Review of the Demand, Capacity and Design of Neurodevelopmental Services: Summary Report

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Key Points

- Demand for diagnostic assessment has outstripped the capacity of both Children's Neurodevelopmental (ND) services and the IAS, and it is expected to remain high. The fundamental problem has been the small size of services relative to demand, rather than issues and constraints in the diagnostic assessment process or the design and structure of ND services.

- New service models, such as an adult ND service, are likely to increase demand and the purpose of any redesign of services should therefore be to address unmet needs (rather than to try to close demand-capacity gaps).

- No change is not an option. Demand-capacity gaps in relation to diagnostic assessments increase waiting times, delaying support (where support depends upon a diagnosis), increasing people's distress and the risk that problems can multiply and/or escalate as opportunities to intervene early are missed. Moreover, weaknesses in support reduce the value of a costly ND diagnostic assessment. The consequent unmet needs cause significant human, social and economic costs.

- Some groups, such as adults with attention deficit hyperactivity disorder (ADHD), adults with co-occurring ND or mental health (MH) conditions, or those who do not meet diagnostic thresholds can face particular difficulties in accessing diagnostic assessments and/or support.

In response to the challenges, the review identifies the need for:

- a whole systems approach with a focus upon raising awareness and understanding of neurodiversity, strengthening access to early help and support, the active involvement of a range of sectors (including health, education, social care and the third sector), and a lifelong (cradle to grave) approach;

- investment in, restructuring of, and greater collaboration between services, to address demand-capacity gaps (including gaps in service provision), deliver a national support offer, and ensure a more person-centred approach which is better able to handle complexity, difference and diversity;

- a focus upon short to medium term measures to improve experiences and outcomes and to reduce the pressure upon existing ND services; and consideration of the development of new service models in the longer term; and

- strengthening monitoring and evaluation, focused upon what is important to service users, to inform decisions about the development of services, and provide transparency and accountability to stakeholders.

1. Research aims and methodology

1.1 This paper is a summary report on a review of the demand, capacity and design of ND services for children, young people and adults in Wales, undertaken in order to develop recommendations and evidence-informed options for improvements to services. It focuses primarily upon two ND conditions (NDCs), autism and ADHD, and two ND services, Children's ND services[1] and the Integrated Autism Service (IAS)[2].

1.2 A range of methods were used for this review, including:

- a desk based review of policy, research and data provided by ND services;
- primary qualitative research with over 70 interviewees drawn from ND services (principally, Children's ND services and the IAS); the National Autism Team (NAT); the Together for Children and Young People (T4CYP) (2) programme; Adult Mental Health Services (AMHSs); a number of Royal Colleges; the NHS Collaborative and NHS Delivery Unit; the Wales Autism Research Centre; Dyfed Powys and Gwent Police services; and third sector organisations[3].
- online questionnaires completed by 29 professionals involved in ND or MH services;
- interviews with, or online questionnaires completed by, 37 parents or carers accessing Children's ND services or the IAS and 23 adults accessing the IAS;
- two workshops to discuss emerging findings with stakeholders; and
- facilitation of a Working Group, including contributors to the review, to identify feasible and sustainable options for improvement to children's and adults' ND services, considering all the evidence generated as part of the review.

1.3 A full report, presenting the findings and recommendations in more detail, will be published shortly, alongside a supplementary paper on a workforce strategy to support the report's proposals for ND services.

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[1] In order to reduce the time from referral to diagnostic assessment for autism and/or ADHD, ensure a child centred assessment and provide some (albeit limited) post diagnostic support, a national ND pathway for assessment and diagnosis was developed and ND services or teams were established across Wales in 2015.

[2] The national Integrated Autism Service (IAS) was established in 2016 to help fill gaps in assessment, diagnostic and support services for adults 'who do not meet the eligibility criteria for statutory services', such as MH and learning disability (LD) services (with the expectation that these services would continue to assess and support those eligible for their services) (Autism Wales, 2020).

[3] The third sector organisations included ADHD Connections, the ADHD Foundation, Autism Spectrum Connections Cymru (ASSC), the National Autistic Society (NAS) and Credu Carers.

2. Key findings

Demand and capacity

2.1 The numbers of children seeking a diagnostic assessment of autism have been increasing since the millennium. The proportion of children reported by schools to have Autistic Spectrum Disorder (ASD) as their major special educational need (SEN) was 1.9 per cent in 2018/19, somewhat higher than the expected rate of around 1.2 per cent (NICE, 2018). In contrast, the increase in the numbers of children reported by schools to have ADHD as their major SEN has been much lower. The proportion stood at 0.7 per cent in 2018/19, which is lower than the expected rate of around 1-2 per cent using a narrow definition (NHS Digital, 2018) and around 5 per cent using a broader definition (NICE, 2021). However, it is reported that data from the Welsh Secure Anonymised Information Linkage (SAIL) databank suggests a lower rate of ASD diagnosis and a higher rate of diagnosis of ADHD, closer to expected prevalence rates, than the Pupil level Annual School Census (PLASC) data suggests (Pers. Comm. Anita Thapar and Kate Langley).

2.2 The numbers of adults seeking a diagnostic assessment of autism have been high since the IAS was established in 2017-2018 and shows no sign of falling in the short term. Data on the numbers of adults seeking a diagnostic assessment of ADHD is not available, but is reported to be high by MH services. There is also thought to be substantial latent (unmet or unfulfilled) demand for ADHD diagnostic assessments for adults, given weaknesses in pathways and provision, making this a key gap in service provision.

2.3 The increasing awareness and recognition of autism and other NDCs like ADHD, is to be celebrated, but demand for diagnostic assessment has outstripped the capacity of both Children's ND services and the IAS. The data that is available suggests that over the last two years, for roughly every two children or adults referred for a diagnostic assessment, one diagnostic assessment has been undertaken.

2.4 The review identifies a number of issues and constraints that limit the capacity of ND services, such as a lack of administrative support, adequate IT equipment and/or clinical space, and the structure of some teams. Therefore, there is likely to be some scope to generate efficiencies and increase capacity with only a modest

increase in funding for ND services. Digital solutions are also likely to be important. However, the marginal gains this can be expected to realise are unlikely to be sufficient to close in full the demand-capacity gap facing ND services.

2.5   The review identifies that the fundamental problem has been the small size of services relative to demand, rather than issues and constraints in the diagnostic assessment process or the design and structure of ND services. Indeed, many options which involve redesigning services are likely to increase demand, rather than reduce existing demand-capacity gaps. The purpose of redesigning services should therefore be focused on better meeting unmet needs rather than trying to close the demand-capacity gap, and action to restructure and expand ND services will be required to increase capacity.

2.6   Much of the demand for diagnostic assessment, particularly in relation to children, can be explained by a diagnosis being needed, or believed to be needed, to access support and/or to provide assurance that support could be accessed in the future. This fuels demand for diagnostic assessments that might otherwise not be needed. The link between assessment and access to support delays intervention, as it can be years before a diagnostic assessment is undertaken. Moreover, despite the longstanding policy aspiration that support should not depend upon a diagnosis (e.g. WAG, 2008), in practice it is often a diagnosis rather than need that determines access to support.

2.7   Looking beyond Children's ND services and the IAS, the evidence suggests that stigma and misconceptions about ADHD can mean it is sometimes not understood, dismissed or missed, particularly in adults, and referral pathways are sometimes unclear or poorly understood by gatekeepers in primary care, denying or delaying access to services. Moreover, the current model of relying upon secondary MH services to assess and diagnose ADHD in adults, is not working well.

Demand for, and ND services' capacity to provide, pre- and post-diagnostic support

2.8   The capacity of Children's ND services to provide post-diagnostic support is limited and inconsistent, and their capacity to provide pre-diagnostic support is even more limited. There is reliance upon other services, most notably education and the third sector, to provide support to children and families. Although it is appropriate that a range of services provides support, the support varies across Wales and can often

be disjointed (uncoordinated). Many families interviewed for this study also reported what they describe as a 'battle' with services to access support.

2.9   In contrast, the IAS has greater capacity to provide post-diagnostic support to autistic adults eligible for the service[4] and, to a lesser degree, to the parents and carers of autistic children. Some IASs also offer pre-diagnostic support, via, for example helplines and drop in sessions. Nevertheless, the support IASs offer varies; support for parents and carers has been constrained by demand for diagnostic assessments and support for adults; and while welcomed, support from the IAS for adults, which is generally limited to short term interventions, does not always meet people's hopes and expectations.

2.10   Some groups were reported by interviewees to face particular difficulties accessing support. For example:

- support for adults with ADHD was reported to be much less developed and often limited to monitoring of medication. Interviewees reported that adults with ADHD may need services such as support with executive functioning difficulties, sleep and relationships. These types of support needs are provided for adults with autism by the IAS and the third sector, but there are very few equivalent services reported for adults with ADHD; and
- children and adults who fall short of diagnostic thresholds for ASD or ADHD but who still have very real needs, and children and adults with co-occurring NDCs and/or MH difficulties, whose needs can be considered 'complex', as they do not easily 'fit' into existing service structures.

The impact of demand-capacity gaps

2.11   The review is clear that no change is not an option. Demand-capacity gaps in relation to diagnostic assessments increase waiting times far beyond that which most would consider acceptable, delaying support (in those cases where support depends upon a diagnosis) and fuelling frustration. It means problems can multiply and/or escalate as opportunities to intervene early are missed, and adults and families interviewed described what they felt were 'lost years', before they felt their difficulties, or their children's, were properly understood. The pressure upon

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[4] The IAS is intended to support adults who are not eligible for support from statutory services such as MH or learning disability services (Autism Wales, 2020).

services was also reported to exacerbate the difficulties ND services face in relation to workforce retention and recruitment, and the risk of losing skilled and experienced staff was reported by interviewees to be a threat to the sustainability of services.

2.12   Moreover, for many families and for some adults (and particularly those diagnosed with ADHD), a diagnosis does not offer the 'magic key' many hoped would unlock access to support. Instead, it is simply another stage along what many experience as a long and difficult journey to access support. Weaknesses in support reduce the value of a costly ND diagnostic assessment.

2.13   Finally, there have been failures to identify and effectively engage and reach out to some groups, such as autistic girls and people from some Black, Asian and minority ethnic communities who were reported by interviewees to be under-represented in services. This is important because interviewees reported substantial human, social and financial costs associated with undiagnosed and/or unsupported NDCs. In addition, very few services have an active offer of Welsh[5].

The design of ND services

2.14   The establishment of the (national) Children's ND service and IAS are important innovations in service design that put Wales at the forefront of developments in the UK (Embracing Complexity, 2020) and have helped address gaps in diagnostic assessment services and in post-diagnostic support for adults (WG, 2019a, 2019b).

2.15   Nevertheless, the evidence from the first stage of the review and the Working Group also suggests that the current structure and design of services is too service-centred, rather than person-centred; for example:

- autism, which affects roughly one per cent of children and adults, 'dominates the agenda' as one interviewee put it, while provision for other NDCs, most notably for adults with ADHD, has been neglected;

- those with co-occurring conditions or who fall short of diagnostic thresholds can find it difficult to access services or support; and

- transitions between services can be difficult.

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[5] Providing a service in Welsh without someone having to ask for it

2.16   The review identified that neither the Children's ND service nor the IAS offer the perfect model, although each have strengths; for example:

- The establishment of a Children's ND, rather than condition-specific, service was seen as a strength. However, there can still be separate pathways for ASD and ADHD and not all Children's ND services cope with 'complex' cases, although there are examples of innovative practice within some Children's ND services seeking to address this. Moreover, services were widely reported by interviewees to be underfunded; some services have 'virtual' teams, which are reported to be more difficult to manage and less efficient than dedicated teams; and Children's ND services' lack of capacity to offer pre- and post-diagnostic support is seen as a major weakness.

- The IAS's model of an integrated health and social care service means that it is better able to offer post-diagnostic support, and also some limited pre-diagnostic support, which is seen as important (and much needed). However, it can still struggle to provide longer term support that autistic adults or parents and carers can 'dip in and out of'. Moreover, the IAS's focus upon autism was seen as both a strength but also a missed opportunity to establish an adults' ND service. As a condition-specific service, it excludes many adults with NDCs, such as those with ADHD, who may have comparable needs to autistic adults, and assessments for ASD and ADHD are done sequentially by different services.

2.17   The review identifies a clear need for change and an appetite and interest in developing new ND services for both children and adults, but also widespread concern about disrupting existing services that have taken time to establish and which continue to develop. Change will not be easy to realise. Clear and inspiring leadership at multiple levels, alongside 'enablers' like new tools and potentially new service models, and 'cultural changes', such as greater understanding of neurodiversity, will be required to forge a shared vision and drive change not only within ND services but across the wider system (T4CYP, n.d.). Given the challenges highlighted by the review, some stakeholders favoured developing new services, such as an adult or all-age ND service. Although establishing new services may appear to some stakeholders to be easier than trying to reform existing services, any moves to redesign or reconfigure services should also consider the experiences of establishing the Children's ND service and the IAS, which were challenging,

costly and time consuming (WG, 2018), as well as the strengths and weaknesses of these two different models.

2.18 Moreover, although there was a fair degree of consensus in the Working Group about the goals of reform, outlined in paragraph 2.20, and a range of actions needed to underpin changes to the wider system, judgments were divided over the merits of different ND service model options, such as developing an adult ND or all-age ND service, which offer different combinations of potential benefits, costs and risks.

Improving transitions between services

2.19 Research (e.g. WG, 2020; Asherson et al., 2022) consistently identifies a range of factors that support transitions from children's to adults' services, reflected in the new guidance on Transition and Handover (WG, 2022); they include:

- supporting the transition to adult services where appropriate and available, and identifying alternative services where this is not possible;
- providing information and support for young people and their families, and involving them in decisions about the transition process;
- collaboration between child and adult services, and flexibility that enables person-centred rather than service-centred approaches to transitions and care;
- ensuring that both child and adult services get 'the simple things right' and are, for example, 'welcoming, friendly and warm' (CQC, 2017, p.58 cited in WG, 2020); and
- effective quality assurance, monitoring and evaluation, covering users' experiences and outcomes (WG, 2020).

A long-term vision for ND services and the wider system

2.20 The review's Working Group endorsed three key goals to guide investment in and reform of ND services and the wider system:

- swifter access to early help and support when people who have, or who are suspected to have, an NDC, and/or their families, need it;
- swifter access to a specialist ND assessment for those who would benefit from it; and
- equity of access to services and support, to ensure that, for example, access to a diagnostic assessment and/or support is not dependent upon an individual's

characteristics such as their age, gender, NDC, ethnicity, or language preference.

2.21 The review's Working Group also endorsed three principles that should underpin a long-term vision for ND services:

- a whole systems approach with, for example, a focus upon early help and enhanced support; the active involvement of a range of sectors, including health, education, social care and the third sector; and a lifelong (cradle to grave) approach;

- moving, as far as possible, to a more person-centred, needs-led approach (rather than being diagnosis-led), which has 'no wrong door' and is better able to handle both complexity and the diversity of strengths and difficulties people with NDC experience; and

- reform of ND services and the wider system should be informed by evidence, done co-productively, and be subject to 'intelligent' monitoring and evaluation that, for example, focuses upon what is important to service users and offers greater transparency and accountability to stakeholders than the current arrangements.

2.22 Realising these goals in line with these principles will require investment and reform of ND services and the wider system. The review's recommendations are outlined in the following section, with more detail to be provided in the full report to follow shortly.

3. Recommendations

Enhancing access to early help and support and ensuring equity of access

3.1 Early help and support is vital to help prevent difficulties escalating or multiplying. Enhancing access to early help and support, without requiring a diagnosis, could also help diffuse demand across the system and potentially reduce the demand for diagnostic assessments (reducing pressure upon ND services). This is likely to require the following actions:

- Raising awareness and understanding of neurodiversity in services, to reduce the risk that (i) children's or adults' difficulties are missed or misunderstood (including actions to address the stigma and misconceptions linked to NDCs

such as ADHD) and/or (ii) difference (i.e. neurodiversity) is referred to specialist services (rather than being embraced by universal and targeted services). This is likely to require training and easy access to expertise, to build confidence in and understanding of neurodiversity, in universal and targeted services such as schools, primary health services and the third sector, while also ensuring that staff understand how and when to refer to specialist services, when appropriate.
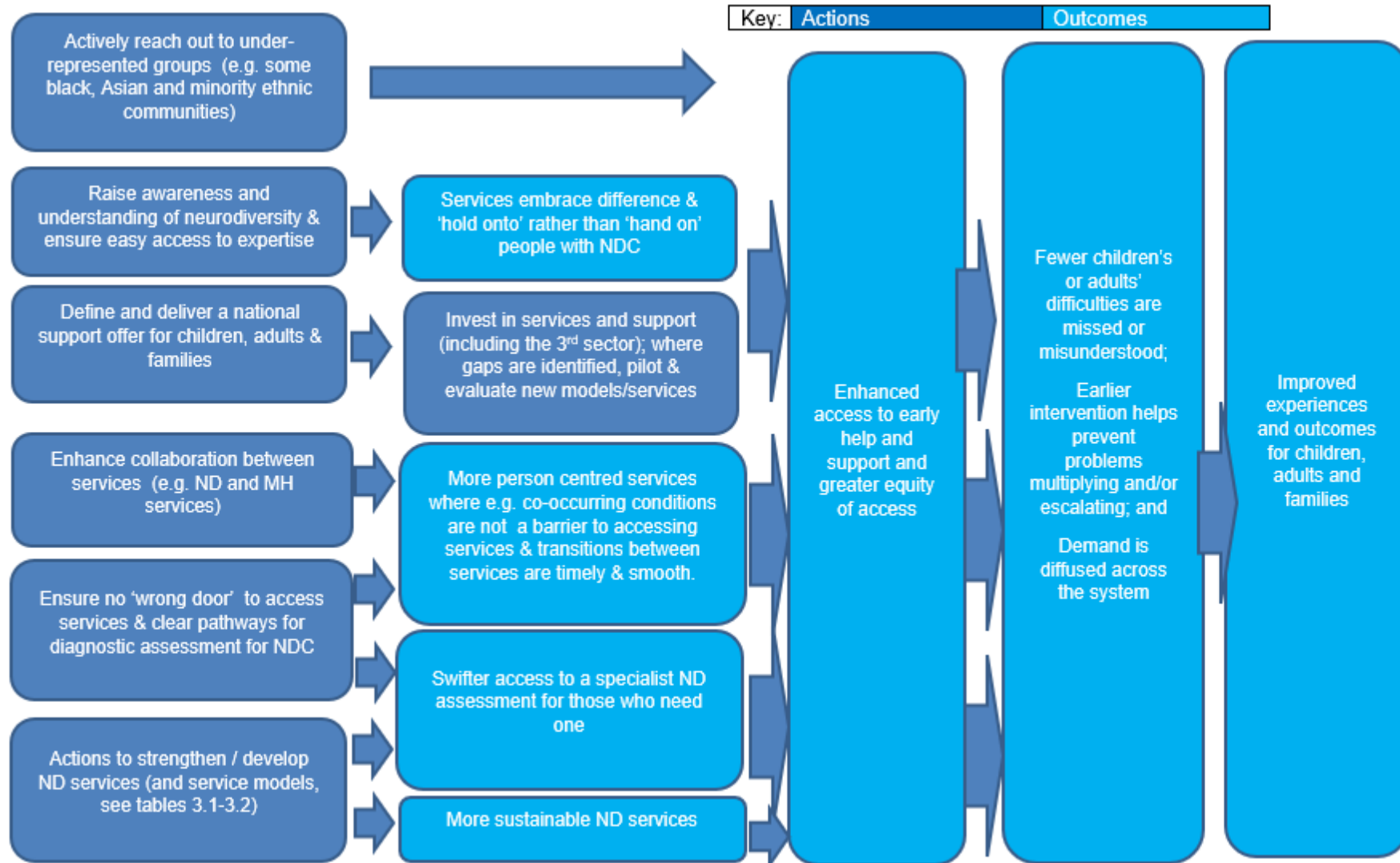
- Actively reaching out to engage under-represented groups (such as children and adults from Black, Asian and minority ethnic communities) and ensuring that services have an active offer of the Welsh language.

- Ensuring there is 'no wrong door' to access extra help (as advocated by the Children's Commissioner for Wales, 2020) through, for example, work with 'gatekeepers' such as GPs, social services, and Information, Advice and Assistance (IAA) services; and single points of access (SPOAs), which can be supported by multi-agency panels who determine which service(s) are best placed to provide support.

- Defining a national support offer, based upon the current National Institute for Health and Care Excellence (NICE) guidelines and standards such as the Additional Learning Needs and Autism Codes of Practice. Given differences in local services (including those provided by the third sector), it is recommended that there be regional – or local – determination of how a national support offer would be delivered and by whom (which services). This would ensure access to early help and support and equity of access to services and support. Regional Partnership Boards (RPBs) are the logical bodies for planning and determining how the national support offer can most cost-effectively be delivered at a regional and local (authority) level. Where gaps or weaknesses are identified, new models or services should be piloted, monitored and evaluated.

- ND services should have a key role in providing access to help and support and actions to develop and strengthen these services, discussed in the next section, are important, but they are only one of a range of services that should offer this. Delivering a national support offer will also require effective implementation of polices like the ALN Transformation Programme and development of other

services (e.g. through workforce development and greater funding[6]), including the third sector.

- Enhancing collaboration between services (e.g. through co-location, joint training and greater opportunities for dialogue to build understanding and trust) to ensure that, for example, services work together rather than sequentially, where a child or adult has, or is suspected to have, co-occurring difficulties such as an NDC and MH condition, and to help ensure that transitions between services are smoother.

- The Welsh Government should commission an independent review to identify why people with NDC can struggle to access MH services and what action is required to address this.

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[6] Assessing the demand-capacity gaps in the wider workforce is beyond the scope of this study. However, reviews such as Mind Over Matter (NaFW, 2018) and Workforce Planning of Special Educational Needs (SEN) Specialist Services (WG, 2015b) have considered the issues and made recommendations.

Figure 3.1: Roadmap for enhancing access to early help and support and ensuring equity of access

Key: Actions | Outcomes

Actively reach out to under-represented groups (e.g. some black, Asian and minority ethnic communities)

Raise awareness and understanding of neurodiversity & ensure easy access to expertise

Services embrace difference & 'hold onto' rather than 'hand on' people with NDC

Define and deliver a national support offer for children, adults & families

Invest in services and support (including the 3rd sector); where gaps are identified, pilot & evaluate new models/services

Enhance collaboration between services (e.g. ND and MH services)

More person centred services where e.g. co-occurring conditions are not a barrier to accessing services & transitions between services are timely & smooth.

Ensure no 'wrong door' to access services & clear pathways for diagnostic assessment for NDC

Swifter access to a specialist ND assessment for those who need one

Actions to strengthen / develop ND services (and service models, see tables 3.1-3.2)

More sustainable ND services

Enhanced access to early help and support and greater equity of access

Fewer children's or adults' difficulties are missed or misunderstood;

Earlier intervention helps prevent problems multiplying and/or escalating; and

Demand is diffused across the system

Improved experiences and outcomes for children, adults and families

Developing ND service models

3.2   The review's recommendations focus upon both:

- the short to medium term measures needed now to address key gaps and weaknesses in services (including demand-capacity gaps), which are supported by evidence from the review; and

- the ways in which these short to medium term measures could be implemented to provide a foundation for the further development of services in the future, if, for example, the decision was taken to establish an adult or all-age ND service.

3.3   The short to medium term measures would aim to improve experiences and outcomes for children, adults and families and reduce the pressure upon existing ND services, without fundamentally changing the ND service model. This should help ensure that ND services have the capacity, in the sense of time and mental bandwidth, to consider and contribute to further development of services, including taking on new roles and strengthening monitoring and evaluation. These actions are discussed in more detail below in tables 3.1-3.4, focusing upon recommendations for:

- developing Children's ND services and improving transitions;
- developing the IAS;
- addressing the gaps in provision for adults with ADHD and the parents and carers of children with ADHD; and
- enhancing assessment and support for those with co-occurring conditions or who fall short of diagnostic thresholds.

3.4   Where the evidence is clear, the recommendation is that action "should" be taken and where the evidence is more uncertain and the review identifies alternative options, the recommendation is that action "could" be taken.

3.5   Developing a long-term vision for services to consolidate and extend the improvements will take time, particularly if it is to be part of a systems-wide approach to addressing neurodiversity (which was strongly advocated by the Working Group), which invests in, and draws upon, strengths and resources in health, education, social care, the third sector and others. It also should be developed co-productively, with involvement from service users, practitioners, policy makers and the third sector (which was also strongly advocated by the Working Group).

The potential to transform experiences and outcomes

3.6   Although no single action is likely to be transformative, the net (or cumulative) effect of action to address demand-capacity issues, coupled with changes across the system to ensure access to early help and support and greater equity, should improve people's experiences and outcomes. These actions are ambitious, but not new, in the sense that they are rooted in existing policy. A key challenge will therefore be ensuring that policy on paper translates to changes in practice. A focus upon short and medium term actions should ensure that change happens at pace where there is the strongest evidence for change, while also providing the foundations that can inform and help enable longer term change, such as the development of new service models, where the evidence base is currently weaker.

Table 3.1: Developing Children's ND services and improving transitions

Short term actions	Medium and longer term actions and options
• Increase the efficiency and capacity of teams through increased funding to tackle issues and constraints, such as the lack of administrative support, shortages of adequate IT equipment and clinical space. The specific issues differ for individual ND services, and individual ND services would therefore need to put forward costed proposals to the Welsh Government and LHBs for additional investment to increase efficiency. • Implement the new guidance on Transition and Handover (WG, 2022) and agree protocols for the transition of young people awaiting diagnostic assessment and approaching their 18th birthday from Children's ND services to the IAS.	• Address recruitment challenges and increase the capacity and diversity of teams by, for example, recruiting more therapists and specialist nurse practitioners to ease the difficulties in some areas of recruiting clinicians such as psychiatrists and clinical psychologists and ensure that Children's ND services have the right staff with the right skills. This should include ensuring that teams are competent and confident dealing with complex co-occurring NDCs. Expanding core ND teams with staff who are dedicated to the service is also important. • Improve the comprehensiveness of data on the demand for services, their performance and funding, in order to better understand the challenges services face and their performance. More intelligent monitoring and evaluation of Children's ND services, which not only focuses upon waiting time targets but also, for example, on measures of children's and families' experiences and outcomes, and improved collaboration with services such as CAMHS, will also be important. • If the capacity of Children's ND services is increased, their role in providing advice, support and, potentially, training to education settings and other services, such as social care and the voluntary sector, could be strengthened. ND services' pre- and post-diagnostic support offer could be strengthened by, for example, employing specialist nurses who could help ensure that appropriate support is put in place in schools and at home and reinforce signposting to other support. Identifying and reviewing what is working well will be important in sharing good practice and identifying changes that could be made to Children's ND services. Consideration should also be given to whether responsibilities for providing advice and support to parents or carers of children with NDCs in areas such as sleeping and behaviour, should rest with Children's ND services. • Given the small size of Children's ND services, consideration could also be given by LHBs to developing capacity to diagnose ADHD beyond Children's ND services, although this could run counter to the current vison for ND services in Wales (NHS Collaborative, 2021).

	• Consideration should be given by the Welsh Government and LHBs to expanding the range of NDCs that Children's ND services assess and support, to address what are reported to be gaps in areas such as provision for Tourette's Syndrome. • If actions to improve transitions between children and adult services, including the transfer of young people from Children's ND services to IAS waiting lists (e.g. through implementation of the Welsh Government's Transition and Handover Guidance (WG, 2022)), were not successful, an alternative strategy will be required. Consideration could be given to establishing a national working group to examine the feasibility of establishing an all-age ND service. • Similarly, over the long term, if actions to ensure that services are more person-centred and, for example, better able to cope with 'complex' cases (e.g. by diversifying staff teams and improving collaboration between services) were not successful, consideration could be given to establishing a national working group to examine the feasibility of developing needs-led services. Actions to improve monitoring and evaluation of services will be important in providing evidence to inform these decisions.

Table 3.2: Developing the IAS

Short term actions	Medium and longer term actions and options
• Increase the efficiency and capacity of IAS teams through increased funding to tackle issues and constraints, such as shortages of adequate IT equipment and clinical space. The specific issues differ for individual IASs, and individual IASs would therefore need to put forward costed proposals to the Welsh Government, the NAT, LHBs and RPBs for additional investment to increase efficiency.	• Address recruitment challenges and increase the capacity and diversity of teams by bringing, for example, more assistant psychologists and specialist nurse practitioners into teams to ease recruitment challenges and increase the scope for progression within services. Changes to the core staffing structure of IASs could require changes to the current guidance covering IASs (Autism Wales, 2020), and would therefore need to be agreed nationally (e.g. through the NAT). • The Welsh Government and/or NAT should commission a thorough review of the rationale for differences in the support offered by each IAS. • If, as outlined in table 3.3, adult ADHD services were established, collaboration between IASs and ADHD services would be required to ensure a joined-up response, where, for example, it was suspected that an adult might have both autism and ADHD. • In the longer term, if actions to improve transitions between children and adult services failed, an alternative strategy would be required, and consideration could be given to establishing a national working group to consider the feasibility of developing an all-age service. • Similarly, if actions to improve access to a diagnostic assessment and support for adults with (or suspected to have) a co-occurring NDC failed, consideration could be given to establishing a national working group to consider the feasibility of developing an all-age ND service and/or needs-led service. Actions to improve monitoring and evaluation of services will be important in providing evidence to inform these decisions.

Table 3.3: Addressing gaps in provision for adults with ADHD and the parents of carers of children with ADHD

Short term actions	Medium and long term actions and options
• Ensure there are clear pathways for diagnostic assessment for ADHD and action by LHBs to ensure that relevant professionals in, for example, health, social care, education, employment services and the third sector are aware of the local ADHD pathway and how to access services. • Awareness raising work may also be required to address the stigma and misconceptions about ADHD, and ensure that a diagnosis of ADHD, or suspicion that someone has ADHD, does not become a barrier to accessing MH services (as is sometimes reported to be the case).	• If as outlined in table 3.1, the capacity of Children's ND services can be increased in the medium term, it may appropriate for RPBs to support Children's ND services to offer support to parents and carers of children with ADHD in partnership with, for example, schools and/or the third sector. • LHBs should pilot new models, such as adult ADHD services (as a number already are), to increase capacity to undertake diagnostic assessments, and monitor and evaluate the new service models developed in Wales and other parts of the UK, including assessment of costs, demand, capacity and service users' experiences and outcomes. • Increase the capacity to support adults with ADHD. To achieve this, LHBs and RPBs should either look to replicate the IAS's integrated model (which includes support workers) as part of an adult ADHD service or explore the potential for IAS support workers to be trained and confident to also support adults with ADHD. • In the longer term, if monitoring and evaluation identifies that actions to strengthen access to and collaboration between services is not sufficient to improve adults' experiences and outcomes, an alternative strategy will be required. A national working group could be established to consider the feasibility of developing alternative service models, such as an adults' ND or needs-led service.

Table 3.4: Enhancing assessment and support for those with co-occurring conditions or who fall short of diagnostic thresholds

Short term actions	Medium and longer term actions and options
• The Welsh Government should commission an independent review to consider why people with NDC, who also have MH difficulties, can struggle to access MH services.	• Actions outlined in table 3.1. to strengthen and diversify Children's ND services teams should help increase services' expertise and confidence in undertaking diagnostic assessments where NDCs co-occur. This should be complemented by the establishment of SPOAs and robust triage processes (where not already established) by LHBs to ensure that children get on the right pathway and if, for example, a more holistic assessment of multiple potential NDCs is indicated, this can be done by experienced clinicians. • LHBs should strengthen collaboration between Children's ND services, the IAS and MH services, such as co-location, joint training and joint management, to ensure that those with an NDC and co-occurring MH condition experience a joined-up service and ensure that a NDC is not a barrier to accessing MH services. • The Welsh Government and LHBs should review provision for people with other NDCs and those who fall short of diagnostic thresholds, and if appropriate, develop and pilot new models. • In the longer term, if monitoring and evaluation identifies that actions to strengthen access to and collaboration between services supporting people with co-occurring conditions is not sufficient to improve people's experiences and outcomes, an alternative strategy will be required. A national working group could be established to consider the feasibility of developing alternative service models, such as an adults' ND or needs-led service.

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