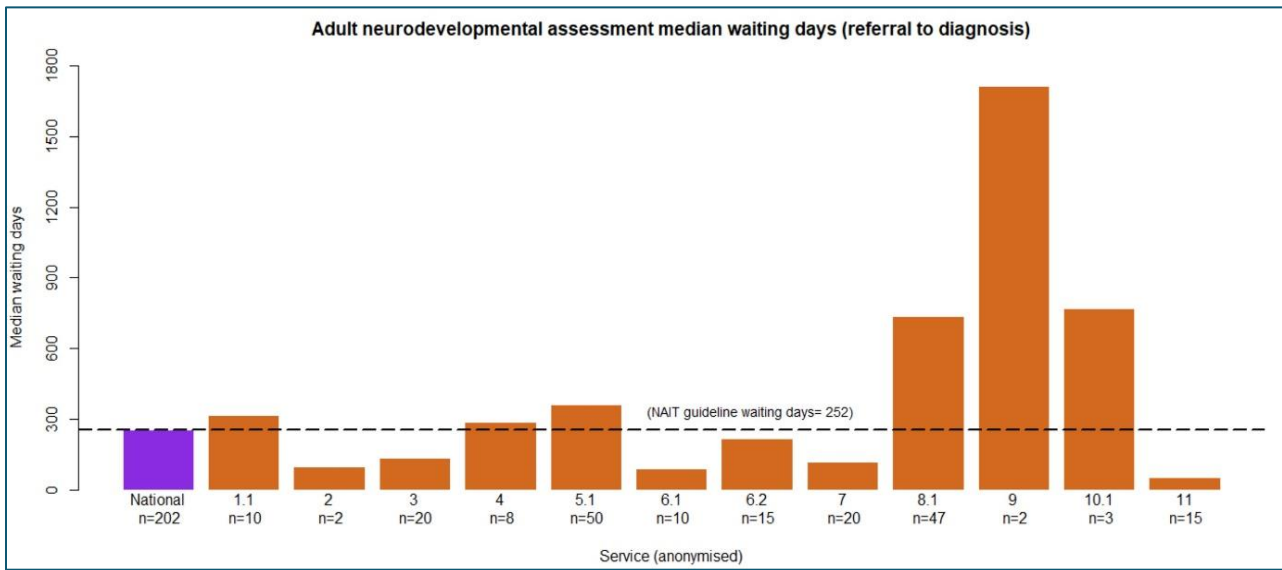
Together these give the total wait for diagnosis (i.e. from referral to receiving diagnosis).

Adults (n=202)

For the adult cases reviewed, the median total wait for diagnosis from referral to receiving the diagnosis was 252 days (IQR 106-611) for adults.

- Under half (45%) of the adult cases reviewed received their first appointment within the recommended 84 days period.
- Around three quarters (73.3%) completed the assessment process within the recommended 154 days period.
- Under half (47%) of the adult cases met the overall 252 day target for full waiting time from referral to diagnosis.

Figure 6



Future considerations

There are key aspects of an effective neurodevelopmental pathway that we know about from related work children's services which were not included in the early phase of work but will be important as services progress:

1. A pathway and workforce which give consideration to a wider range of neurodevelopmental conditions: Pre-natal alcohol exposure and Fetal Alcohol Spectrum Disorder, Tic Disorders and Tourette's syndrome, Developmental Language Disorder, Developmental Co-ordination Disorder and Intellectual Disability.
2. Health economic evaluation to understand the costs and benefits of a neurodevelopmental approach.
3. The development of recommended outcomes to measure success against which are meaningful and relevant to neurodivergent adults as well as to those planning and delivering services.
4. A focus on transitions between child and adult services, linked to the children's neurodevelopmental specification and taking account of the range of naturally occurring environments where adaptation may be needed and new sources of information and support, as well as health related transitions. Much of the current work is focussed on people seeking a new diagnosis as adults but neurodevelopmental conditions are lifelong and there are many people diagnosed in childhood who have a difficult time in adulthood. This is a time when sources of support, expectations and levels of requirement for independence change.
5. A focus on improving neurodevelopmental understanding and support for people in 'high risk' and vulnerable groups or those who are detained or living with high levels of supervision and support.
6. Ongoing partnerships with neurodivergent people at all levels, to inform priorities, needs and deployment of resources.
7. There may be a need for a focus on societal or universal approaches to celebrating and understanding neurodiversity in healthcare, education, employment and community contexts, building on the Different Minds campaign and the Leadership and Engagement work underway.
8. Ongoing review and evaluation are fundamental requirements when we are at such an early stage in understanding what is essential, what is desirable or indeed what is less of a priority.

Conclusions

The ultimate aspiration of this work is that there will be timely access to support, assessment and diagnosis for adults with neurodevelopmental conditions through local stepped care pathways, led by a multi-disciplinary and cross sector workforce with relevant knowledge, skills and resources and including strong partnerships with neurodivergent people.

This has the potential to lead to better participation, experiences and outcomes for neurodivergent adults with earlier and more local support and less escalation of distress, thereby reducing the need for more expensive or longer term support.

Four pathfinder site areas received funding in 2022, to support focussed local work to take initial actions towards the development of a local Stepped Care Neurodevelopmental Pathway. We are not there yet but we are heading in the right direction. There is no route map or existing plan to emulate and roll out, so collectively we are learning as we go with the benefit of implementation science principles. There will be mistakes and actions we look back and learn from, as well as successes and unintended consequences.

The highly committed teams within pathfinder sites and across Scotland are taking very practical steps to understand local priorities and make the changes needed. They are looking for ways to best use the resource and time of the most skilled and experienced team members to support capacity building. There is an undoubted need for workforce planning which includes opportunities for a more diverse and neurodevelopmentally informed workforce across health, education and social care at informed, skilled, enhanced and specialist levels.

Where services are being developed, currently demand is growing rapidly and there is a need to gather data to understand demand and to take explicit steps to manage expectations of referrers, people seeking assessment or support and employees. Although resources are in high demand, there will be a need to consider ways that existing resources can be used differently or ways teams can work differently, along with the need for new resources to meet a previously unmet need.

Diagnostic rates are high which suggests that there is often little doubt about the diagnosis, it just needs a local team member to make the decision and share it. Although in some areas waiting times are very long, there are examples where assessments happen well within the time standards set. Most waits are for assessment to start and once assessment starts, most are completed within time standards set for children's services.

Work is required to agree a consensus on time standards for adult neurodevelopmental assessment, at different tiers of the service and for more straightforward or more complex differential diagnosis, as part of a neurodevelopmental service specification.

The NAIT Adult Neurodevelopmental Network is forming a community of practice to bring together research and practice guidance in a way that local teams can support implementation and the hard but rewarding work of making changes happen.

National and local leadership is required to build on the work of 2022 in the years ahead.

Recommendations and next steps

There are some actions which can be taken forward in the short term, to build service capacity and improve experiences for adults with neurodevelopmental differences.

Local Areas: For local areas to better meet the needs of adults with neurodevelopmental conditions we recommend the following:

Recommendation 1: An adult neurodevelopmental pathway strategy and planning group to be hosted in all HSCPs

- Including neurodivergent people to identify a local action plan priorities
- Actions at all four tiers of the stepped care pathway to work towards providing a joined up autism and ADHD service
- A plan to support all mental health staff to engage in professional learning focussed on up to date *Neurodevelopmentally Informed practice* at skilled level
- Engagement with Primary Care Mental Health teams in relation to including AHP and nurse led neurodevelopmental teams offering assessment, diagnosis, psychoeducation, prescribing and health review and other brief direct access interventions with a focus on environmental modification and supports in naturally occurring environments
- Development of information for referrers and people seeking support
- Review of how communication accessible and inclusive the local health care settings are, with reference to the RCSLT Communication Access¹⁵ training and 'More Than Words'¹⁶ guidance
- Review of partnerships with third sector organisations to join up information and local support provision, with consideration of diagnostic assessment being part of a shared governance agreement

Recommendation 2: Support to develop local Neurodevelopmental Pathway action plans:

- The National Autism Implementation Team should support development and review of local action plans overseen by local strategy groups.

National: A national programme of work to support local areas could include Short Term actions (over the next 12-24 months):

Recommendation 3: Establish a Neurodiversity Affirming Community of Practice:

- NAIT will provide leadership to the Adult Neurodevelopmental Professionals network to build relationships and support and combine expertise as work progresses. This network will be aligned to a new Community of Practice.

Recommendation 4: A focus on ‘Post Diagnostic Support’ or ‘Support before, during and after diagnosis’

- ‘Post Diagnostic Support’ for adults seeking and receiving diagnostic assessment should be relevant, proportionate and individualised. There is a role for online and face to face support and access to informed peers and multi-disciplinary professional teams.
- Local services to work in partnership with third sector organisations funded by Scottish Government to provide support under the umbrella of ‘Post Diagnostic Support’.
- Further development of resources, signposting and supports before, during and after diagnosis, which are relevant across co-occurring neurodevelopmental conditions.
- Undertake a review and tests of change with a focus on ‘Support Surrounding Diagnosis’ to understand key components and the optimal range of provision (for example SPARKS programme in Glasgow and the Fife psycho education programmes). This work, building on current work underway in local areas, could develop materials and guidance for local delivery with the combined expertise of neurodivergent people, AHPs, Psychologists, Nurses and Third Sector staff.

Recommendation 5: Build a Neurodevelopmentally Informed workforce in Scotland

Workforce development and professional learning. The focus on this is important in the short and longer term and will continue to be informed by the Scottish Government Leadership and Engagement work with neurodivergent people. NHS Education for Scotland (NES) is a key partner in the development, provision and implementation of the range of up to date professional learning, that will build capacity in the workforce across informed, skilled, enhanced and specialist levels across professional groups.

- The delivery of an Informed level neurodevelopmentally informed professional learning resource led by NES, in partnership with key stakeholders for all health and social care professionals.
- The delivery of Skilled – Enhanced level neurodevelopmentally informed professional learning building on the work from NAIT, Pathfinder sites, NES, professional bodies, stakeholders and inclusive of NES co-ordination of ADOS training, ADHD training and other related professional learning planning.

- Dedicated resource for Speech and Language therapists and Occupational therapists working in all neurodevelopmental teams to undertake diagnostic assessment and to deliver supports focussed on psychoeducation and environmental modification in naturally occurring environments.
- A national focussed programme of work to increase provision of non-medical prescribers to work in all neurodevelopmental teams.
- Develop core neurodevelopmentally informed practice materials for health professional pre-qualification training programmes and require their inclusion in accredited courses in the same way as the Initial Teacher Education Autism resources, developed from the Scottish Government Autism Round Table and Action Plan are now being used in all initial teacher training programmes.
- Formal planning in collaboration with Primary Care Mental Health leads, to enable alignment and implementation of services which are neurodevelopmentally informed and part of a stepped care pathway.

Based on the work outlined in this report and the wider context, we recommend Longer Term actions to improve experiences of adults with neurodevelopmental differences:

Recommendation 6: Development of Adult Neurodevelopmental Pathway standards and guidelines for assessment, diagnosis and support

- A co-produced National Adult Neurodevelopmental Specification and Standards would provide integrity to the work underway.
- Update SIGN guidelines relevant to autistic people and people with ADHD.
- Develop a 'Once for Scotland' neurodevelopmental conditions information and signposting resource, to include self-help resources and links to sources of a range of support.
- Development of a position statement on self-identification, which explores risks and benefits and associated support needs.

Recommendation 7: Understand demand and capacity within the system, to meet the needs of neurodivergent adults

- Develop a systematic approach to understanding demand and capacity within the system, in partnership with Public Health Scotland.

Recommendation 8: Neuroinclusive Further Education and Employment environments

There is a greater need for support which do not seek to 'fix' or 'cure' a person or to work to make them more neurotypical, rather there is a need for updated approaches which start with anticipatory or early support and adjustments to enable participation and engagement in naturally occurring environments (e.g., education, employment, home life, community, leisure and health and social care settings).

- Identify ways to involve these sectors as mechanisms for support within neurodevelopmental pathways.
- Review the provision and professional learning needs in Universities and Further Education establishments for people with neurodevelopmental conditions.
- Promote the public sector as inclusive employers– building on the NAIT systematic review and national research programme to understand experiences of autistic people working in the public sector, develop guidelines, information and resources to support our peers, colleagues and employees who are neurodivergent.
- Aim to increase the proportion of autistic and neurodivergent people in employment. Continue to make local and national connections with regard to people with expertise in support for training, recruitment and maintaining employment including how to ask for and access individualised reasonable adjustments and use of Individual Placement Support (IPS).

Recommendation 9: Build a shared expectation that support should be available at any stage for people who identify as neurodivergent

- Support across the lifespan; before, during and after diagnosis.
- Recognition that diagnosis, where considered important to an individual, should be made available.

Recommendation 10: Seek to understand the changes needed to effectively meet the mental health needs of neurodivergent people

- In partnership with neurodivergent people.
- Considering anticipatory and responsive approaches for all levels of distress.
- Including recognition of both neurodevelopmental and mental health needs.
- With trauma informed and neurodiversity affirming models of care.

Proposed standards for Adult Neurodevelopmental Services

This report and work that has contributed to it provides a strong basis for the development of standards by consensus. These should reflect the range of sources of evidence and perspectives and both support and challenge those leading and working in contexts where the standards will apply.

Recommendations

Based on learning so far, ten recommendations are provided to support the development of services in Scotland, locally and nationally, which better meet the needs of neurodivergent people. These include short term steps, over the next 12-24 months and longer term work.

1. An adult neurodevelopmental pathway strategy and planning group to be hosted in all HSCPs.

Including neurodivergent people and cross sector multi-disciplinary partners, who can support a Stepped Care approach and local action planning.

2. Support to develop local Neurodevelopmental Pathway action plans.

The National Autism implementation Team (NAIT) should support development and review of local action plans, overseen by local strategy groups.

3. Establish a Neurodiversity Affirming Community of Practice.

NAIT will provide leadership to the Adult Neurodevelopmental Professionals Network to build relationships, facilitate support and combine expertise as work progresses. This network will be aligned to a new Community of Practice.

4. A focus on 'Post Diagnostic Support' or 'Support before, during and after diagnosis'.

Develop relevant, proportionate and individualised support for neurodivergent people. Provision to include online, face to face support, access to informed peers and multi-disciplinary professional teams.

5. Build a Neurodevelopmentally informed workforce in Scotland.

This is important in the short and long term. It will continue to be informed by the Scottish Government Leadership and Engagement work with neurodivergent people, with NES and NAIT as key partners.

6. Work towards development of Adult Neurodevelopmental Pathway standards and guidelines for assessment, diagnosis and support.

Including a co-produced National Adult Neurodevelopmental Specification and Standards, which would provide integrity to the work underway and updated SIGN guidelines.

7. Understand demand and capacity within the system, to meet the needs of neurodivergent adults.

Develop a systematic approach to understanding demand and capacity within the system in partnership with Public Health Scotland.

8. Neuroinclusive Further Education and Employment environments.

Develop updated approaches to anticipatory or early support and adjustments to enable participation and engagement in naturally occurring environments.

9. Build a shared expectation that support should be available at any stage for people who identify as neurodivergent.

Whilst recognising that diagnosis, where considered important to an individual, should be made available.

10. Seek to understand the changes needed to effectively meet the mental health needs of neurodivergent people.

In partnership with neurodivergent people and considering anticipatory and responsive approaches for all levels of distress; including recognition of both neurodevelopmental and mental health needs, with trauma informed and neurodiversity affirming models of care.

References

1. [NAIT Feasibility Study](#)
2. [Rapid Review of Mental Health in Autistic Adults](#)
3. [Children's Neurodevelopmental Pathway](#)
4. [Development of a pathway for multidisciplinary neurodevelopmental assessment and diagnosis in children and young people](#)
5. [Rethinking Autism Assessment, Diagnosis, and Intervention Within a Neurodevelopmental Pathway Framework](#)
6. [Adult Neurodevelopmental Pathways Interim Report, June 2022](#)
7. [NAIT Webinar Supporting Neurodevelopmental Differences in Adults](#)
8. [Adult Neurodevelopmental Assessment Workbook](#)
9. [NAIT Early Neurodevelopmental History Questionnaire](#)
10. [NAIT Assessment of Sensory Preferences](#)
11. [NAIT Sensory Preferences checklist for adults](#)
12. [NAIT Guides](#)
13. [NHS Fife Neurodevelopmental Hub](#)
14. [NHS Lothian RefHelp information for GPs about local adult autism and ADHD referral](#)
15. [RCSLT Communication Access training and accreditation](#)
16. [More Than Words: Supporting effective communication with autistic people in health care settings](#)

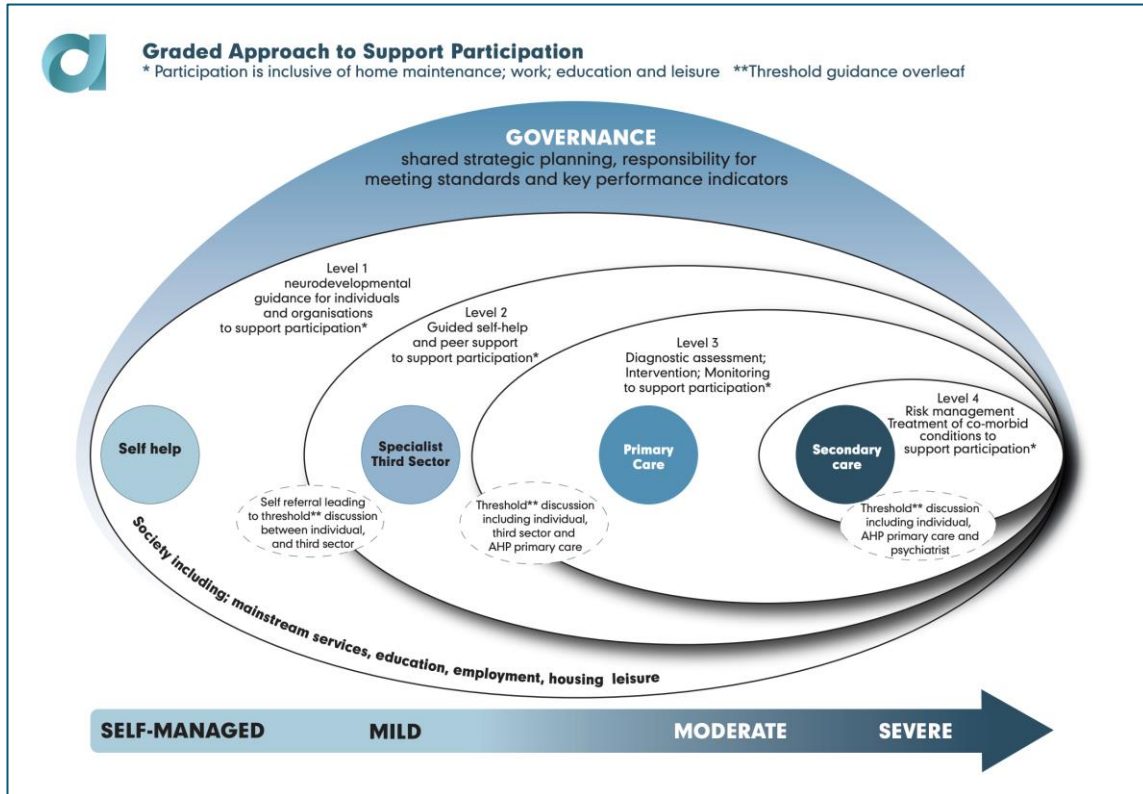
Appendix

Appendix 1: NAIT Stepped Care Neurodevelopmental Pathway

Appendix 2: Summary of NHS neurodevelopmental, autism and ADHD pathways for adults and children in Scotland, May 2021

Appendix 3: NAIT Resources for Adult Neurodevelopmental Pathways

Appendix 1: NAIT Stepped Care Neurodevelopmental Pathway



Self-managed: symptoms are well managed with no impact on life

Outcome: self help

Threshold statements

Symptoms of ADHD: symptoms present and struggling to self-manage.

Impact on life: minimal impact on life which could be appropriately self-managed.

Health risk: no risks.

Health complexity: no complexity.

Red flag questions: does the person have difficulty accessing or engagement with self-help materials?

Mild: symptoms have some impact on life, no co-morbidity, no complexity, no significant risk.

Outcome: self-referral to specialist third sector.

Threshold statements

Symptoms of ADHD: evidence of 5 or more symptoms of inattention, and/or 5 or more symptoms of hyperactivity, present since before age 12 and occur in more than two settings.

Impact on life: clear evidence symptoms interfere with, or reduce quality of social, educational/work functioning. Work/educational: at risk of breaking down or not in work/education but wants work/education. Home maintainer: at risk or not currently a home maintainer but wants to have their own home. Leisure: maintaining leisure activity and/or social relationships at risk, feeling lonely and isolated.

Health risk: Mental health problems may be present, but no thoughts/plans regarding harm to self/others. Risk of deterioration to mental health should symptoms not be addressed. May engage in impulsive self-harm behaviour as maladaptive coping. Patient is confident about maintaining his/her own safety, minimal evidence of physical vulnerability or risk.

Health complexity: Maybe a suggestion of comorbid common mental health condition, no evidence of complex problems or previously complex problems are now stable.

Red flag questions: Is quality of life impacted? Is there a risk to sustaining educational/employment/relationships/housing? Is there risk/evidence of deterioration in mental health? Is there an unstable comorbid other mental health condition?

Moderate: symptoms and impairment suggestive of diagnosis, no complexity, comorbidity if present mild/moderate.

Outcome: Primary care referrals from voluntary sector/primary/secondary care.

Threshold statements

Symptoms of ADHD: Symptoms suggestive of serious mental health problem, Mental state at risk of further deterioration, lack of diagnostic clarity unable to engage with other services.

Impact on life: Clear evidence symptoms interfere with, or reduce the quality of social, education/work functioning, Work/educational: broken down or not in work/education. Home maintainer: broken down or not currently a home maintainer but wants own home, Leisure: No leisure activity or social relationships, feeling lonely and isolated leading to consistent low mood.

Health risk: Risk to self or others (not immediate), Risk from others/exploitation/vulnerability/ self-neglect. Substance misuse, Safeguarding child/adult issues, Evidence of complexity; nature, duration and severity of mental health problems (including comorbidity and neurodevelopmental disorders)

Health complexity: Co-occurring drug and alcohol-use disorders, coexisting physical health problems, availability and quality of personal and social support networks, suboptimal associated functional impairment, current treatment not effective, current support not effective.

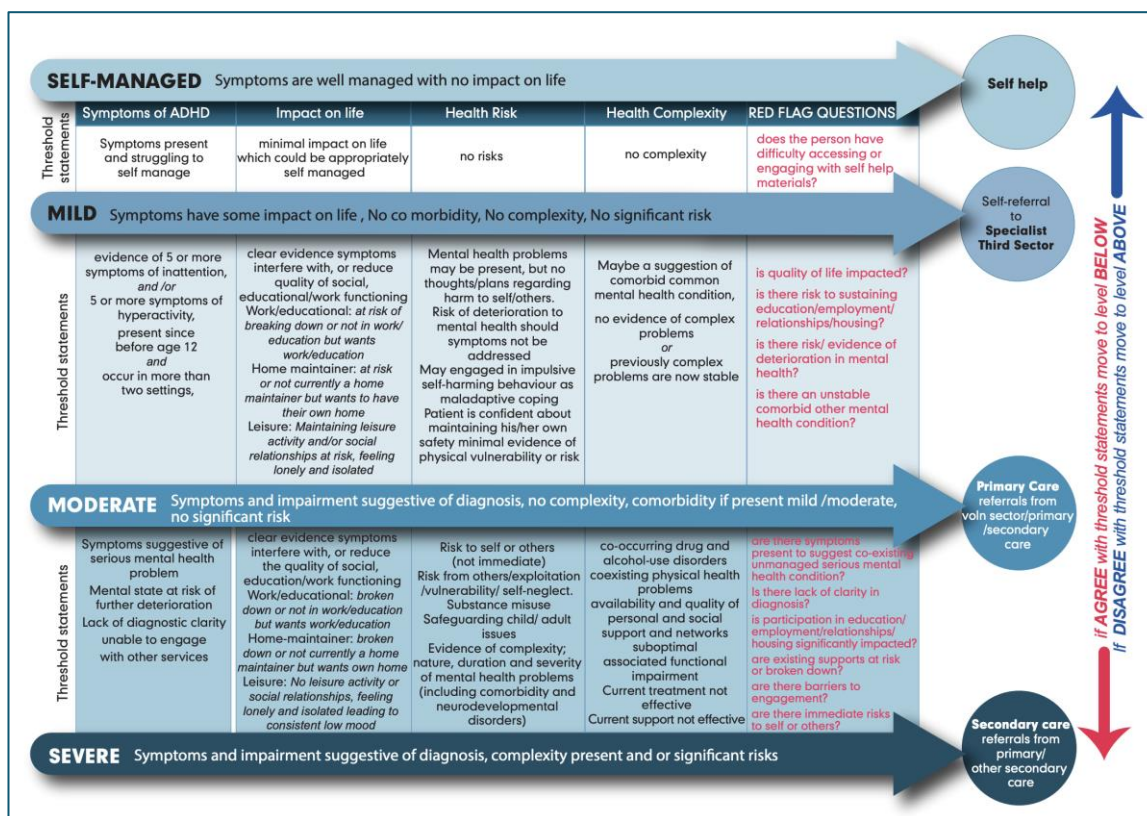
Red flag questions: Are there symptoms present to suggest co-existing unmanaged serious health condition? Is there lack of clarity in diagnosis? Is participation in

education/employment/relationships/housing significantly impacted? Are existing supports at risk or broken down? Are there barriers to engagement? Are there immediate risks to self or others?

Severe: symptoms and impairment suggestive of diagnosis, complexity present and or significant risks.

Outcome: secondary care referrals from primary/other secondary care.

Below table is a visual representation of the above:



Appendix 2: Summary of NHS neurodevelopmental, autism and ADHD pathways for adults and children in Scotland, May 2021

North

NAIT Region and NHS Health Board	Child Autism Pathway	Child ADHD Pathway	Child ND Pathway	Adult Autism Pathway (LD)	Adult Autism Pathway (non LD)	Adult ADHD Pathway	Adult ND Pathway
Grampian	Yes	Yes	In development	Yes	Yes: Aberdeen, Aberdeenshire No: Moray	No*	No
Tayside	Yes	Yes	In development	Yes	Yes	No*	No: one clinician joint ASD and ADHD assessment
Highland	Yes	Yes	Yes	Yes	Yes	No*	No
Orkney	Yes		No	The Island Health Boards do not have their own adult pathways. They have agreements with Grampian (Orkney and Shetland) and Highlands (Eileanan Siar) to allow access to a range of health services on the mainland, including assessment for neurodevelopmental disorders. They are therefore dependent on provision in these boards.			
Shetland	Yes		No				
Eileanan Siar	Yes		No				

East

NAIT Region and NHS Health Board	Child Autism Pathway	Child ADHD Pathway	Child ND Pathway	Adult Autism Pathway (LD)	Adult Autism Pathway (non LD)	Adult ADHD Pathway	Adult ND Pathway
Lothian	Yes	Yes	In development	Yes	Yes	Yes	Yes
Forth Valley	Yes	Yes	Yes	Yes	Yes	No	No
Borders	Yes	Yes	Yes	Yes	No	In development	No
Fife	Yes	Yes	Yes – developed, awaiting resource	Yes	Yes	In development	No

West

NAIT Region and NHS Health Board	Child Autism Path-way	Child ADHD Path-way	Child ND Pathway	Adult Autism Path-way (LD)	Adult Autism Pathway (non LD)	Adult ADHD Pathway	Adult ND Pathway
Greater Glasgow & Clyde	Yes	Yes	In development	Yes	Yes	In development	No
Lanarkshire	Yes	Yes	Yes	Yes	No	Yes: single clinician	No

South

NAIT Region and NHS Health Board	Child Autism Path-way	Child ADHD Path-way	Child ND Pathway	Adult Autism Path-way (LD)	Adult Autism Pathway (non LD)	Adult ADHD Pathway	Adult ND Pathway
Dumfries & Galloway	Yes	Yes	Yes	Yes	No	No*	No
Ayrshire & Arran	Yes	Yes	In development	Yes	Yes	No	No

*Although there is no ADHD pathway in this area, this is either under discussion or there is one clinician or a group of clinicians who have expressed interest.

Appendix 3: NAIT Resources for Adult Neurodevelopmental Pathways

NAIT Feasibility Study

[NAIT Feasibility Study Report 2021: National ADHD pathway](#)

[NAIT Feasibility Study Report 2021: Executive Summary](#)

[NAIT Feasibility Study Report 2021: What is the bottom line?](#)

[NAIT Adult Diagnosis Referral Thresholds Stepped Care Pathway 2021](#)

Neurodevelopmental Pathways

[Key Messages for Supporting Neurodevelopmental Differences in Adults](#)

[NAIT Guidance on who can Diagnose Autism](#)

[Language Matters: NAIT Terminology for Neurodevelopmental Pathways](#)

Neurodevelopmental Assessment

[NAIT Neurodevelopmental Assessment Workbook March 2022](#)

[NAIT Guide to Assessment of Sensory Preferences in Adults 2022](#)

[NAIT Sensory Checklist for Adults 2022](#)

[NAIT Early Neurodevelopmental History Questionnaire 2022](#)

[Who can Diagnose ADHD?](#)

NAIT Guides

[NAIT Guide to Autistic Masking](#)

[NAIT Guide to ICD 11](#)

[NAIT Guide to using ADOS with adults](#)

[NAIT Guide to Complexity in Diagnostic Pathways 2021](#)

[NAIT Guidance to Prescribing ADHD medication to adults following private sector diagnosis in Scotland 2022](#)

[NAIT Guidance on Digital Consultation for Neurodevelopmental Assessment and Diagnosis 2020](#)

[NAIT Eating and Drinking Guidance](#)

Employment

[NAIT Key Messages for Employers Poster](#)

[Autism in Employment Support](#)

Research Studies

[Research Study: Mental Health in Autistic Adults](#)

[Research Study: Mental Health in Autistic Adults with Appendices](#)

[Research Study: Autistic Professional Study Flier](#)

[Research Study: Autistic Professional Study Information Sheet](#)

Webinar

[NAIT Supporting Neurodevelopmental Differences in Adults Webinar](#)

[NAIT Supporting Neurodevelopmental Differences in Adults Webinar Slides](#)

Book Chapter

[Rethinking Autism Assessment, Diagnosis, and Intervention within a Neurodevelopmental Pathway Framework.](#)

Coming soon...

- Assessment of Communication Preferences

To achieve a different outcome, we need to do things differently.

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