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

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Glossary

Acronym	Definition
ADHD	Attention Deficit Hyperactivity Disorder
ADO	Autistic Diagnostic Observation (Schedule)
ALN	Additional Learning Needs
ALNCo	Additional Learning Needs Co-ordinator
ALP	Additional Learning Provision
AMHS	Adult Mental Health Services
ASCC	Autism Spectrum Connections Cymru
ASD	Autistic Spectrum Disorder (also referred to as Autistic Spectrum Condition and autism)
CAMHS	Child and Adolescent Mental Health Service
CAPA	Choice and Partnership Approach
CBT	Cognitive Behavioural Therapy
CfW	Communities for Work
CMHT	Community Mental Health Team
COVID	Coronavirus disease
CQC	Care Quality Commission
DCD	Developmental Co-ordination Disorder
DIVA	Diagnostic Interview for ADHD in Adults
DLD	Developmental Language Disorder
EP	Educational Psychology (service)

GP	General Practitioner
HEIW	Health Education Improvement Wales
IAA	Information, Advice and Assistance
IAS	Integrated Autism Service
ICF	Integrated Care Fund
IDP	Individual Development Plan
IPC	Institute of Public Care
ISCAN	The Integrated Service for Children with Additional Needs
IT	Information Technology (IT)
LA	Local Authority/Authorities
LD	Learning Disability
LHB	Local Health Board
LPMHSS	Local Primary Mental Health Support Service
MDT	Multi-Disciplinary Team
MH	Mental Health (services)
NAfW	National Assembly for Wales
NAS	National Autistic Society
NAT	National Autism Team
ND	Neurodevelopmental
NDC	Neurodevelopmental Condition
NDWSP	Neurodiversity Wales Shared Platform (previously called the Do-It profiler)

NEST	Nurturing, Empowering, Safe and Trusted
NHS	The National Health Service
NICE	The National Institute for Health and Care Excellence
OCD	Obsessive Compulsive Disorder
OECD	Organisation for Economic Co-operation and Development
OED	Oxford English Dictionary
PLASC	Pupil Level Annual School Census
PMHS	Primary Mental Health Service
PSB	Public Service Board
RCN	Royal College of Nursing
RCPsych	Royal College of Psychiatrists
RCSLT	Royal College of Speech and Language Therapists
RPB	Regional Partnership Board
SAIL	Secure Anonymised Information Linkage
SAP	Strategic Action Plan
SEN	Special Educational Needs
SLT	Speech and Language Therapist
SPACE-WB	The Single Point of Access for Children's Emotional Well-being and Mental Health
SPOA	Single Point of Access
T4CYP	Together for Children and Young People
TAF	Team Around the Family

THP	Transition and Handover Plan
UHB	University Health Board
UKAAN	The UK Adult ADHD Network
WG	Welsh Government

1. Introduction

Neurodevelopmental conditions

- 1.1 Neurodevelopmental conditions (NDCs) are disabilities that affect the functioning of the brain and impact on, for example, social behaviour or the ability to learn. There are a range of NDCs¹, and this review focuses upon autism and attention deficit hyperactivity disorder (ADHD) which are the main NDCs that neurodevelopmental (ND) services focus upon, and which affect roughly 5-6 per cent of children and young people². Both autism and ADHD are lifelong conditions; however, ADHD symptoms tend to decline somewhat with age, so rates amongst adults are lower, and it is estimated that around 2-4 per cent of adults would meet diagnostic ADHD thresholds ([NICE, 2021](#); [Young et al., 2021](#)).
- 1.2 Although autism and ADHD are the main NDCs that ND services focus upon, co-occurrence of different NDCs, including ADHD, autism and learning disabilities (LDs) is common ([Cleaton and Kirby, 2018](#) ; [NICE, 2018a, 2021](#)). Moreover, the total number of children with other NDCs, such as dyslexia, dyscalculia, developmental language disorder (DLD), developmental co-ordination disorder (DCD) and tic disorders, such as Tourette's Syndrome, is greater than the number with autism or ADHD ([Cleaton and Kirby, 2018](#)). Therefore, while the focus of this review is upon autism and ADHD, consideration is given to other NDCs.
- 1.3 The language used to describe NDCs such as autism is contested, as different people prefer different terms. There is some evidence that there has been a shift

¹ ND conditions include Specific Learning Disorders such as dyslexia and dyscalculia; Motor Disorders such as developmental coordination disorder (DCD) and dyspraxia; Communication Disorders such as developmental language disorder (DLD); Tic Disorders, such as Tourette Syndrome; Intellectual Disability; autism; and ADHD ([Cleaton and Kirby, 2018](#)).

² There is considerable debate over the prevalence of autism and ADHD; for example, NICE report that prevalence rates for ADHD are 1-2% in childhood, using the ICD-10 definition of hyperkinetic disorder but that under the less stringent Diagnostic and Statistical Manual IV criteria, childhood prevalence rates were 3-9% ([NICE, 2018b](#)), while a meta review identified a world-wide rate of around 5% (Polanczyk et al., 2007). Although ADHD is a lifetime condition, the impact upon functioning may change over time, making it harder to calculate rates for adults. Changes in the criteria in the forthcoming DSM-5 and ICD-11 may change prevalence rates further. Rates of autism are in the range of 1-2% for children and adults ([NICE, 2021](#)) and estimates based on a sample of children and young people in England (aged 5-19) identified a rate of 1.2% ([NHS Digital, 2018](#)).

toward more assertive language like ‘autistic adults’ rather than ‘adults with autism’ (NAS, n.d.) and we have chosen to use this where appropriate in this report.

Policy context

- 1.4 The Together for Children and Young People Programme (T4CYP) was launched in February 2015 to reshape and refocus emotional and mental health (MH) services for children and young people, as ‘access and support for young people and families was particularly difficult, with some areas offering little or no service at all’ and with long waiting lists in many areas ([NHS Wales, 2015](#)). One of the programme’s priorities was improving ND services for young people, and the work stream to support this included plans for developing care pathways for autistic children and young people and for those with ADHD (ibid.). The programme was extended for a further two years in 2019, with focus upon three areas: Early Help and Enhanced Support; Neurodevelopmental Services; and Regional Partnership Boards ([NHS Wales Collaborative, 2020](#)).
- 1.5 The national Integrated Autism Service (IAS) was developed after 2016, as part of the refreshed Autistic Spectrum Disorder Strategic Action Plan (ASD SAP) ([WG, 2016a](#)). It was intended 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). The IAS also provides post-diagnostic support for the parents and carers of autistic children ([Autism Wales, 2020](#)).
- 1.6 The Code of Practice on the Delivery of Autism Services ([WG, 2021a](#)) ‘sets out what autistic people, their parents and carers can expect from public services in Wales’ and how the Welsh Government ‘intends to adapt the way we organise society to be more aware and more attuned to neurodiversity’ (ibid., p.1). It highlights and reinforces existing duties of the Social Services and Well-being (Wales) Act 2014 and the NHS (Wales) Act 2006.
- 1.7 As section 4 of the report outlines, a range of other policies in education, health and social care shape the support that children and adults with NDCs and their parents and carers can expect; they include:

- the Additional Learning Needs (ALN) Transformation Programme, which aims to improve support for learners with ALN ([WG, 2020a](#));
- the Social Services and Well-being (Wales) Act 2014, which aims to improve the well-being of people who need care and support, and carers who need support ([WG, 2019a](#)); and;
- A Healthier Wales: Our Plan for Health and Social Care ([WG, 2021b](#)), which aims to 'bring health and social care services together' (ibid., p.1).

Neurodevelopmental services in Wales

1.8 This review focuses primarily upon two ND services: children's ND services and the IAS³. Despite the investment in these two new services, they have struggled to meet the demand for diagnostic assessment, resulting in long waiting lists ([WG, 2019b](#), [WG, 2019c](#)). The asymmetry between a children's ND service and adult's autism service also poses challenges for children making transitions as they become adults and raises questions about provision for adults with NDCs such as ADHD, for which there is no dedicated service ([WG, 2019c](#)).

Aims and objectives

1.9 Given this context, the aim of this work is to review the demand, capacity and design of ND services for children, young people and adults in Wales, in order to develop recommendations and evidence-informed options for improvements to services.

1.10 The main objectives of the review are as follows:

- to assess the demand, capacity and design of ND services for children, young people and adults across the seven health boards;
- to identify issues, bottlenecks, constraints and gaps that are impacting on the ability to deliver timely and high-quality services;
- to understand how the transition between children's and adults' services is managed and identify where improvements could be achieved;

³ Consideration is given to the role other services such as Adult Mental Health services (AMHS) and Learning Disability (LD) services play in diagnostic assessment and support for children and adults with (or suspected to have) autism and/or ADHD, but this was not comprehensively assessed.

- to identify existing good practice and consider how it could be integrated into a national approach;
- to consider the feasibility, as well as potential advantages and disadvantages, of alternative structures and models of service delivery, including a holistic all-age, pan-NDC model;
- to consider implications of the forthcoming Code of Practice on the Delivery of Autism Services, which will place statutory duties on health and local authorities to deliver services for autistic people and their carers; and consider the implications of other relevant policies and work streams;
- to consider the current and potential future impact on the capacity of ND services of: wider autism/ND services such as those provided by the Child and Adolescent Mental Health Service (CAMHS), local authorities (LAs), and national and local third sector services; autism/ND services provided through non-devolved functions such as the criminal justice system and welfare support services; third sector grant scheme projects currently funded by the Welsh Government between April 2020 and March 2023; and also initiatives such as the Do-It profiler pilot (the new digital Neurodiversity Wales Shared Platform (NDWSP)⁴;
- to consider the current and potential future impact of the design and delivery of ND services on individuals with protected characteristics as set out in the Equality Act 2010; on the ability to implement the ‘active offer’ as set out in More Than Just Words, the strategic framework for Welsh language services in health, social services and social care ([WG, 2019d](#)); and on the ability to comply with the Welsh language standards;
- to develop recommendations/options for improvements to services to address current demand, capacity and design issues, and any gaps in provision;
- to facilitate a Working Group to identify feasible and sustainable options for improvement to children’s and adults’ ND services, taking into account all the evidence generated as part of the review;
- to develop two proposals for a national ND service model that would improve and maximise the timeliness and quality of services – one which could be achieved

⁴ [Do-It Profiler](#)

within the existing budget and another which could be achieved with an increased budget; and

- to develop a workforce strategy to support proposals for future ND services.

1.11 The review identifies that developing a long-term vision for ND services in Wales is an ambitious and challenging goal and that realising it will require the engagement and support of a range of stakeholders. It is envisaged that the process of co-producing the long-term vision for ND services in Wales will continue after completion of this review.

Structure of the report

1.12 Following this introductory section:

- section 2 of the report outlines the approach and methodology, including details of the stakeholders who contributed to the review and the Working Group which helped identify and articulate the long-term vision and high-level principles for ND services for children and adults;
- section 3 outlines the current position, including demand for ND services and their capacity to meet demand; the strengths and weaknesses of the current service structure, including consideration of those groups of children and adults who do not easily 'fit' into existing service structures (and whose needs are not currently being met); transitions from children's to adults' services; and services' Welsh language offer;
- section 4 outlines the long-term vision and principles for reform of ND services and the wider system; actions to realise these (including policies and existing good practice which could be integrated into a national approach); and options for strengthening or restructuring ND services for children and/or adults (including alternative structures and models of service delivery) identified by the review's Working Group;
- section 5 outlines the review's conclusions and recommendations; and
- the appendices provide additional detail on demand and capacity including, for example, issues, bottlenecks, constraints and gaps that are impacting on ND services' ability to deliver timely and high-quality services.

- 1.13. A supplementary paper on a workforce strategy to support the report's proposals for ND services will be published shortly, alongside a supplementary paper summarising the key themes in the written comments made by participants in the two stakeholder workshops and the ND Review's Working Group's discussions of options to reduce demand and/or increase capacity in the short term.

2. Methodology

2.1 The review was structured in two phases. The first phase focused upon gathering data about the demand, capacity and design of ND services in Wales. The second phase focused upon facilitating a Working Group to identify feasible and sustainable options for improvement to children's and adults' ND services.

Assessing the demand, capacity and design of ND services in Wales

2.2 The first phase of the review integrated several desk-based elements, including a review of:

- secondary data, including the Pupil Level Annual School Census (PLASC) data and data provided by ND services and the National Autism Team (NAT) on demand and activity (such as the number of referrals for diagnosis accepted and the number of diagnostic assessments undertaken);
- Welsh Government policies, such as the [Additional Learning Needs Transformation Programme](#), the [Framework on Embedding a Whole-school Approach to Mental Health and Emotional Well-being](#); and [The Code of Practice on the Delivery of Autism Services](#);
- NICE guidance covering autism ([NICE, 2017](#); [NICE, 2021](#)) and ADHD ([NICE, 2018a](#));
- research and evaluation, including the evaluation of the IAS ([WG, 2018](#); [WG, 2019b](#)), papers produced by the T4CYP(2) Programme (e.g. [NHS Collaborative, 2021a](#)) and the Embracing Complexity Coalition ([Embracing Complexity, 2020](#)); and
- examples of ND services in other parts of the UK.

2.3 The desk-based review was enriched and extended by primary qualitative research with over 70 policy makers and practitioners, who were interviewed⁵ in spring, summer and autumn 2021 drawn from:

- each of the seven children's ND services;

⁵ Interview schedules were drafted, focusing upon the review questions, and were informed by findings from the desk-based review and were discussed and agreed with the Welsh Government. Copies of the interview schedules are included in a supplementary paper.

- each of the seven IASs;
- the T4CYP(2) programme;
- the National Autism Team (NAT);
- adult mental health services (AMHS) in Cwm Taf Morgannwg, Hywel Dda, Powys and Swansea Bay;
- the Royal College of Speech and Language Therapists (RCSLT), Royal College of Occupational Therapists, Royal College of Psychiatrists (RCPsych), the Chartered Society of Physiotherapy, the Royal College of General Practitioners, the Royal College of Paediatrics and Child Health, and the Royal College of Nursing (RCN);
- the NHS Collaborative and NHS Delivery Unit;
- the Wales Autism Research Centre;
- two police services; and
- third sector organisations, including ADHD Connections, the ADHD Foundation, Autism Spectrum Connections Cymru (ASSC), the National Autistic Society (NAS) and Credu Carers.

2.4 In addition:

- six professionals involved in ND services invited to take part in the research chose to contribute via an online questionnaire⁶, rather than an interview; and
- a link to an online questionnaire⁷ was sent by the RCPsych to its members in Wales, to explore practice and experiences outside ND services (e.g. in CAMHS and AMHS). 23 members of the RCPsych responded.

2.5 Parents or carers accessing children’s ND services or the IAS, and adults accessing the IAS were contacted by ND services or an IAS and asked if they would be willing to contribute through interviews or an online questionnaire. As a result, seven parents or carers and nine adults were interviewed, and 30 parents or carers and 14 adults completed online questionnaires. Their stories and experiences informed the

⁶ The online questionnaires focused upon the review questions and invited a narrative response to explore stakeholders’ experiences of services.

⁷ The online questionnaires focused upon the review questions and were informed by findings from the desk-based review and interviews with stakeholders, to identify the key issues MH services faced in relation to assessing autism and ADHD and services’ ability to offer post-diagnostic support.

analysis and findings, and illustrate many of the points made in this report, particularly around the impact of gaps and weakness of ND services. To protect their anonymity, pseudonyms rather than real names are used, and elements of their stories have been omitted, where this might mean they were identifiable.

- 2.6 The first phase of the review concluded with two workshops in November 2021 to discuss emerging themes with stakeholders from ND and other health services, the T4CYP(2) programme, NAT, LAs, the third sector and the Welsh Government, providing opportunities to check, confirm and develop the key findings. The first workshop focused upon children's ND services and included 42 stakeholders. The second workshop focused upon adult ND services and included 30 stakeholders. The workshops validated and enriched the findings from the first stage of the review, and a summary of the key themes from the two stakeholder workshops is included in a supplementary paper.

Strength and limitations of the first phase of the review

- 2.7 It was envisaged that the review would be able to draw upon data on demand and capacity generated by an initial phase of work. This began in 2019, with the NHS Delivery Unit providing support to children's ND services and the IAS to collect data on their existing demand and capacity. Unfortunately, the work was disrupted by the COVID-19 pandemic and, as outlined in section 4, the Demand and Capacity Tool that was developed by the NHS Collaborative to help children's ND services generate data on demand and capacity, proved problematic. Therefore, data on the number of referrals for diagnostic assessment accepted by children's ND services and the number of diagnostic assessments undertaken was requested directly from LHBs, as a measure of demand and activity⁸. Four LHBs (Aneurin Bevan, Cardiff and Vale, Hywel Dda and Powys) provided this data, providing an important, if incomplete, picture of levels of demand and activity. In contrast, the NAT (which collects data from IASs on a quarterly basis) was able to provide data on the

⁸ 'Activity' measures what services actually do (e.g. the number of diagnostic assessments completed), while 'capacity' is a measure of what services could do (e.g. the maximum number of diagnostic assessments a service could complete).

number of referrals for diagnostic assessment received by IASs and the number of diagnostic assessments undertaken by each of the seven IASs.

- 2.8 A wide cross section of stakeholders including practitioners (such as representatives from each of the seven children's ND services and the seven IASs), policy makers and service users contributed. In the case of practitioners and policy makers, the sample was purposive and in the case of service users, in effect, it was a convenience sample. Particularly in relation to service users, the sample cannot be assumed to provide a comprehensive picture of service users' experiences. However, the scope to triangulate (systematically compare) responses from different groups and stakeholders (such as service users and practitioners) and the secondary data provides greater confidence in the external validity of findings drawn from these samples.

Identifying options for improvement to children's and adults' ND services

- 2.9 The second phase of the review involved facilitating a Working Group to identify feasible and sustainable options for improvement to children's and adults' ND services. The Working Group was composed of representatives from children's ND services and the IAS, the T4CYP(2) programme, the NAT, the RCSLT, Cardiff University, the third sector, the Welsh Government, and people with lived experience of NDCs.
- 2.10 A briefing paper was prepared and shared with members of the Working Group in advance of each of the two online workshops and a presentation was delivered to inform the discussions. MS Teams was used to enable the discussions and xLeap⁹ was used to capture participant thoughts and input as they responded to the presentations and questioning during the workshop.
- 2.11 The Working Group met online twice, in December 2020 and in January 2021. The first meeting aimed to identify actions that could be taken in the short term to address (i) demand-capacity gaps in ND services and (ii) gaps in ND service provision, within existing budgets or with a modest increase in funding. Eighteen people attended and members of the Working Group were invited to articulate how

⁹ Online flipchart paper software.

demand-capacity gaps and gaps in provision could be addressed. A summary of the key themes from the Working Group's first workshop is included in a supplementary paper. The second meeting focused upon the design and structure of ND services and aimed to identify and articulate the long-term vision and high-level principles for ND services for children and adults which could be realised with additional funding over the longer term. Nineteen people attended and participants reviewed and discussed the proposed goals and principles of change and proposed actions. The results of the second phase of the review are presented in section 4.

- 2.12 Because there was not sufficient time in the second workshop to discuss the potential advantages and disadvantages of alternative structures and models of service delivery, members of the Working Group were invited to comment (through an online form) on the appraisal of five key options for developing adult ND services. Ten members of the Working Group responded, and written comments were also provided by a representative of the Children's Commissioner for Wales and from a representative for Cardiff and Vale University Health Board (UHB). The results are presented in section 4.

Strength and limitations of the second phase of the review

- 2.13 The Working Group brought together a broad cross section of stakeholders, including experienced practitioners representing ND services, the NAT and T4CYP(2), and the third sector. The group discussed and challenged emerging themes from the first phase, providing both validation and opportunities to develop and refine findings.
- 2.14 The online format and platform worked well, but the breadth and complexity of issues and the policy landscape was a challenge and there was, for example little time to discuss alternative structures and models of service delivery in the second meeting (although an online consultation provided opportunities for further comment). The Working Group struggled to identify short term solutions to address demand-capacity gaps (although the review suggests there are not simple solutions, so this may have been unachievable). Moreover, while the facilitation of the Working Group aimed to identify if there was consensus, there was not sufficient time to try to build consensus when members of the Working Group expressed

different judgments. Therefore while, as outlined in section 4, the Working Group endorsed a proposed set of goals and principles, it was not able to reach agreement on two proposals for a national ND service model that would improve and maximise the timeliness and quality of services – one which could be achieved within the existing budget and another which could be achieved with an increased budget.

3. Neurodevelopmental services: demand, capacity and design

3.1 This section outlines what drives demand for ND services and then considers data on trends in the numbers of children and adults seeking a diagnostic assessment.

Why do parents and carers and/or young people seek a diagnostic assessment from children's ND services?

3.2 There was broad consensus amongst interviewees about what drives demand for diagnostic assessment from children's ND services. The main reasons given for why parents or carers, or young people themselves, sought a diagnostic assessment were:

- to access additional support now, or as a guarantee of continued support in the future; for example, as a parent of a child with an NDC explained: 'a lot of schools will say that a diagnosis doesn't matter because they will support needs but then when the young person leaves school no-one is supporting them'
- to provide an explanation of a child's needs and behaviours and why, for example, their child was struggling at school and/or they were struggling with their child's behaviour, and to provide insights into how to better support their child. As an interviewee from a children's ND service put it: 'autism is a nice, acceptable way to describe their needs...for parents and professionals, it gives an answer.... It [can] explain extreme challenging behaviour and affects how people respond to that child'.

3.3 The experiences of Ian, the parent of a child suspected of having an NDC, illustrate both these points, although it is important to note that not all adults or parents or carers of children with an NDC want a diagnosis. As Ian described:

'I want to know if there's a better way of doing things, I've had to decide for myself what's best, but it's difficult to do research when you don't know what it is, is it ADHD or autism, where does he fall into, there are so many classifications. He's by no means unmanageable, but there may be other good ways of dealing with it.'

3.4. Ian went on to explain that he felt a diagnosis would also help his son in school:

'Not all the teachers have been great with him, I don't want him to be labelled a naughty kid when it's something he possibly can't help and there may be better ways of dealing with it, I'd like more understanding, some have just shouted at him, and he hates that. He gets upset and doesn't like people looking at him. Every year we have to explain his behaviour to the new teacher. There was a good teacher last year and he'd try things that would work for a few weeks, but then the behaviour would creep back in. I know as he's getting older, he's pushing boundaries and that's typical, but I do think there's something there. He reacts emotionally to events and can't seem to control that emotion.'

- 3.5. Similarly, the mother of Steve, a nine-year-old boy who was recently diagnosed described how: 'we can't praise Neurodevelopment enough.... they have given Steve a chance in life, that's what we feel, he now has a chance'. She explained that:

'Now he's got the diagnosis, he seems to accept things better, he knows there's a reason for it, why he reacts as he does, why he does certain things, he seems more settled, and his behaviour is better. He also has strategies to deal with situations that are difficult for him'.

Why do adults seek a diagnostic assessment from adult ND services?

- 3.6. There was similarly a broad consensus amongst interviewees about what drives adult demand for diagnostic assessment from the IAS or AMHS (where ADHD was suspected). The main reasons given for why adults sought a diagnostic assessment were to provide an explanation, understanding and sense of identity; for example, as Neil, an autistic adult interviewed for the study, put it, diagnosis meant: 'I can now answer the question "is there something different about me?" – it has given me a framework to understand myself'. Similarly, as Alice put it following her diagnosis:

'They [the IAS] sent me information and links which were really helpful, it explained some of the things I'd been struggling with. I didn't know much about autism before that. When I struggled with things, I just put them to the back of my head. Now, I know why I struggle, and I know there are other ways of doing things. I have strengths. There are things I'm better at. For ages I thought I was

lazy. After the diagnosis, I knew it wasn't something I was doing wrong. I just do things differently. I know working in a law firm isn't for me and now that's ok. I'm re-training as a personal trainer as I've always been interested in fitness and running. When I'm released from the mental health services, I will change career. I feel I'm clearer about my strengths and a lot more confident'.

- 3.4 In addition, albeit to a lesser degree than children and their parents or carers, adults seek a diagnosis to access additional support. As an interviewee from an IAS reported: 'they feel [with a diagnosis] they will be able to negotiate the type of support they need from primary or secondary mental health services and ensure that they respond and adapt their practice'. Similarly, it was reported that a diagnosis could make it easier to claim rights under the Equality Act and to negotiate with employers about reasonable adjustments in the workplace.
- 3.5 For some adults, a diagnosis was sought following a crisis or period of difficulties; for example, as an interviewee from an IAS put it, many of the adults they saw had 'gone to university and it didn't work out. They had struggled with life skills, social demands, unstructured learning – or they had had problems with work...and come to us [the IAS] and a diagnosis can be really helpful for them'. A small number of adults in the survey, or who were interviewed, reported that their request for a diagnosis was triggered by a mental breakdown and, as one interviewee from an IAS put it, we 'get a lot of referrals from mental health [services]'¹⁰.
- 3.6 Others were referred because their family or partner were struggling or fearful about the future. As an interviewee from an IAS put it: 'families may be struggling even if the person themselves may be indifferent... [it] may be older parents becoming aware of their mortality...or a young person entering their 20s [who relies upon their parents] still providing a great deal of support and [whose parents are] wondering why it might be'.

Trends in demand for a diagnostic assessment

- 3.7 PLASC data suggests that the numbers of children seeking a diagnostic assessment of autism have been increasing since the millennium. By 2018/19, the

¹⁰ The IAS was established for those who do not meet the eligibility criteria for statutory services, such as LD or MH services, and these services are expected to continue undertaking diagnostic assessment of autism.

proportion of children reported by schools to have ASD as their major SEN was 1.9 per cent ([Stats Wales, 2021](#)), higher than the expected rate of around 1.2 per cent ([NHS Digital, 2018](#); [NICE, 2020a](#)).

- 3.8 In contrast, increases in the numbers of children reported by schools to have ADHD recorded as their major SEN have been much lower, with rates at 0.7 per cent in 2018/19 ([Stats Wales, 2021](#)), 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](#)). This raises concerns that ADHD is being missed or misdiagnosed.
- 3.9 However, the accuracy of the PLASC data has been questioned and 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 PLASC data suggests (Pers. Comm. Anita Thapar and Kate Langley). The data on children is discussed further in the appendix.
- 3.10 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. The data on adults is discussed further in the appendix.
- 3.11 Data on the total number of adults seeking a diagnostic assessment of ADHD is not known, and there is thought to be substantial latent (unmet or unfulfilled) demand, given weaknesses in pathways and provision (making this a key gap in provision).

Why are more people being referred for an NDC diagnosis?

- 3.12 There was broad consensus amongst interviewees that the key factors driving the increase in the numbers of children and adults suspected to have NDCs were:
- increasing awareness of NDCs, such as autism and ADHD, amongst parents and carers and professionals, meaning that more children and adults were identified;
 - the broadening of diagnostic criteria and thresholds¹¹, particularly for autism, as the 'categorical view' of autism has been superseded by a spectrum view and

¹¹ One interviewee from an ND service noted that, assuming normal distribution of NDCs within the population, each successive widening of the threshold created a disproportionate increase in the number of children or adults who met the threshold.

more sub-groups, such as Asperger Syndrome, are included (Baron-Cohen, 2008);

- the establishment of new ND services, particularly where there was little or no provision before, which released latent or previously unmet demand;
- the introduction of new responsibilities for ND services, such as work with those in the secure estate (e.g. prisons) and at a local level, population growth (e.g. of cities).

3.13 There is uncertainty about whether demand for diagnostic assessments will continue to rise or plateau or even fall. In addition, the impact of the COVID-19 pandemic has further complicated efforts to interpret long term trends (as it disrupted both demand and capacity). However, there was little expectation amongst interviewees that demand would subside in the short to medium term and, for example, one interviewee from a children's ND service described it as 'inexorable'. Over the longer term, if we assume that prevalence rates remain stable, demand for children's ND services is likely to remain high without actions to reduce demand. However, demand for adult services may lessen somewhat if more children are diagnosed¹², although there will remain a large number of undiagnosed older adults for generations to come.

Is increasing demand a problem or to be celebrated?

- 3.15. For those interviewees who felt a diagnostic assessment was beneficial, increasing awareness and increasing demand were seen as important, despite the pressure it places upon ND services. As one interviewee from a children's ND service put it, they were 'almost victims of their own success' as efforts to raise awareness had increased demand, which they were struggling to meet. Moreover, in relation to ADHD, where medication is an option if there is a diagnosis, there is a clear case for welcoming increasing demand for diagnostic assessment (see e.g. [Young et al., 2021](#)).
- 3.16. A few interviewees from children's ND services and IASs reflected that demand ought to be higher because they were still not reaching all those who would benefit

¹² At present around 40% of those accessing the IAS who declared their age were aged 18-25, although this includes both those seeking a diagnosis and those seeking support.

from a diagnostic assessment for autism or ADHD. Interviewees from both children's ND services and IASs, and also parents and carers, expressed frustration about delays, where children or adults with clear needs and symptoms of an NDC had not been referred earlier because their signs and symptoms had been missed or misunderstood, meaning opportunities for earlier intervention had been missed; for example, Clare, the mother of an autistic child, Sam, described him as a child who:

'Loves football and computer games, like most young people and is a very loving child. He is our middle child. He's mostly ok at home and in one-to-one situations, but has struggled and does struggle outside, especially in school, he has a lot of anxiety in these situations. He spent a lot of his primary education being called "naughty". He couldn't cope with being teased, he'd lash out and then get into trouble, but the ones who'd been teasing him didn't get into trouble at all. It's been a tough time for him'.

'I knew there was a problem when Sam was two years old. It was as if he entered into the tantrums of a two-year-old and never came out of it. I knew something wasn't right. School kept saying he was too young for an assessment'.

'We were referred to CAMHS when he was 6 or 7 years old and after an assessment, were told there was nothing wrong. We were referred to CAMHS a second time, but they refused to see him because they'd already seen him. The third referral to CAMHS we saw a social worker and were offered family therapy and on the fourth referral to CAMHS, they again refused to see him'.

'Eventually, the school referred us to [the children's] Neurodevelopment [service].... we met Neurodevelopment in March 2020 and because of the lockdown there was a delay. We eventually got the assessment and diagnosis in September 2020'.

3.14 Nevertheless, some of the reasons for increasing demand were seen as undesirable, and action to address these was supported; such reasons included:

- the perception (real or imagined) that a diagnosis was required to access support was seen as inappropriate, given the long-standing aspirations that a diagnosis should not be required to access support or services (e.g. [WAG, 2008](#));
- unmet needs that could have been addressed, given proper support, without requiring a diagnostic assessment; for example, as an interviewee from a children's ND service put it, there 'shouldn't be so many [children] that need top tier interventions: something is going wrong' and that 'referrals into the [children's ND] service are indicative of the lack of capacity below the service'; and
- inappropriate referrals; for example, one interviewee from a children's ND service said that sometimes a school might make a referral for an ND assessment for families to 'feel like something is being done. It's the thing itself, it's easy to make a referral and it takes the pressure off the school'. As another put it, sometimes referrals were made to the ND services as the 'default service' for those children whose needs were not understood. Several interviewees from children's ND services linked this to gaps in services, sometime described as the 'missing middle'¹³.

3.18. Several interviewees from children's ND services said that, almost without exception, those they saw 'had a problem', even if they did not always meet diagnostic thresholds or criteria for a specific NDC. In these cases, the ND service's assessment can and should inform a profile of the child's strengths and difficulties. However, interviewees from ND services reported that there were often gaps in provision for those who fell short of diagnostic thresholds.

3.19. It was also observed that assessment and diagnosis can have negative implications for people; for example, autism is a lifetime condition that can limit people's employment options and also a label that can stigmatise people. Therefore, as the mother of Steve reflected, for Steve:

¹³ As the Mind over Matter report put it, this reflected: 'the lack (and in some cases absence) of services for children and young people who need support but do not meet the threshold for specialist CAMHS or ND support' ([NAFW, 2018](#), p.76).

'The diagnosis has been bittersweet. It has helped him understand his behaviour and accept it, but he also gets upset when talking about it, he doesn't want to be different. The diagnosis may [also] make things difficult for him in the future when he's older, but on the whole now, it helps. He has strategies to use'.

3.20. As a researcher (interviewed for this study) reflected:

'Many autistic people are proud of the label [but] there needs to be some space in the middle between the value that autistic people put on having a diagnosis and the public perception of such a weighty label. The diagnosis should not be defining, it is not the entirety of the person. The diagnosis flags up traits, but it does not always help the individual. As a society we should be considering why we need such labels'.

Neurodevelopmental services' capacity to undertake diagnostic assessments

3.15 The establishment in Wales of children's ND services and the IAS was seen as an important achievement which increased capacity and meant diagnostic assessments undertaken by the services could be assessed against the 'gold standards' outlined by the National Institute for Health and Care Excellence (NICE) guidelines for diagnostic assessments for autism and ADHD. However, although the increasing awareness and recognition of autism and other NDCs, like ADHD, is to be celebrated, it means demand for diagnostic assessment has outstripped the capacity of both children's ND services and the IAS.

Issues, bottlenecks, constraints and gaps

3.21. Qualitative research with each children's ND service and IAS was used to explore the issues, bottlenecks, constraints and gaps each service experienced¹⁴. It was reported by interviewees from both children's ND services and IASs that their capacity was constrained by three key factors:

- the time (typically between 10-15 hours) and multidisciplinary approach (with contributions from a range of clinicians such as paediatricians or psychiatrists,

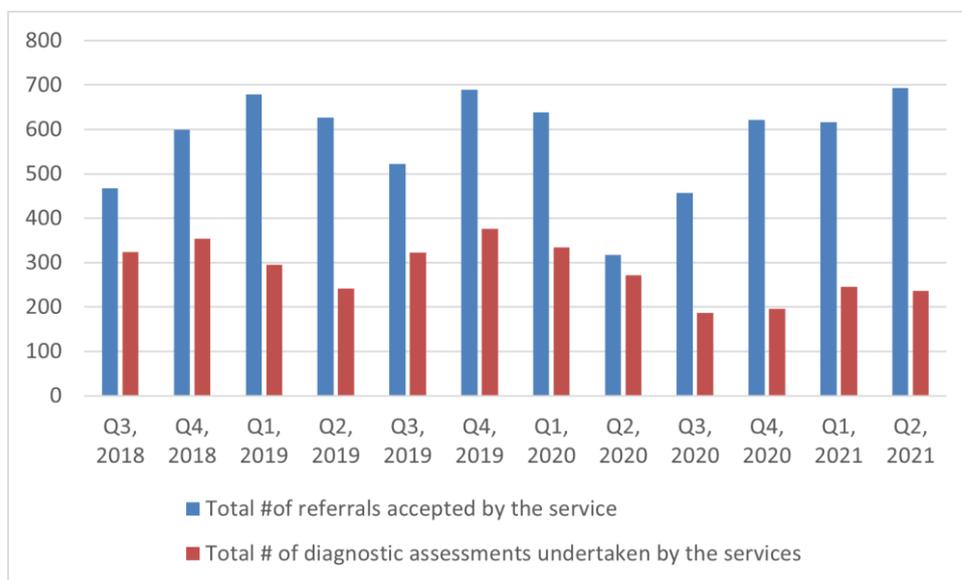
¹⁴ This was complemented by written material provided in demand and capacity reviews undertaken by each IAS.

psychologists and/or speech and language therapists) required for a robust diagnostic assessment of autism, which complies with NICE guidelines. In contrast, a diagnostic assessment for ADHD can be done much more swiftly (in around three hours) by a single clinician;

- the small size of teams, which left them particularly vulnerable to problems recruiting and/or retaining staff and/or staff absence (e.g. due to sickness) and which also restricted opportunities for progression within services; and
- a range of more specific constraints, issues or bottlenecks that limited teams' ability to use staff time as efficiently or effectively as they wished, such as problems with accommodation, the time needed to travel to appointments (particularly in large rural areas) or a lack of administrative support in a particular team or service.

3.22. These issues are discussed in more detail in section 7 (the appendix) and mean that, given the level of demand for the service, as graph 3.1 illustrates, the number of children seeking diagnostic assessment has consistently been higher than the number of diagnostic assessments undertaken in the four health boards that provided data. Both demand and activity fell during the COVID-19 pandemic, but activity remains lower than it did pre-pandemic, while demand has increased again. Over the period (quarter 3 2018 to quarter 2 2021) 6,381 children were referred for an assessment and 3,160 assessments were undertaken, meaning that, for roughly every two children seeking an assessment, one assessment was undertaken.

Graph 3.1. The numbers of children referred for diagnostic assessment and the numbers of children assessed in each quarter of 2019/20 and 2020/21 (total for Aneurin Bevan, Cardiff and Vale and Hywel Dda University Health Boards and Powys Teaching Health Board)

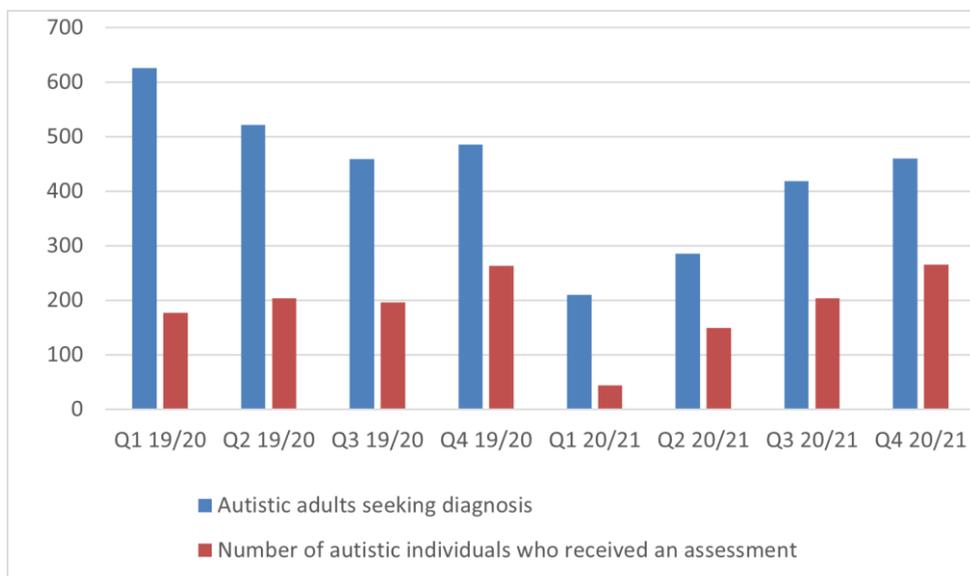


Source: Aneurin Bevan, Cardiff and Vale and Hywel Dda University Health Boards and Powys Teaching Health Board

3.23. As graph 3.2 illustrates, the number of adults seeking diagnostic assessment has consistently been higher than the number of diagnostic assessments undertaken¹⁵. Both demand and activity fell during the COVID-19 pandemic. While demand remains lower than it was before the pandemic, activity has now returned to peak pre-pandemic levels. Over the periods April 2019-March 2020 and April 2020-March 2021, 3,466 adults sought an assessment, and 1,502 assessments were undertaken, meaning that, for just over every two adults seeking an assessment, one assessment was undertaken (the ratio of adults seeking an assessment to assessments undertaken was 2.3:1).

¹⁵ The data has limitations; for example, some of those adults seeking a diagnostic assessment will not be accepted by an IAS, although the numbers are reported to be small. They may, for example, live in a different health board area or may not provide sufficient information. However, data on the numbers of adults seeking a diagnostic assessment who are accepted by each IAS is not currently available. The impact of COVID-19 upon both demand and capacity also makes it difficult to extrapolate future trends based upon the historical data.

Graph 3.2. The numbers of adults seeking diagnostic assessment and the numbers of adults who received an assessment in each quarter of 2019/20 and 2020/21 (total for all seven IASs)



Source: NAT

3.24. Further details on the numbers and trends in demand and capacity is provided in the appendix.

The impact of demand – capacity gaps

3.25. Demand-capacity gaps increase waiting times for children, young people, adults and families, which can be exacerbated when there have been delays in making a referral. Many families interviewed in this and earlier studies ([WVG, 2019b](#)) felt they had been waiting since concerns about their child were first raised, rather than since a referral to an ND service was made (which is the focus of the current waiting time target). As a consequence, they described often tortuous and harrowing experiences of waiting, which some felt became ‘lost’ years; for example, as Clare described:

‘We knew at two years old that there was an issue, and we finally got a diagnosis in September 2020 around the time of his twelfth birthday, a decade of heartache with consequences for us individually and as a family’.

3.26. In those cases where support depends upon a diagnosis, problems can multiply and/or escalate as opportunities to intervene early are missed, while families wait for an ND assessment. For example, Clare, whose long wait for an assessment for her son, Sam, is outlined above (see paragraph 3.16) described how Sam has a lot of anxiety and spent a lot of his primary education being called 'naughty.' As she explained, 'he couldn't cope with being teased, he'd lash out and then get into trouble' and as a result, 'it's been a tough time for him'.

3.27. Things began to change in 2020, when Sam was 11 and the school referred him to the ND service for an assessment. After waiting for nine months (on the ND service waiting list), he was assessed and diagnosed with autism, and Clare was able to share the one-page profile the ND service created for Sam, with the school's SEN/ALN Co-ordinator (SEN/ALNCo). Clare explained that this helped the ALNCo create a profile for him in the school and that now she can phone the ALNCo at any time and she has been 'very good with us and Sam'. She also explained that now the 'teachers are aware. His profiles are adapted every year as his needs change, adjustments can be made and for now, that's all he needs.'

3.28. Clare went on to describe how that now Sam's got the diagnosis:

'He seems to accept things better, he knows there's a reason for it, why he reacts as he does, why he does certain things, he seems more settled, and his behaviour is better. He also has strategies to deal with situations that are difficult for him.

3.29. As she summed it up, 'finally, we felt he was getting what he needed, he's calmer, he was always angry before, misunderstood and him being understood is a major relief for us.' However, as she also described:

'Our eldest daughter who is [age] has gone to live with my parents as we couldn't cope with the [Sam's] tantrums. We still see her regularly, we go on holiday together, but it has damaged our family. If we'd seen Neurodevelopment earlier, if we hadn't been prevented from getting access to them [it might have been different, but], we wasted years and the stress and frustration that caused us as a family'.

3.30. Similarly, as a parent of Rhys, a nine-year-old boy who loves football, playing on his play station and with his friends, recounted:

'It was school more than me who wanted the referral. I have an older son and knew that Rhys was an emotional boy, he was up and down a lot, fine one minute, inconsolable over small things. We just thought that he was an emotional boy. The Year 1 teacher recommended the referral. There were low level things she was concerned about, things like he couldn't sit still on the mat, he'd overreact to things. I was happy for the referral to be made. The teacher knew how long these things take, so she was keen to make the referral early. We've [now] been waiting for four years'. [16]

'The older he's getting, I feel he's getting worse, and we're worried about when he goes to high school, worried that if he doesn't have a diagnosis, he'll be labelled 'naughty' and treated in that way. I want to know ways of dealing with different behaviour, how to mitigate them and be able to support the school. Rhys will concentrate if he's interested in something, but if he's not interested or finds something difficult, he can get frustrated. How do we deal with his behaviour best, without making it worse?'

3.31. For adults, experiences were generally somewhat different. Some, like Alice (whose story is described above), described struggling for years but not knowing or understanding why. A number of those interviewed had been in contact with MH services, but unlike children, whose difficulties were initially assessed by schools, and potentially then other services, such as Educational Psychology (EP), before a referral to an ND service was made (extending the time parents felt they had waited), adults were more likely to describe the period they had waited as the time from a referral to the IAS being made to their assessment being undertaken. Chris, one of the autistic adults interviewed for this study, described how he thought that it would

¹⁶ This waiting time is longer than that reported for most ND services. This may be because families calculate the waiting times from the time when concerns are first raised, rather than from the date the assessment is made or accepted by an ND service.

not change anything for him to get a diagnosis, but his mental health was getting worse, so he went to his GP who referred him to the primary MH service, and they did a short assessment with him and referred him to the IAS, who then put him on a waiting list. He says that the IAS was going through a difficult time then – a staff member had left – and he was waiting for two years. During this time his mental health continued to deteriorate. Chris says that waiting for the diagnosis for two years, and then another year for the post-diagnosis course felt like his life was stopped for all that time; ‘my entire full-time job became my physical health – because when that gets bad it damages my mental health. I had just not been looking after myself’.

- 3.32. Chris’s case highlights the difficulties some people with co-occurring conditions, such as an NDC and mental health difficulties, can experience accessing services (discussed further below), and the ways in which weaknesses in services, in this case, staff shortages, contributed to his difficulties, but also some complexities; his mistrust or lack of faith in MH services became a barrier to accessing those services. Chris explained that while waiting for a diagnostic assessment from the IAS, he went back to his GP for help but was told there were long waiting lists for mental health support as well. He was offered cognitive relationship therapy, but he did not want to go back over the traumatic events of his childhood as he was afraid of doing this.
- 3.33. Lengthy waiting times also mean that, in children’s ND services particularly, staff’s attention is driven to try to meet waiting time targets rather than children, young people and families’ needs; for example, the pressure to focus upon diagnostic assessment means services’ capacity to provide post-diagnostic support is severely constrained.
- 3.34. The impact upon staff also means that the pressure upon ND services is not sustainable. There are examples of both children’s ND services and, to a somewhat lesser degree, IASs, where there is a risk of staff ‘burning out’ or leaving services because of the pressure. Workforce retention and recruitment are key challenges for children’s ND services and some IASs, and losing skilled and experienced staff due to sickness or resignation can cause serious problems.

3.35. COVID-19 and lockdowns were reported to have increased the pressure upon services by reducing staff capacity (e.g. due to redeployment of staff, sickness or self-isolation) and reducing opportunities for staff to release their stress. As a result, as one interviewee from an IAS put it, they ‘felt done in’ and had ‘hit the wall’, increasing the risk of ‘burnout’. The impact of COVID-19 upon the health workforce is a wider concern and, as the Kings Fund identifies: ‘without a physically and psychologically safe and healthy workforce, excellent health care is not possible’ ([Bailey and West, 2020](#)).

ND services’ capacity to support children with autism or ADHD

3.36. Increasing recognition of neurodiversity means there is increasing demand for support. However, the post-diagnostic support offered by children’s ND services varies and is generally limited. As one interviewee from an ND service put it: ‘we are an assessment service, not a support service’. This is compounded by weakness in support from other services; for example, as an interviewee from another children’s ND service described it:

‘Ideally, if for example a three-year-old was diagnosed with autism, we’d offer a course, like Early Bird and a third sector group like [name omitted to protect the anonymity of the interviewee] and an appointment to talk about problems, but we discharge too early. There can, for example, be sleep problems...80% come in with sleep problems, but there’s not enough resources, not enough capacity to deal with them, ideally we’d offer a basic sleep programme and, if needed, refer to CAMHS, but the situation in CAMHS is just as bad’.

3.37. The support offered by children’s ND services was reported to vary. Some services described discharging to specialist nurses who could, for example, ensure that appropriate support is put in place in school once diagnosis is confirmed and reinforce signposting to other support, such as psychology support and family groups. Some ran courses such as Cygnet¹⁷, EarlyBird and EarlyBird+, and Teen

¹⁷ Cygnet is a parenting support programme for parents and carers of children and young people aged 5-18 with autism.

Life¹⁸, or occasionally intervention groups¹⁹. Others focused primarily upon signposting to LA services, such as family support or education services and third sector organisations, who were a key source of support, and/or providing resources for the family on, for example, sleep problems.

- 3.16 In addition, the IAS has a role in supporting parents and carers. However, its capacity to do this has shrunk, given the high level of demand from adults for diagnostic assessments and support. Interviewees from ND services, third sector organisations, and parents and carers themselves, reported a need for longer term support (the IAS currently only offers short term support, like parenting classes), ‘a service you can dip into as needs arise’ (to help with issues like sleep, anxiety, transitions), as an interviewee from the third sector put it.
- 3.17 This model reflects both the constrained capacity of children’s ND services and the ways in which support should be ‘everybody’s business’, given differing areas of expertise and responsibility. It would not, for example, be appropriate to expect ND services to be involved in educational provision.
- 3.18 However, it is clear from the review and the stakeholder workshops that this model is not working. For many, a diagnostic assessment is seen as the ‘key’ to unlocking services and support, but gaps and weaknesses in the system of support provided by health, education and social care, leave many disappointed; for example, cuts to other services, such as EP, were felt to constrain the scope to support schools. As an interviewee from an ND service put it: ‘we’ve not [currently] got the workforce who can support them [children with NDCs]’ and ‘we should be able to refer straight onto a workshop to give families strategies [before diagnosis], but we can’t because there are no courses’. The reliance upon other parts of the system to provide support also

¹⁸ Early Bird (for parents or carers of children aged under five years), Early Bird +(for parents or carers of children aged 4-9), and Teen Life (for parents or carers of children aged 10 -16) are support programmes run by NAS and offer advice and guidance on strategies and approaches to support autistic children.

¹⁹ As one interviewee from an ND service described it, occasionally, they run intervention groups with parents and even more rarely 1-1 interventions with parents. These interventions are open to anyone on the list or diagnosed – but not to people who have been assessed and not received a diagnosis. They are primarily about behaviour management strategies. She says parents want this help from ND services because they think that their child having a special condition or need means that it is not appropriate to access generic family support programmes. They want to know things like how to keep their child and others safe if the child has a meltdown. They also want to cope with the child’s anxiety and there is a lot of concern around anxiety. Parents want 1-1 support that helps with the specific issues their family faces but there is nothing out there for them.

creates a postcode lottery in provision, given differences in the support offered by different ND services, schools, LAs and third (voluntary) sector organisations.

3.19 The model can also feel disjointed. As an interviewee from the third sector put it, parents and carers expect that ‘a diagnosis will bring a more coordinated response [from education, health and social care] but it doesn’t’. As an interviewee from the NAT observed, there have been a number of attempts, such as My Orange Book²⁰ and the original vision for the ALN Individual Development Plan (IDP)²¹, to bring together the assessments of education, health and social care through, for example, a single planning process and plan, but these have not succeeded. As a result, each service conducts its own assessments before deciding on what support to offer²². A further danger with a model that makes support ‘everyone’s business’, is that it is ‘no-one’s responsibility’. The gaps in the wider system of support and the disconnect between an ND assessment and the provision of support is one factor which contributes to the ‘battle’ many parents and carers interviewed as part of the evaluation of the IAS described, when trying to access support ([WG, 2019b](#)). As Deborah described, too many parents or carers have ‘had to fight for all the support they have’, information is not at all clear about what people are entitled to, and the default is to say no and then let people fight. She described how her professional role and family contacts have meant that she has been able to find out about entitlements, such as an assessment by social care. Deborah described how, when she rang up to ask for an assessment, they said they were not entitled until her daughter was 18. Deborah put in a complaint, and they were referred to Team Around the Family (TAF), but when TAF got in touch they said her daughter was too complex and that she needed social care intervention (which Deborah knew) and that they were referring the family back to the disability team in social care. They waited

²⁰ The All Wales Hand Held Record for Disabled Children and Young People with Complex Needs ([WAG, 2004](#)).

²¹ The Individual Development Plan (IDP) is a statutory plan maintained by a school, college or LA that describes a child’s or young person’s ALN and the additional learning provision therefore required ([WG, 2014](#)).

²² As members of the T4CYP(2) and the NAT observed, the purpose of the assessment was not, as one interviewee put it, to ‘tell other services you should do this.... [the assessment] should be [to identify that] this support is needed, not that this service is needed’ and it was, for example, up to education services to assess and provide for educational needs. Several interviewees from children’s ND services, therefore, suggested that other professionals, such as EPs, needed to have a greater role after a diagnostic assessment in identifying educational needs.

four months with no contact and then Deborah contacted the disability team who said they had closed the case down because the TAF record said that the parent closed the case because the family did not want support. Deborah made another complaint and eventually they were allocated a social worker. She described this as 'brilliant' because they can now access direct payments. However, all of this caused so much stress that the occupational health service said she must go off sick, even though the stress was not work related.

- 3.20 As a consequence, as an interviewee from the third sector summed it up: 'it can feel like the current system doesn't work for anyone: you wait for years for a diagnosis and [then] don't get any support...you're made to feel getting a clinical assessment will open additional doors ...a diagnosis can open lots of doors, but not necessarily the doors you want'. In turn this meant that there was widespread concern about the value of a diagnostic assessment without a robust system for providing post-diagnostic support.

IASs' capacity to support autistic adults and parents and carers

- 3.38. Increasing recognition of neurodiversity means there is increasing demand for support for adults. The IAS is an integrated service, bringing together clinical staff and support workers, with a wider post-assessment support offer for adults diagnosed with ASD and parents and carers than children's ND services can offer; this includes:
- support and interventions by clinicians such as psychologists, occupational therapists, dieticians and support workers; and
 - signposting and referral to other services, such as adult MH services and the third sector.
- 3.39. Support workers who, as one interviewee from an IAS put it, were 'less pressured than clinicians' and had more time to help, were described as offering a range of support which could include:

- courses for autistic adults or parents and carers²³;
- walk and talk support sessions (when community buildings were closed);
- advice sessions by phone or drop in sessions;
- support groups for autistic adults or parents and carers;
- travel and life skills training; and
- signposting and referrals to adult MH services.

3.40. The value of this support was illustrated by a parent of an adult, Katie who had accessed the IAS; as they described it:

‘IAS understand the condition and they are patient. Katie sees [IAS worker] for a weekly session every Friday. We think she’s a support worker. She is excellent. She is liaising with the mental health team and when we organised for Katie to go to college for a year, [IAS worker] went with her and advocated on her behalf, so they had a good understanding of her needs, and she had the best chance of succeeding. IAS also find things out for us, and they always come back to us. They keep our heads afloat on a daily basis’.

‘In [County], there didn’t seem to be an understanding of autism and the strong link with mental health. The mental health services didn’t seem to cater for autism. The fall off is evident everywhere even in Wales [they had moved from England to Wales]. The mental health support still isn’t very substantial. IAS help us navigate all of this. They’ve been a life saver. They’ve been very good. They talk to you from a position of understanding and always come back to you. They are a God-send’.

‘We also went on a six-week course with the IAS for carers, on-line. It was very good. For us as parents it’s just been a massive relief that the IAS are there, to feel that someone is battling for us. They supported us

²³ For example, as Tim put it: ‘I was offered the post diagnosis course, the six-week session. There was a waiting list, and my wife is still waiting for her course. I think I went on it in May 2021. It was well-structured, they shared a lot of knowledge; there were six or seven of us and two trainers. It was very good, very simple, no talking down to you, it was relaxed, we laughed, and it was informative. There was a lot of information, we were given a booklet and a copy of the PowerPoints’.

to get a free bus pass for Katie, they gave a letter of support and as we mentioned they advocated for Katie with the college. Katie still gets agitated a lot, she likes the routine of college, but she still worries a lot, she frets’.

3.41. Katie summed it up:

‘Knowing IAS is here is amazing, it takes a little weight off and does support our psychological well-being, just knowing there’s someone there who understands and whoever we phone, they’re all very good’.

3.42. It was also observed by interviewees from the third sector and IASs, that some IASs offered greater access to support through, for example, open access drop-in sessions, before a diagnostic assessment was completed.

3.43. The range of support differed across IASs and there was still frustration amongst interviewees from the IAS and third sector that IASs could not do more, particularly given the high hopes and expectations raised by the announcement and establishment of the service; for example:

- concerns were raised by some interviewees from the third sector about signposting. As one interviewee put it: ‘you should only refer people to services you know and trust and we always follow up to check what has happened and often “introduce” people to a new service’. As they explained, autistic people often struggle to retain and understand information so if you just tell them to go to another organisation, it can be problematic.
- it was also stressed that IASs offered, as one interviewee from an IAS put it, ‘short interventions’ and if someone needed ‘longer term support, social care should take it up’. However, some difficulties in accessing social care were reported where, for example, a person’s difficulties were felt not to have been adequately assessed or identified by social services. The high thresholds for eligibility also constrain who can access social care.
- the focus upon short interventions also meant that IASs often struggled to offer more flexible support that people could ‘dip in and out of’ as one interviewee from

the third sector put it, when problems arose. The value of this is illustrated in the example below on 'touching base'.

Touching base: An example of long term, but intermittent, support

An interviewee from the third sector described their work with a man who was clinically depressed and homeless and who had been recently diagnosed with autism. He had been in the army but was now in a poor state and could not work. They described linking him with other organisations and sorting out benefits and accommodation – then he dropped out of sight. He was receiving disability benefit and was okay – but it was only temporary, as his problems were seen to be a mental health issue rather than his autism. He got back in touch when his disability benefit was being reviewed as his anxiety levels rise considerably when he has to deal with forms and officials. They helped him get employment and supported him and his employer to ensure he sustained his work. Now he just gets in touch when something happens e.g. his benefits come up for renewal or an official letter arrives that makes him anxious. As they described it, the third sector organisation supporting him is just somewhere to 'touch base'.

- 3.44. The diversity of autistic adults' needs, which (amongst those interviewed) ranged from those who had struggled to live independently without support and were eligible for social care, to those with high powered jobs, but who struggled with interpersonal relationships at work, is a challenge. As a number of interviewees from IASs and the NAT observed, while the IAS has a key role it cannot and should not try to meet all needs. As with children's ND services, health, education, social care and other services, such as employment and housing, all have important roles to play in providing support so autistic adults can achieve their potential and lead fulfilling lives.

Diagnostic assessment and support for adults with ADHD

3.45. There is an adults' ADHD service in Hywel Dda (see boxed text below paragraph 3.48 on the next page), one is being set up in Gwent²⁴ and the feasibility of establishing one in Powys is being explored, although it is not clear whether the Local Health Board (LHB) is committed to this or not²⁵. However, in other areas access to a diagnostic assessment for ADHD is largely dependent upon the skill and interest of individual clinicians. Even where clinicians have the skill and interest, lack of time to undertake a diagnostic assessment is a key barrier; for example, as one respondent to the online survey of RCPsych members put it in a written comment:

'There is no current diagnosis service for adult ADHD in [name of LHB], which has been an unacceptable unmet need for some time. This is mainly because of very high caseloads of adult psychiatrists and not having time to do proper assessments and also due to lack of resources to safely initiate treatment and monitor. There should be a dedicated neurodevelopment service for adults in [name of LHB]'.

3.46. The issues are discussed further in the appendix and reflect a UK-wide gap in provision for adults with ADHD ([UKAAN, 2018](#); [Young et al., 2021](#));).

Post diagnostic support

3.47. It was reported by interviewees that adults with ADHD may need services, such as support with executive functioning²⁶ difficulties, sleep and relationships. However, interviewees from both health services and the third sector reported there was very little support for adults diagnosed with ADHD beyond medication and, if they had mental health difficulties, support from primary or secondary MH services. As an interviewee from an AMHS described it, they give advice and some support on

²⁴ The service will be provided from within secondary MH services and a small group of consultant psychiatrists have been identified to deliver this service. They have attended diagnostic training and are awaiting medication and prescribing training. Referrals to the service will be made by GPs.

²⁵ Adult ADHD is seen as a real challenge in Powys and there is interest in researching the feasibility of developing an adult service staffed by two band 7 non-medical staff. Each of the mental health consultants runs one ADHD clinic a month but demand is much higher than this provision. They are looking at a model with a psychiatrist providing an overview supported by band 7 staff.

²⁶ 'The executive functions are mental skills that help people 'plan and organise' their lives and achieve their goals. They include, for example, 'flexible thinking', 'emotional control', 'impulse control', 'working memory', 'self-monitoring', 'planning and prioritisation' and 'task initiation' ([ADHD Foundation, 2022](#), pp 16-17).

managing the condition and can signpost other areas of help such as finances, but there was 'no specific ADHD support' service in their area. This was supported by the responses of members of the RCPsych who completed the online survey, with none of the 20 respondents agreeing that there was sufficient capacity to provide post-diagnostic support in their health board, although just over half (n=12) were unsure. This lack of support from the NHS increases reliance upon the third sector, accentuating postcode lotteries (given differences in third sector provision) and can strain the third sector, which often lacks the resources and sometimes lacks the skills needed to support people with ADHD and/or their parents and carers ([Young et al., 2021](#)).

- 3.48. For adults with ADHD, the co-occurrence of ADHD and substance misuse problems was reported to be common, and NICE guidelines note the association between ADHD and an increased risk of substance misuse ([NICE, 2018a](#)). As one interviewee from an AMHS put it: 'substance misuse and ADHD is the rule' although this may reflect the profile of people with ADHD accessing AMHS, rather than the profile of all adults with ADHD. When services work sequentially, rather than collaboratively, and adults are unable to access MH and substance misuse services at the same time, this causes particular problems. Models, such as the adults' ADHD service in Hywel Dda (see boxed text) with strong links to substance misuse services, were therefore reported to be worth considering.

Hywel Dda's Adult ADHD Service

The service developed out of the special interest of a consultant psychiatrist working with patients dealing with substance misuse. He saw how many patients seemed to have ADHD and developed the service. The service is now led by a clinical nurse specialist, supported by a specialist mental health pharmacist, an administration worker and two sessions a week from the consultant psychiatrist. The clinical nurse specialist and specialist mental health pharmacist can do the Diagnostic Interview for ADHD in Adults (DIVA) assessment and are training to become non-medical prescribers so that they can offer diagnosis and treatment. This will help free up the consultant's time, who is currently the only one able to do the medical examination or prescriptions, as at least one of his weekly sessions

can be totally absorbed in writing prescriptions. The service also has a shared care arrangement with primary care – especially in relation to prescribing; they stabilise the client and then hand back to the General Practitioner (GP) with a review every 6 months. However, they report that sometimes GPs do not take over the prescribing so the unit must continue to prescribe. Because there is no template for an adult ADHD service (which is seen as novel), they are exploring what they should provide and are focusing on diagnosis, treatment and funnelling people to support services.

Who doesn't 'fit' into existing service structures?

3.49. The demand-capacity gap is not the only reason ND services struggle to meet needs. The establishment of children's ND services and IASs has been important in filling gaps in services²⁷. However, some groups of children and adults are still considered 'complex' because they do not easily 'fit' into existing services structures; they include the following groups, who are discussed further in the following subsections:

- those with co-occurring NDCs;
- those with an NDC and other co-occurring difficulties, such as mental ill health or drug or alcohol misuse; and
- those whose difficulties fall short of diagnostic thresholds.

3.50. In addition, some groups, such as people from some Black, Asian and minority ethnic communities, appear to be under-represented in ND services²⁸ and there were some (but by no means universal) concerns that autistic girls or women could be missed because they were better able to 'camouflage' their differences (see [NICE 2020a](#), [2020b](#)). However, it is worth noting that the gender split of those accessing the IAS, roughly five males to four females, is much smaller than that reported in other studies.

²⁷ Autism is neither a mental health condition nor a learning disability (also both may co-occur with autism), and autistic children and adults therefore often struggled to 'fit' into either mental health or learning disability services before the establishment of children's ND services and the IAS ([WG, 2016a](#)).

²⁸ As one IAS interviewee reflected, there was a large population of European economic migrants in their area and asked rhetorically: 'where are they?' Interviewees from children's ND services, the IAS and the third sector also highlighted some ethnic groups, such as Chinese, or religious groups, where it was felt autism could be stigmatised, so there was greater reluctance on the part of an adult or parents of a child to pursue a diagnosis.

3.51. Table 3.1. summarises how access to services and support differ for different groups.

Table 3.1. Assessment and diagnosis and post-diagnostic support services for different groups

	ND services covers these groups, but have weaknesses (given e.g. demand-capacity gaps)	Groups not covered by ND services and alternative services are patchy	Groups who may be missed and/or services struggle to engage
Assessment and diagnosis	<ul style="list-style-type: none"> • Autistic children and adults • Children with ADHD 	<ul style="list-style-type: none"> • Adults with ADHD • Children and adults with some NDCs other than autism or ADHD* • Children and adults with co-occurring NDCs** 	<ul style="list-style-type: none"> • Autistic girls • Children and adults from some Black, Asian and minority ethnic communities.
Post-diagnostic support	<ul style="list-style-type: none"> • Autistic adults • Parents/carers of autistic children 	<ul style="list-style-type: none"> • Children with NDC*** • Parents and carers of children with NDCs other than autism (e.g. ADHD) • Adults with NDCs other than autism (such as ADHD) or who fall short of diagnostic thresholds 	<ul style="list-style-type: none"> • Children, adults and parents and carers from some Black, Asian and minority ethnic communities.

* Some children’s ND services will assess and diagnose NDCs such as Tourette Syndrome, but others do not, and there are reported to be gaps in provision. Some NDCs, such as dyslexia and dyscalculia, are usually diagnosed within education (rather than ND) services.

** Some children’s ND services will take ‘complex’ cases, with co-occurring NDCs, but others do not. The IAS will take ‘complex’ cases but, for example, an assessment for ADHD would still need to be conducted by AMHS; and where an adult was eligible for MH or LD services, the expectation would be that those services would undertake the assessment, although the IAS could support this. In addition, other services such as MH services can be reluctant to assess or support children or adults who are waiting for an ND assessment²⁹.

*** The capacity of children’s ND services to offer post-diagnostic support varies but is typically very limited.

**** Research suggests that more boys and men than girls and women are currently diagnosed with ASD. It is thought this is mainly because females are better able to ‘camouflage’ their difficulties ([NICE, 2018a; 2020a](#)).

²⁹ This can be because where MH services attribute people’s mental health difficulties to their NDC, they are reluctant to act before a suspected NDC is diagnosed, and/or staff lack the confidence or capacity to work with people with NDCs.

Adults and children with co-occurring NDCs

- 3.52. Research suggests a high degree of co-occurrence of different NDCs ([Cleaton and Kirby, 2018](#)). On paper, children's ND services should be better placed to manage this than the IAS, which is a condition-specific service. However, in some children's ND services there are separate pathways for ASD and ADHD, and differences in the depth of staff experience and expertise mean that, in a small number of cases, interviewees from a children's ND service were clear they could not deal with complex cases; for example, as one interviewee from a children's ND service described it: 'if there is ADHD and complex behaviours, we need a joint clinic [with CAMHS], we're out of our depth, co-morbidities best sit in generic CAMHS'. Similarly, where they suspected other NDCs like Tourette Syndrome, children were referred to CAMHS for the assessment. These arrangements could cause problems where the symptoms of a potential NDC were missed or misinterpreted and, for example, a parent who completed an online response reported the frustration of their child waiting for an ASD assessment only to be put on the waiting list for an ADHD assessment once finally seen. This can delay support, add to parents' and carers' frustration and distress, and is inefficient (where children are initially assessed by the wrong service or for the wrong condition and then reassessed by another service or for another condition).
- 3.53. For adults assessed for ASD (by the IAS) but suspected by an IAS to have ADHD, interviewees from the IASs described referring them back to the GP, with the recommendation that the GP refer them to secondary AMHS.

Children and adults with autism or ADHD and co-occurring mental health difficulties

- 3.54. Research suggests a high degree of co-occurrence of NDC and mental health difficulties ([Cleaton and Kirby, 2018](#)) and also increasing rates of mental health difficulties and disorders amongst children and young people ([Sellers et al., 2019](#); [NHS Digital, 2020](#)). As an interviewee from a university reported, these difficulties may worsen the impact of an NDC such as autism or ADHD (i.e. may make the NDC more impairing) and may help explain increasing rates of diagnosis.
- 3.55. The support offered by MH services to children and adults with NDCs was not a primary focus of the review. However, the number of concerns raised by interviewees

about difficulties for people with NDCs accessing MH services was notable. This also featured in several of the accounts given by autistic adults to the review.

3.56. This co-morbidity posed challenges to both ND and MH services which sometimes work in sequence, rather than concurrently or collaboratively; for example:

- there can be a reluctance for MH services to work with or assess a child or adult who is suspected of having an NDC; as an interviewee from the IAS put it: 'diagnosis is almost a barrier to accessing mental health services³⁰'. More forcefully, another interviewee from a public service described AMHS as 'a joke', given their reluctance to work with autistic people who have mental health difficulties. MH services' reluctance to work with autistic people was reported by both ND services and some service users who contributed to the review³¹, to mean that mental health difficulties were not addressed by MH services and worsened as a consequence. Cases reported to the Children's Commissioner for Wales also confirmed the lack of support while awaiting assessments and the risk that referral for an ND assessment prevents access to other services; and
- it was also reported by a number of different interviewees from both children's ND services and IASs, that thresholds for accessing secondary MH services were so high that children and adults with, for example, mild anxiety or difficulties with emotional regulation, often linked to their ASD or ADHD, could not access therapeutic support³².

3.57. This sequential model is linked to the pressure many MH services face, which increases incentives to divert people to other services, but also, in some cases, is

³⁰ As an interviewee from an IAS explained: 'we're pushing for joint assessments [with AMHS] but it's one sided (MH aren't); they may be able to discharge back to the GP who can then refer them to us.' As another explained: ideally if someone is referred into PMHSs, and 'autism is suspected, they should be proficient to identify it could be autism, so refer to IASs, but if they are referred to secondary mental health, we can't see them, they get stuck in a mental health system that's ineffective for their needs'.

³¹ It was reported by a number of different interviewees from both children's ND services and IASs, that their clients had told them that mental health services said: 'they would not do anything until they've had our [ND] assessment'. As an interviewee from the T4CYP(2) programme put it: 'that's shocking' and 'mental health services can't exclude 10-20% of children and young [people (who have NDCs), particularly given the lengthy waiting lists for ND services.'

³² Interviewees from the IAS also reported that there were gaps between PMHSs, typically offering short term help such as counselling or cognitive behavioural treatment, and secondary MH care services like CMHTs, which some autistic adults were felt to fall between.

reported to be linked to a lack of confidence and/or training in undertaking diagnostic assessments and/or supporting people with NDCs, meaning that (as outlined above) services can become overly reliant upon the expertise of individual clinicians. It can also reflect the difficulties in identifying the cause of someone's difficulties, and therefore the most appropriate service to support them; as a researcher interviewed for this study described it:

'Research has looked at anxiety and autism and identifies two kinds – one that is linked to the autism and one that is a more general issue and is basically the same as everyone (with anxiety) experiences – so not all anxiety is linked to people's autism [but] too often clinicians [in mental health services] just work from their own experience [rather than looking to the research evidence]'.³³

- 3.58. When considering co-occurrence, it is also notable that the IAS does not assess people who are already accessing MH services, although it might support a diagnostic assessment undertaken by MH services, and many of those accessing the IAS also have mental health difficulties³³.
- 3.59. Despite the widespread concerns, positive examples were also given, most notably the IASs' work with adult MH services around joint assessments, although this is not without its challenges. Similarly, as an interviewee from an adults' ADHD service described it, while the adult ADHD service does not have the resources to support those with ADHD and mental health difficulties, they have good links with AMHS who have the resources needed.

Those whose difficulties fall short of diagnostic thresholds

- 3.60. Those with trait disorders who, as an interviewee from the T4CYP(2) programme described it, have very real needs, but which are 'not bad enough to get a diagnosis', or, as another interviewee from a children's ND service put it: 'have got a lot of

³³ As the IAS Guidelines outline: 'the service will provide diagnostic assessment for those aged 18 and over who are not eligible for diagnostic assessment from LD or MH services due to eligibility exclusion' (Autism Wales, 2020, p.6). Nevertheless, as an interviewee from the IAS put it: 'the idea we don't work with people with mental health difficulties is wrong'. They estimated 80-90% of those diagnosed have had mental ill health at some point and they described 'picking up' a lot of people with trauma, complex OCD or 'complex lives', who do not meet thresholds for social care or secondary MH services.

everything, but not enough of anything', can be assessed by ND services, but can struggle to access support. The concern, as an interviewee from an ND service put it, was that 'there's nothing for them...they can't access specialist provision' and family support services struggled to meet their needs. It was also observed that this created perverse incentives for parents and carers to focus upon the negative and all their child's problems, to increase their chance of meeting diagnostic thresholds.

- 3.61. Similarly, in relation to adults, an interviewee from the IAS highlighted the lack of support for adults who do not meet diagnostic thresholds. As they vividly put it: 'where's the service for people who have crappy lives and need long term support, but who don't meet diagnostic thresholds for a label?' In these cases, the focus of IASs was reported to be primarily upon signposting and referrals (where eligibility criteria were met) although, while outside their remit, they might also ask 'support workers to see what we can do'.

Transitions between services

- 3.62. The transition from children's ND service waiting lists to IAS waiting lists was a source of friction between some children's ND services and IASs and the guidance issued by the Welsh Government, outlining principles, was reported to have not resolved the difficulties. One interviewee from an IAS reported that they felt the pandemic and pressure both children's ND services and the IAS faced had made it harder to resolve the tensions, because the two services no longer regularly met, as they were both 'overwhelmed'.
- 3.63. While it was accepted that, in many cases, the IAS might be a more appropriate service to diagnose a young person approaching their 18th birthday (given their experience and expertise in working with adults), a transfer of a young person from the children's ND waiting list to the IAS was reported to be difficult because:
- criteria for accepting a referral could differ between children's ND services and IASs and information supporting the referral might, for example, be out of date because of the time that had elapsed³⁴, so there was some reluctance on the part

³⁴ Gathering additional information in this type of case could also be difficult.

of IASs to automatically accept a young person on an ND waiting list approaching their 18th birthday; and

- depending on the age when a young person made the transition, they could end up waiting for longer, because they could wait on both a children's ND waiting list and then again on an IAS waiting list, unless they were expedited by the IAS.

3.64. The question of expediting those young people who transferred from a children's ND to an IAS waiting list was a thorny one. As one interviewee from a children's ND service put: 'it's not fair to make them [young people] wait again on a new list'. In contrast, as an interviewee from an IAS put it, expediting those transferred from a children's ND to an IAS waiting list meant 'disadvantaging' those already on the IAS waiting lists.

3.65. The transitions of young people with ADHD from ND services or CAMHS to AMHS were also reported to be potentially difficult ([Young et al., 2021](#)). This reflects wider challenges linked to the transition from children's services to adults' services ([WG, 2020b](#)), linked to factors such as:

- poor communication and weakness in transition planning;
- cultural, structural and organisational differences between children's and adults' services; and
- the anxieties that young people and their families can feel as they move from a service they know and often trust, to something new, often at a point in their lives where they are making other transitions (for example, from school to college or work, and from childhood to adulthood), which leave them feeling particularly vulnerable.

3.66. In response, the Welsh Government introduced new guidance on transition and handovers from children's to adults' health services in 2022 ([WG, 2022a](#)).

3.67. Finally, it is important to note that the lack of post-assessment support offered by many children's ND services (outlined above) has lessened the impact of differences between children's ND services and the IAS. The lack of support means many children are discharged from ND services and therefore do not make a transition

from children's ND services to the IAS³⁵. However, it was observed by an interviewee from T4CYP(2) that, if the capacity of children's ND services to offer support was increased, more children would probably be supported by children's ND services and might make a transition at 18, meaning that the differences between the two services, and the lack of an equivalent service to the IAS for adults with ADHD, would pose more of a challenge.

ND services' Welsh language offer

- 3.68. Only Betsi Cadwaladr and Hywel Dda's children's ND service and IAS reported having an active offer of Welsh language provision. Children's ND services and IASs in other areas generally reported providing most material bilingually but relied upon people to actively request Welsh language provision. It was reported this happened rarely, if at all, although there was some anxiety within some services about how they would manage this request, were it made³⁶. This reflected what one interviewee from a third sector described as a 'wider issue' about health services' Welsh language offer.

³⁵ It was also reported that some young people who were diagnosed by children's ND services were not referred or signposted to the IAS so they could access support when they reached the age of 18.

³⁶ The IAS has an agreement that if a request were made, a Welsh language speaker from another service would undertake the assessment.

4. Options for developing ND services and the wider system

Key goals and principles

4.1. Any redesign of ND services and reform or transformation of the wider system should be guided by goals and principles. Given the issues outlined in section 3, the review identifies three overarching goals for reform; these are ensuring:

- 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.

4.2. The review also identifies that the following principles should underpin a long-term vision for ND services:

- a whole systems approach with, for example, a focus upon early help and enhanced support to help improve people's and their families' well-being and to help reduce demand for specialist services; the active involvement of a range of sectors, including health, education, social care and the third sector, to maximise capacity and better address what is important to and for people; and a lifelong (cradle to grave) approach³⁷;
- moving, as far as possible, to a more person-centred, needs-led approach, rather than being diagnosis-led³⁸, which is better able to handle both complexity where, for example, people have co-occurring difficulties or fall short of diagnostic thresholds (as advocated by the T4CYP(2) programme) and also the diversity of strengths and difficulties people with NDC experience, and which

³⁷ A contributor to the Working Group noted that the language needed to be chosen carefully; for example, they noted that a lifelong (cradle to grave) approach could be misinterpreted as meaning 'they can have support at all times on a lifelong basis, rather than accessing services for shorter periods of time, dipping in/out as needed'.

³⁸ In some cases, such as prescribing ADHD medication, a diagnosis will remain essential.

has 'no wrong door' (as advocated by the Children's Commissioner for Wales and others); and

- reform of ND services and the wider system should be informed by evidence, done co-productively, working with service users and services, 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.

4.3. These goals and principles were discussed and broadly endorsed by the review's Working Group. Members of the Working Group were asked if they agreed (or not) with the goals, using a five-point scale, ranging from 1 = Strongly Disagree; 2 = Disagree; 3 = Neither Agree or Disagree; 4 = Agree; and 5 = Strongly Agree. The mean response for each of the three goals were 4.9, 4.6 and 4.4 indicating a high level of agreement. There was somewhat less agreement when asked if the goals were comprehensive enough, with a mean score of 3.5, but no clear consensus on what other goals were required. In relation to the three principles, the mean response to each was 4.6, 4.6 and 4.4, indicating a high level of agreement. However, questions were raised about the precise wording of the goals and principles³⁹.

4.4. Agreeing the goals (and principles) was reasonably straightforward but, as anticipated, articulating how to achieve them was more challenging. As one member of the Working Group summed it up: 'it is the how that is really complex'. Table 4.1. (below) outlines the key actions identified by the review to contribute to realisation of these three goals. It is founded upon two key messages from the review:

- if there was an easy solution, services would have already identified it and solved the problems and, as two contributors to the Working Group summed it up: 'just throwing money at it won't work on its own' and 'a whole system approach is required as part of a long-term ND strategy'; and

³⁹ For example, in relation to the second goal which was originally phrased as: 'swifter access to a specialist ND assessment for *those who need it*', one contributor commented: 'when you say diagnostic assessments for those who need it - how are you defining and deciding on that need?' While, in relation to the principle advocating a whole systems approach, one member of the Working Group commented: 'need to be wary of idea of lifetime. People often assume this means they can have support at all times on a lifelong basis, rather than accessing services for shorter periods of time, dipping in/out as needed'.

- demand-capacity gaps across the system are a challenge (and cannot be wished away) but are not the only problem that needs to be addressed.

- 4.5. Therefore, as the table illustrates, a range of actions across the system have been identified by the review (including the Working Group). No single action is likely to be transformative – there is no ‘silver bullet’ – but the net (or cumulative) effect of changes across the system could be transformative of people’s experiences and outcomes. The contribution made by different actions is outlined in figure 4.1.
- 4.6. These actions are ambitious, but not new, in the sense that they are informed by work in this area including, for example, the visioning undertaken by the T4CYP programme and NAT and a range of existing policies (outlined in table 4.1). Indeed, a key challenge will be ensuring that policy on paper translates to changes in practice and, as one member of the Working Group put it: ‘we should start to implement the policies that exist across Wales’ and as another put it: ‘there are plenty of policies ... why aren't they being implemented?’ Equally, a focus upon actions embedded in existing policy also means that funding to take forward these actions should be available in the system.
- 4.7. The actions and principles, including examples identified by the review⁴⁰, and potential barriers to implementation, are discussed in more detail in the remainder of the section. This is then followed by a discussion of options for further developing ND services, where there is less consensus.

⁴⁰ This addresses the objective ‘to identify existing good practice and consider how it could be integrated into a national approach’.

Table 4.1. Summary of the goals, actions and principles identified by the review

Goals	(i) 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.	(ii) swifter access to a specialist ND assessment for those who would benefit from one.
	(iii) equity of access to services and support irrespective of age, gender, ethnicity or NDC.	
Actions	<ul style="list-style-type: none"> • 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. 	<ul style="list-style-type: none"> • Diffusing the demand across the system rather than concentrating demand upon ND services. This should focus upon (i) swifter access to early help and support when people have, or are suspected to have, an NDC (discussed in column 1), which may reduce demand; and (ii) diffusing the demand for an ND assessment for children and for adults (e.g. by developing capacity to undertake formulations; ensuring diagnostic assessments are undertaken in MH and LD services when appropriate (as outlined in section 3, lack of time is currently a key barrier to this, so increasing capacity in these services will be important); and professionals (who are not part of the ND team) can contribute to the assessments (e.g. by undertaking observations).

<ul style="list-style-type: none"> • Ensuring there is ‘no wrong door’ to access extra help, 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 support. • Actively reaching out to engage under-represented groups (such as children and adults from Black, Asian and minority ethnic communities). • Ensuring that services are offered in Welsh and English. • The Welsh Government, working with partners such as the NAT and third sector, should define a national support offer for children and adults with NDC and their parents or carers, based upon the current NICE guidance and standards such as the ALN and Autism Codes of Practice. This would outline the support that should be offered across Wales and also identify which types of support would require a diagnostic assessment to confirm that someone had autism and/or ADHD, and which could be 	<ul style="list-style-type: none"> • Increasing the capacity of ND services in the short term, by tackling issues and constraints in the diagnostic assessment process (e.g. by improving the quality of information that informs an ND assessment through the new digital Neurodiversity Wales Shared Platform and increasing funding for ND services to address constraints, such as shortages of administrative support and inadequate accommodation or IT equipment. • Increasing the capacity of ND services in the medium term, by restructuring staff teams and increasing funding to build stronger and more diverse ‘core’ teams with, for example, more therapists, specialist nurse practitioners and assistant psychologists to ease recruitment (as these professions would be easier to recruit) and diversify skills, so that ND services have the right staff with the right skills and teams are better able to handle ‘complex’ cases. This should also offer more opportunities for staff progression within services. • Enhancing the sustainability of ND services through action to address demand-capacity gaps (outlined above); more intelligent performance management of services, to shift to a
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	<p>accessed without a formal diagnosis. In considering what types of support should require a diagnosis, the review advocates moving toward a model in which access to support, depends more upon needs, rather than whether thresholds for specific diagnoses are met.</p> <ul style="list-style-type: none"> • Actions to enhance access to support should be supported by the ALN Transformation Programme with, for example, its focus upon the importance of identifying needs early and ‘putting in place timely and effective interventions’ (WG, 2020a) . This should include actions to decouple access to support from a diagnosis; for example, building capacity to undertake formulations⁴¹ to identify interventions to address a child’s or adult’s difficulties, without requiring a full ND assessment (see e.g. the Community Embedded Team in Gwent and the CAMHS In-Reach programme). 	<p>broader suite of measures that includes, but is not limited to, waiting times; creating more opportunities for progression within services; and longer term funding and staffing commitments, to ensure that, for example, staff are on permanent, rather than fixed term contracts, and their pay is commensurate with their roles and responsibilities.</p> <ul style="list-style-type: none"> • Action by LHBs to ensure that there are clear pathways for diagnostic assessment for NDC such as adults suspected to have ADHD, and that relevant professionals in, for example, health, social care, education, employment services and the third sector are aware of the local pathways and how to access services. • Where LHBs and RPBs identify gaps or weaknesses in services, such as provision for adults with ADHD, new models should be piloted, monitored and evaluated.
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⁴¹ There are differing approaches to formulation. It may, for example, adopt a ‘biopsychosocial’ model that focuses upon identifying the range of factors contributing towards the child’s or adult’s presentation, such as an NDC, but also, for example, their home life and education, rather than determining the symptoms the individual has, how long the symptoms have persisted, and how their life is being affected, and then evaluating if those symptoms match the criteria outlined in, for example, the Diagnostic and Statistical Manual of Mental Disorders, in order to make a diagnosis.

	<ul style="list-style-type: none">• The Welsh Government and/or NAT should commission a review to consider the rationale for the differences in the support offered by each IAS. This should help inform RPBs decisions about how best to deliver a national support offer.• Increasing the capacity of children's ND services to provide post-diagnostic advice and support to children, families and services (e.g. schools), by addressing demand-capacity gaps to free up clinicians' time (see actions in column 2) and extending services through e.g. recruitment of specialist nurses able to offer post-diagnostic advice and support in areas like sleep and behaviour (moving them closer to the IAS model), may be important to deliver a comprehensive national support offer.• A range of other services are also likely to deliver elements of the national support offer. Tackling demand-capacity gaps facing targeted and specialist support services like autism outreach, EP and MH services (e.g.	
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	<p>through workforce development and greater funding⁴²) is likely to be important, so that they more have time to help when people (including staff in other services) turn to them for advice or support. This should help ensure that there is easy access to expertise across the system.</p> <ul style="list-style-type: none">• Ensuring adequate funding for the third sector (a key source of support for children, adults and families), focusing upon areas where the third sector can provide support more cost-effectively than public services, is also likely to be important to delivering a comprehensive national support offer.• Where LHBs identify gaps or weaknesses in services, such as provision for the parents and carers of children with ADHD, new models or services should be piloted, monitored and evaluated.• Enhancing collaboration between services (e.g. through co-location, joint training and greater opportunities for dialogue to build understanding and trust). This should	
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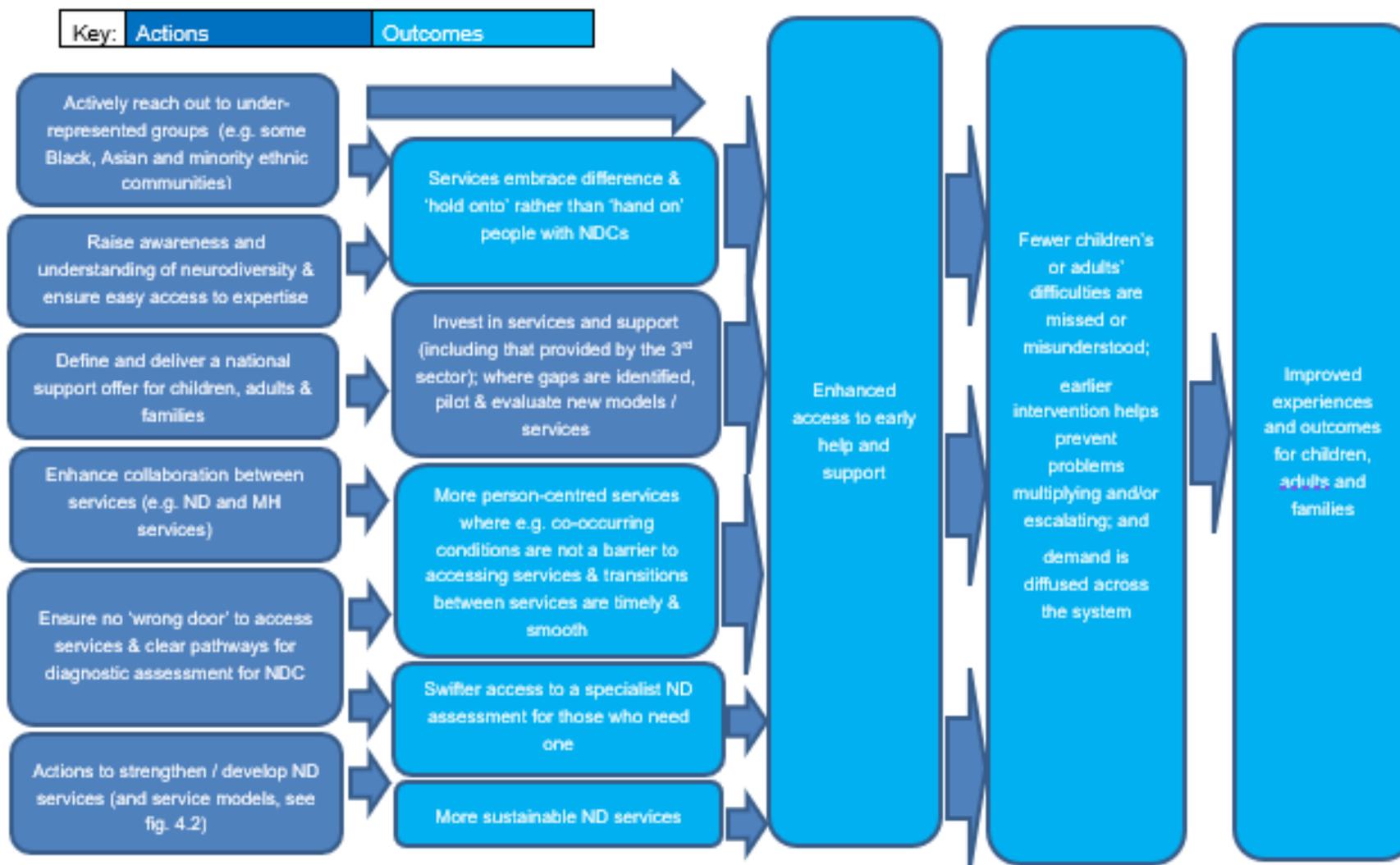
⁴² Assessing the demand-capacity gaps in the wider workforce is beyond the scope of this study. However, reviews such as Mind Over Matter ([NaFW, 2018](#)) and Workforce Planning of Special Educational Needs (SEN) Specialist Services ([WG, 2015b](#)) have considered the issues and made recommendations.

	<p>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 mental health condition (and help ensure that an NDC is not a barrier to accessing MH services) and help ensure that transitions between services are smoother.</p> <ul style="list-style-type: none"> • Alongside awareness raising work and steps to improve collaboration, 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. 	
<p>Principles</p>	<ul style="list-style-type: none"> • A whole systems approach with equal emphasis upon access to support and a diagnostic assessment, the active involvement of a range of sectors, including health, education, social care and the third sector, to maximise capacity and better address what is important to and for people (which will require strong leadership at national (Welsh Government and the NAT), regional (RPB) and operational (service) levels); and a lifelong (cradle to grave) approach; • Moving, as far as possible, to a more person-centred, needs-led rather than diagnosis-led, approach which is more responsive (e.g. providing support that people can dip in and out of as their needs change), better able to handle complexity and which has ‘no wrong door’; and • An evidence-informed and co-productive approach to reform, subject to ‘intelligent’ monitoring and evaluation. 	

Supporting Policy

- The ALN Transformation Programme, which aims to improve support for learners with ALN by improving the planning and delivery of support for learners from 0 to 25 with ALN and focusing upon the importance of identifying needs early and ‘putting in place timely and effective interventions’ ([WG, 2020a](#)).
- The Framework on Embedding a Whole-school Approach to Mental Health and Emotional Well-being, which aims to improve the mental health and emotional well-being needs of all children and young people by ‘promoting a positive cultural environment in schools’ ([WG, 2021c](#)).
- The Nurturing, Empowering, Safe and Trusted (NEST) Framework, which aims to ensure that ‘early help and the right help’ is ‘available at the right time’ ([NHS Collaborative, 2021b](#)).
- The Social Services and Well-being (Wales) Act 2014, which aims to improve the well-being of people who need care and support, and carers who need support and which includes, for example, requirements to provide ‘relevant, clear information and advice about all of the services available in the area’ through bilingual IAAs and also requirements for LAs, health boards and NHS trusts to work together to ensure better integration of health and social care ([WG, 2019a](#)).
- The Health and Social Care Regional Integration Fund, which supports the effective delivery of integrated services in Wales ([WG, 2022b](#)).
- [The Well-being of Future Generations \(Wales\) Act 2015](#), with its focus on collaboration, prevention and early intervention.
- A Healthier Wales: Our plan for Health and Social Care ([WG, 2021c](#)) with its vision of a ‘whole system approach to health and social care’ and ‘new models of seamless local health and social care’, ‘with support tailored to the needs and preferences of that person, even if it is made up of services delivered by several different providers’ (ibid., p.10).
- Together for Mental Health, which aims (among other things) to improve early intervention and treatment services ([WG, 2012](#)).

Figure 4.1. Roadmap for enhancing access to early help and support and ensuring equity of access



4.34. The following paragraphs discuss the rationale for the proposed actions outlined in table 4.1., in more detail. Examples of practice which exemplify these approaches, and policies which support them, are also outlined.

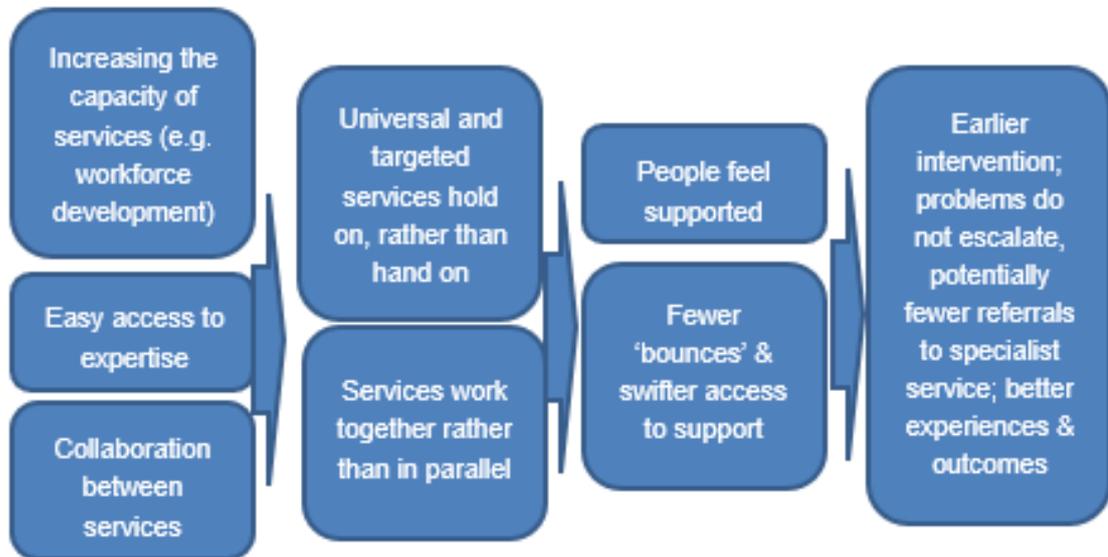
Proposed actions to ensure swifter access to support

4.35. A key message from the review is that access to support should be seen equally as important as access to a diagnosis. However, at present:

- attention and resources are directed to diagnosis at the expense of support;
- too often access to support depends upon a diagnosis, an issue discussed further below, and the support available is determined by the structure and organisation of services, rather than people's needs (so for example an autistic adult can access the IAS, but there is no equivalent service for an adult with ADHD, who may have similar needs); and
- the capacity of services that should be offering support, is constrained by both levels of funding and staff confidence and skills in supporting neurodiverse children and adults.

4.36. In response, a national support offer is proposed. Delivery of this will require a range of actions and changes illustrated by figure 4.2. and discussed further below.

Figure 4.2. Actions to ensure swifter access to support and deliver a national support offer



Decoupling access to support from a diagnosis

- 4.37. As outlined in section 3, the current service model based upon diagnosis has important limitations. It means that intervention is often dependent upon a costly assessment, which may not be undertaken until many years have passed. As one contributor to the Working Group put it: ‘lives don’t need to be put on hold whilst they are waiting for a possible diagnosis’ and during this time, other problems, such as mental health difficulties and exclusion from school, may occur. Failure to intervene early can lead to other problems multiplying and/or escalating and impact upon both children and adults (and their families) and services (as more complex difficulties can be more costly to assess and address⁴³). In addition, this approach:
- focuses upon a child’s or adult’s difficulties (a ‘deficit’ model) rather than building upon their strengths, upon treatment and changing the child or adult rather than, for example, changing society; and

⁴³ For example, as a contributor to the Working Group observed, the failure to intervene earlier meant that the ‘assessments [they undertake are] much more complex, difficult and longer’, as other difficulties escalated.

- means access to support depends more upon whether thresholds for specific diagnoses are met (a binary yes/no approach, which is unhelpful as ‘neurodevelopmental conditions are on a scale’), than upon a child’s or adult’s need (as need does not start/stop at diagnostic boundaries) ([NHS Collaborative, 2021a](#)).

4.38. Therefore, as the T4CYP programme’s Vision for Neurodevelopmental Support and Services in Wales puts it: a ‘diagnosis is still useful but on its own presents an overly narrow and scientifically outdated concept of ND conditions.’ In its place, the vision proposes a ‘balanced approach’, that considers medical⁴⁴, bio-psychosocial⁴⁵ and social⁴⁶ aspects, and an approach where ‘interventions ... start early with tailored profiles that build on a child or young person’s strengths and offer strategies to target difficulties’ rather than waiting for a diagnosis ([NHS Collaborative, 2021a, p.6](#)). As outlined below, decoupling access to support from a diagnosis by, for example, increasing capacity and confidence in universal and targeted services, like education and family support services, is an important element of the proposed strategy to ensure swifter access to support.

Defining a national support offer for people with autism and/or ADHD

4.39. Table 4.2. outlines the different types of support that should be offered to children, young people or adults with autism or ADHD and their parents or carers. It highlights the range of potential support required and the different services, including ND services, other health, education, social care services and also the third sector, which should – or could – be involved in delivering support. As outlined in paragraphs 4.84-4.85, it is recommended that while this should be the national support offer, there is scope for regional determination of how best to deliver it and, for example, the balance between support for parents and carers provided by ND

⁴⁴ Under the medical model, ‘neurodevelopmental conditions are impairments of the growth and development of the brain and/or the central nervous system. Diagnosis can lead to treatment to “change” the child or young person’s symptoms’.

⁴⁵ The bio-psychosocial model ‘considers neurodevelopmental conditions in terms of biological, psychological and social factors’.

⁴⁶ The social model has a ‘focus on skilling up society to adapt around people with neurodiverse conditions, rather than focus solely on trying to change the young person through treatment for a diagnosis.’ ([NHS Collaborative, 2021a, p.6](#)).

services and by the third sector. The support offer draws primarily upon a number of quality standards or codes of practice⁴⁷, including:

- [NICE Guidance: Autism spectrum disorder in under 19s: support and management \(NICE, 2017\)](#);
- [NICE Guidance: Autism spectrum disorder in adults: diagnosis and management \(NICE, 2012\)](#);
- [NICE: Autism Quality Standard \(NICE, 2014\)](#);
- [NICE Guidance: Attention deficit hyperactivity disorder: diagnosis and management \(NICE, 2018a\)](#);
- [The Welsh Government Code of Practice on the Delivery of Autism Services \(WG, 2021a\)](#)
- [The Welsh Government ALN Code of Practice \(WG, 2021e\)](#); and
- The [Welsh Government Transition and Handover Guidance \(WG, 2022a\)](#).

4.40. Although as outlined above, the review proposes decoupling support from a diagnosis, where appropriate, assessing when this is appropriate, is not always clear. While some type of support, such as post-assessment support or medication for ADHD are clearly tied to a diagnostic assessment, others, such as development of an IDP or access to employment support, are not. It is recommended that this be considered as part of determination of the national support offer.

⁴⁷ Additional data was provided by interviewees from ND services.

Table 4.2. The support offer for children, young people or adults with autism or ADHD and their parents or carers

Types of support	Who should deliver this
<p>Post assessment advice and information</p> <ul style="list-style-type: none"> • A follow-up appointment should be offered within six weeks of a diagnostic assessment. This should include a ‘structured discussion’ with people (and their families or carers as appropriate) about how their diagnosis could affect their life; ‘provision of information and guidance on the core features of the diagnosis’ and ‘offer of signposting to relevant support and further information’* 	<p>The service undertaking the assessment (e.g. ND service / IAS / AMHS, LD or ADHD services)</p>
<p>Development of a care or treatment plan and, if appropriate, Individual Development Plan (IDP)</p> <ul style="list-style-type: none"> • For children: ‘a profile of the child’s strengths and difficulties should be produced’, which should include any advice and/or recommendations that flow from the assessment. • For children and adults, there should be a ‘comprehensive, holistic and personalised plan that is informed by the full diagnostic assessment and the individual needs of the...person [such as ‘psychological, behavioural and occupational or educational needs’], and recognises their strengths’, which also takes ‘into account the needs of the family, partner or carer(s).’ • For children, adults and/or parents and carers, where a social care assessment is indicated, ‘assessments need to be carried out in a way that is appropriate for the person being assessed’ and social care assessments must ‘ensure that people’s well-being is reflected in any assessment’. 	<p>The service undertaking the assessment (e.g. ND service / IAS / AMHS, LD or ADHD services)</p> <p>Social care</p>

<ul style="list-style-type: none"> • For children and young people identified as having ALN, developing and regularly reviewing an IDP, which sets out a description of a child or young person’s ALN, the additional learning provision called for by their LD or disability, and other associated information. • Those involved ‘in providing support to children and young people with ALN are expected to work together in the best interests of the child or young person’ to, for example, ‘improve communication between the family, school and professionals’, ‘streamline services to avoid duplication’ and ‘clearly identify which agency will be responsible for providing and funding each element of provision’. 	Education
<p>(If required) Psychosocial interventions⁴⁸ delivered by a trained professional.</p> <ul style="list-style-type: none"> • For autistic children, social communication interventions to address the core features of autism. • For autistic adults, social learning programmes based on developing social interaction. • For children and adults with ADHD, ‘a structured supportive psychological intervention focused on ADHD’ and ‘regular follow-up either in person or by phone’. • For adults with ADHD, ‘when non-pharmacological treatment is indicated’ or ‘whose symptoms are still causing a significant impairment in at least one domain’ despite medication, offer a course of cognitive behavioural therapy (CBT) to address difficulties such as ‘social skills with peers’, ‘problem-solving’, ‘self-control’, ‘active listening skills’ and/or ‘dealing with and expressing feelings’. 	ND service / IAS / AMHS / LD Service EP, SLTs ALNCo Third sector

⁴⁸ ‘This describes social-communication interventions to address the core features of autism in children and young people, including play-based strategies with parents, carers and teachers to increase joint attention, engagement and reciprocal communication in the child or young person’ ([NICE, 2014](#)).

<p>(If required) Medication for children aged 5 years and over, young people and adults with ADHD (in line with NICE Guidelines)</p> <ul style="list-style-type: none"> • ‘After titration and dose stabilisation, prescribing and monitoring of ADHD medication should be carried out under Shared Care Protocol arrangements with primary care’. • ‘A healthcare professional with training and expertise in managing ADHD should review ADHD medication at least once a year and discuss with the person with ADHD (and their families and carers as appropriate) whether medication should be continued’. 	<p>ND service / CAMHS / AMHS / Primary Mental Health Service (PMHS)</p>
<p>(If required) Interventions for behaviour that challenges</p> <ul style="list-style-type: none"> • Assessment of the child or adult and development of a ‘care plan with the child or young person / adult and their families or carers that outlines the steps needed to address the factors that may provoke behaviour that challenges’. • If required ‘psychosocial interventions for behaviour that challenges’. • If required, ‘pharmacological interventions for behaviour that challenges’. 	<p>Paediatrician / Psychiatrists in CAMHS / AMHS / LD service Behaviour support teams/ EP/ ALNCo Third sector</p>
<p>Interventions for life skills</p> <ul style="list-style-type: none"> • For autistic children and adults, ‘support in developing coping strategies and accessing community services, including developing skills to access public transport, employment and leisure facilities.’ 	<p>ND service / IAS and the third sector Schools / ALNCo</p>

<p>Employment support</p> <ul style="list-style-type: none"> For autistic adults without a learning disability or with a mild learning disability, and adults with ADHD who are having difficulty obtaining or maintaining employment, provide access to an individual supported employment programme. 	<p>Mainstream and specialist employment support programmes (e.g. CfW; Engage to Change; IAS; third sector)</p>
<p>Advice and interventions for sleep problems</p>	<p>ND service / IAS / third sector</p>
<p>Dietary advice and interventions</p>	<p>Dietitian / MH specialist / paediatrician third sector</p>
<p>Interventions to support coexisting mental health, learning disabilities or medical problems</p> <ul style="list-style-type: none"> ‘Where autistic people [or people with ADHD] have co-existing conditions, including mental health and/or learning disabilities, pathways should be in place to enable access to support services which can meet their additional support needs in relation to autism [and/or ADHD]’. 	<p>Local Primary Mental Health Support Service (LPMHSS) / CAMHS / AMHS / SLT and other health services,</p>

<ul style="list-style-type: none"> • When a person with ADHD or autism has a coexisting condition, ND services should (with consent) contact the service supporting them to explain: <ul style="list-style-type: none"> - ‘the validity, scope and implications of a diagnosis of ADHD [or autism] - how ADHD [or autism] symptoms are likely to affect the person's behaviour (for example, organisation, time management, motivation) and adherence to specific treatments - the treatment [or care] plan and the value of feedback from healthcare professionals’. 	<p>such as learning disability teams / third sector</p>
<p>Assessment and support for families, partners and/or carers</p> <ul style="list-style-type: none"> • Services should talk to families or carers of people with ADHD and/or autism about ‘how the condition affects themselves and other family members and discuss any concerns they have’. • ‘Provide information about, and facilitate contact with, a range of support groups’. • ‘Offer information, advice, training and support to families, partners and carers if they: <ul style="list-style-type: none"> - need help with the personal, social or emotional care of the family member, partner or friend or - are involved in supporting the delivery of an intervention for their family member, partner or friend (in collaboration with professionals)’. • For parents and carers of children under the age of 5 with ADHD, ‘offer an ADHD-focused group parent-training programme...as first-line treatment’. • For parents and carers of children aged 5 and over with ADHD, provide information and support, including information and advice on: <ul style="list-style-type: none"> - ‘education and information on the causes and impact of ADHD 	<p>ND service / IAS / social services (including family support services) / third sector</p>

<ul style="list-style-type: none"> - advice on parenting strategies⁴⁹ - with consent, liaison with school, college or university’. • The review suggests support should be offered online (e.g. through websites and the Neurodiversity Wales Shared Platform), through telephone and/or video advice lines; and one to one or group based advice and support sessions. 	
<p>Education provision for children and young people aged 0-25</p> <ul style="list-style-type: none"> • School should implement a whole-school approach to mental health and well-being. • Education settings should ensure early identification if a child or young person with autism or ADHD has ALN (or other needs that fall short of a ALN) and offer a ‘graduated response’, with for example, additional learning provision (ALP), ranging from school-based, through ‘targeted provision’ (e.g. ALP delivered by specialist staff such as SLTs) and ‘specific provision’ ‘(such as a placement in a special school) for those children [or young people] with ALN who have more complex needs’, with the ALP outlined in an IDP and regularly reviewed. • ALP could include interventions outlined in the Welsh Government guides: Support for Children and Young People with Autistic Spectrum Disorder (ASD) in educational settings (WG, 2019e) and/or Support for children and young people with Attention Deficit Hyperactivity Disorder (ADHD) in educational settings (WG, 2019f). • ND services may provide advice to educational settings (e.g. to address stigma or myths about NDCs such as ADHD; a person’s strengths and also difficulties, the care or treatment plan, reasonable adjustments and environmental modifications). 	<p>Schools, LA advisory services / ND services / IAS</p>

⁴⁹ An interviewee from a voluntary sector organisation reported that it was important that the effect of programmes tailored to autism or ADHD were much greater than more generic parenting programmes like Triple P or Webster Stratton, and some parents and carers expressed frustration at what were seen as unhelpful generic programmes. However, an assessment of the efficacy of different parenting programmes was beyond the scope of this study.

<p>Ensuring smooth transitions to adult services</p> <ul style="list-style-type: none"> • ‘If continuing treatment is necessary’ services should ‘make arrangements for a smooth transition to adult services and give information to the young person about the treatment and services they may need’. • ‘Transitions must be carefully planned in advance to make them as seamless as possible’. • There should be ‘a Transition and Handover named worker’, ‘to support the transition and handover of healthcare for every child and young person’. • ‘Every child and young person transferring from children to adults’ services will have a documented Transition and Handover Plan (THP), or equivalent’, ‘co-produced in consultation with the child or young person, family, carers and health professionals with support of the Named Worker’ and including ‘information about what is important to them [the young person], the care and treatment required and the timeline’. 	<p>ND service / IAS / CAMHS / AMHS (where accessing CAMHS)</p>
<p>Advice and training to other services</p> <ul style="list-style-type: none"> • ‘Raising awareness of autism [and ADHD] in the community’. • ‘Workforce learning and development’ (undertake a workforce training needs analysis to inform training plan). 	<p>ND service / IAS / NAT / third sector Schools/education</p>

**Irrespective of whether diagnostic thresholds of ADHD or autism are met*

Sources: [NICE, 2012](#); [NICE, 2017](#); [NICE, 2018a](#); [WG, 2021a](#); [WG, 2021f](#)https://www.nice.org.uk/guidance/cg142/chapter/recommendations_-_care-pathway; [WG, 2022a](#)

Increasing the capacity of universal and targeted services

- 4.41. As outlined in section 3, support should be ‘everybody’s business’ and as one contributor to the Working Group observed: ‘access to services doesn’t [only] have to come through [the] IAS’ (or children’s ND services). This is illustrated by table 4.2. (above) which highlights the role played by a wide range of universal and targeted services such as education, Families First, PMHS, social services and the third sector in providing access to support before and after a diagnostic assessment.
- 4.42. The capacity of universal and targeted services and the third sector to support people with NDCs (whether diagnosed or not) varies. This reflects both:
- the overall level of demand services face, relative to their capacity, which can create incentives to raise thresholds for eligibility and seek to divert requests for support to other services; and
 - staff’s skill and/or confidence in working with people with NDCs which, where lacking, can create incentives for services to divert or refer people with NDCs to other, often more specialist, services, such as ND services, for assessment and/or support, rather than embracing people’s differences and working with them (an approach described as ‘holding on’ rather than ‘handing on’).
- 4.43. Action is therefore required to address demand-capacity gaps elsewhere in the system (which cannot simply be wished away or ignored) and workforce training and development to ensure services have the capacity (in terms of time, knowledge and skills) and the confidence to work with and support neurodiverse children and adults. Current policies that support this include, for example:
- the ALN Transformation Programme, which aims to improve the planning and delivery of support for learners with ALN aged 0 to 25 and focuses upon the importance of identifying needs early and ‘putting in place timely and effective interventions’ ([WG, 2020a](#)); and
 - Together for Mental Health, which aims (amongst other things) to improve early intervention and treatment services ([WG, 2012](#)).

Pembrokeshire's Early Help Team

Pembrokeshire's Early Help Team aims to provide access to early help and support for children, young people and families, by offering training and support to families and also those services, such as schools, working with them. The team includes specialist teachers for ND conditions, such as autism and specific learning difficulties; advisory teachers for well-being and for complex needs; and speech and language teaching assistants; and is reported to have good links to the children's ND service.

Adapted from [Pembrokeshire CC, 2022](#) and interviews

4.44. Specific actions identified by the review to complement these could include:

- Developing a cross sectoral plan to embed neurodiversity in training and professional development programmes for staff in a range of universal and targeted services. This plan should cover, for example, education, health, social care and the third sector, to ensure a consistent and joined up approach, given the expectation that training and professional learning would be delivered by a range of different services, including for example the NAT⁵⁰, ND services, CAMHS, EPs and LA inclusion services⁵¹.
- The training and professional development offer should be informed by work to identify universal skills and knowledge (what all staff need to know); advanced skills and knowledge (what some staff need to know); and specialist skills and knowledge (what specialist staff need to know) (see e.g. [WG, 2015a](#));
- increasing funding for ND services to increase their capacity to provide advice and training to other services (as, for example, the IAS currently does); and
- providing easy access to expertise, when staff need advice or support (see e.g. the CAMHS In-Reach model), discussed further below.

⁵⁰In 2021/21, the team provided training to emergency services, the Children and Family Court Advisory and Support Service Cymru and the Department for Work and Pensions ([Autism Wales, 2022](#)).

⁵¹ See for example the evaluation of the CAMHS In-Reach Pilot Programme which explored the training ecosystem ([WG, 2021d](#)).

The CAMHS In-Reach training plus consultation model

The CAMHS In-Reach Pilot Programme developed a model to build school staff's skills and confidence by offering both training and access to specialist advice, liaison and support. The training offer focused upon promoting staff members' and pupils' mental health and well-being and covered a range of areas, including NDCs such as autism and ADHD. It was offered at different levels (reflecting universal, advanced and specialist skills and knowledge that staff performing different roles needed) through a mix of online and face to face delivery.

As the evaluation of the pilot programme identified through consultations with individuals or groups of staff, CAMHS In-Reach practitioners could 'link training to real examples' which was 'very much valued by respondents.' Importantly, this model helped 'address the "use or lose it" challenge', where the skills and knowledge acquired through training can be forgotten, or lost, if not regularly used ([Glaveski, 2019](#)). The model enabled CAMHS In-Reach practitioners to 'guide' staff through consultations and help them identify and connect what they already know from their training, rather than 'telling' staff what to do (as one CAMHS In-Reach practitioner put it).' ([WG, 2021d](#), p.3).

The evaluation identified that being 'alongside' schools in this way helped build skills and confidence and provide reassurance that they were doing the right thing, which could encourage staff to 'hold on' rather than 'hand on' pupils to specialist services. (ibid).

- 4.45. Policy (and funding) to support the third sector is also important, as the sector plays a key role in providing access to lower-level advice and support, including support that people could 'dip in and out of' and, in some cases, more targeted support to children, parents and carers and adults around, for example, welfare claims, employment or mental health.

- 4.46. As the T4CYP programme identifies: ‘the relationships we have with others make a very big difference to our mental health and well-being’ ([NHS Collaborative, 2021c](#), p.4). Having people (and services) to turn to for help and support when you need it, and confidence that people (and services) will be there for you when you need them (see boxed text on trust) can both improve people’s well-being ([What Works Wellbeing, n.d.](#)) and help people and families to cope. Those people to turn to for support include ‘trusted adults’ in services and families.
- 4.47. Most of the support accessed by people with NDCs is ‘informal’, provided by parents or carers and, for adults, their partners. Informing, sustaining and strengthening this through, for example, access to timely and responsive support, is important for both families’ well-being and also to reduce pressure upon services, as when families can no longer cope, the human and financial costs escalate rapidly and sharply (e.g. where expensive specialist placements, such as residential care, are required). Conversely, providing support and early intervention can improve families’ well-being and can help stop problems becoming entrenched and/or escalating, and becoming more complex and costly for services to address (see e.g. [Early Intervention Foundation, 2018; Young et al., 2021](#))⁵².

The importance of trust

Access to support that is responsive (when you need it) and trusted (provided by people/services who you feel can be relied upon) is important. Building trust, ‘the firm belief in the reliability, truth or ability of someone or something’ (OED, 2001) between services and those they work with (people and families) is crucial; without it, people may not be willing to share their experiences or act upon advice and support from services ([NHS Collaborative, 2021c](#)) and, as the experiences of services users interviewed for this and earlier research ([WG, 2019b](#)) illustrate, the negative impact of mistrust and feeling let down by services upon people’s well-being is considerable.

⁵² The evidence base appears most developed in relation to early intervention for children, and much is not specific to children with NDC, and further (desk-based) research to assess the evidence base in relation to early intervention for children and for adults with NDC is warranted, but beyond the scope of this review.

A key challenge here is that the simple actions that build and sustain trust, like fulfilling commitments (doing what you say you will do) and 'returning calls as agreed', 'make a huge difference in creating and maintaining these all-important trusted relationships, [but] often they do not happen in practice' ([NHS Collaborative, 2021c](#), p.29).

4.48. Current policies that support access to timely advice and support when needed include, for example:

- The Framework on Embedding a Whole-school Approach to Mental Health and Emotional Well-being, which aims to improve the mental health and emotional well-being needs of all children and young people by 'promoting a positive cultural environment in schools' ([WG, 2021c](#));
- The NEST Framework, which aims to ensure that 'early help and the right help' is 'available at the right time' ([NHS Collaborative, 2021c](#)) (discussed further below); and
- The Social Services and Well-being (Wales) Act 2014, which aims to improve the well-being of people who need care and support, and carers who need support and which includes, for example, requirements to provide 'relevant, clear information and advice about all of the services available in the area' through bilingual IAA services ([WG, 2019a](#)).

4.49. Action to address demand-capacity gaps and build confidence in, and understanding of, neurodiversity in universal and targeted services (outlined above), supported by actions to ensure easy access to expertise, discussed below, will be crucial in underpinning other actions to ensure there are people to turn to for support.

Easy access to expertise

4.50. The aim of providing easy access to expertise, alongside training and professional learning opportunities, is not to make everyone who works with neurodiverse people, such as school staff, social workers and family support workers, an expert. Rather, it is to ensure that, when they need expert advice, they can access it easily. As the NEST framework identifies, providing 'easy access to expertise' is critical in ensuring

that (i) ‘front line professionals...have the confidence, competence, and support to feel better able to “hold on” when a child or young person is experiencing distress’ (as the example of the CAMHS In-Reach programme illustrates) and (ii) specialist services do not feel ‘remote and inaccessible’ to people with NDC and their families or front line professionals ([NHS Collaborative 2021c](#), p.32).

4.51. As well as supporting services to ‘hold on’ and increasing the accessibility of specialist services, providing easy access to expertise should also increase front line professionals’ awareness and understanding of the support that is available and, for example, help inform decisions about referrals to different services. It should help people choose and navigate what can often be complex systems of advice and support delivered by different organisations within health, education and social care and the third sector. As the boxed text illustrates, the NEST framework identifies a number of ways in which access to expertise can be increased.

Improving access to expertise

The T4CYP programme has identified a number of ways in which access to expertise can be improved for front line professionals, people with NDC and their families; they include:

- providing information and advice in a variety of formats (e.g. leaflets, apps, posters, videos, websites, social media platforms);
- offering regular training sessions - general and bespoke, and telephone advice and consultation lines (in people’s language of choice);
- identifying named and consistent link professionals from within specialist services, whom partners can contact and liaise with, helping develop trusting cross-agency partnerships and relationships;
- offering regular consultation sessions (bookable in advance and drop in).

Examples of this in practice (identified by the review), focused upon improving people with NDCs’ and/or their parents or carers’ access to expertise, include:

- IASs, such as Aneurin Bevan and Cardiff and Vale, which offer access to support via drop-in sessions run by support workers for those accepted on their waiting list for a diagnostic assessment;

- children's ND services, such as Aneurin Bevan UHB, which are piloting offering access to short courses and support groups for those accepted onto the waiting list, to help parents and carers better understand their child and what they could do to help them, and Betsi Cadwaladr UHB which piloted a telephone advice line for those on their waiting list;
- Denbighshire CAMHS who offer joint CAMHS / ND consultations through Choice appointments⁵³. It is reported that parental consultation appointments can happen immediately, without having to wait for a diagnosis; and
- the advice and support offered by a range of third sector organisations, supporting children, parents and carers and/or adults with NDCs.

In addition, the T4CYP programme identifies that access to expertise for professionals within services can be improved through:

- facilitated network consultation meetings about people of concern (with appropriate consent and attendance);
- multi-agency/multi-disciplinary joint formulation sessions;
- embedded mental health practitioners in teams/services; and
- clinically led multi-agency and community-based teams with a focus on specific areas of need.

Examples of improving easy access to expertise for professionals within services (identified by the review) included:

- the community embedded team in Gwent, where an ND nurse can provide support and training for families and schools to help a child, without the need for a full ND assessment;
- the training, advice and joint assessments IASs offer to services such as AMHS, where, for example, autistic adults also have mental health difficulties;

⁵³ Choice appointments are part of the Choice and Partnership Approach (CAPA), which aims to improve service user experiences and outcomes, by (i) engaging and working with service users to identify, for example, what is important to the service user, what they can do themselves, and what they need help with and (ii) responding to this in a flexible, person-centred way (giving people 'choice') ([CQC, 2017](#)).

- the CAMHS In-Reach Pilot Programme, discussed above, which has helped build school staff skills and confidence, and provided easier access to specialist advice, liaison and consultancy when schools needed it ([WG, 2021d](#));
- the National Autism Team, which for example, facilitates The Adults’ Diagnostic and IAS Community of Practice (CoP), coordinates the autism leads forum, and develops, delivers and/or disseminates training and resources; and
- centres of excellence and organisations such as NICE, which provide national guidance and advice to improve health and social care.

Adapted from: [NHS Collaborative 2021c](#) pp 32-33, complemented by interviews undertaken for the review

No wrong door to access extra help

- 4.52. Some people with NDCs and parents or carers will need more specialist support from services such as health, education, social services or the third sector. A Single Point of Access (SPOA) is seen as an important way to ensure ‘there is no wrong front door’ and that people do not bounce between services or get mis-referred to the wrong service, delaying assessment and support ([Children’s Commissioner for Wales, 2020](#)). This was identified as important in the Working Group’s discussions in December (summarised in a supplementary paper). It requires a robust triage process and staff expertise to undertake an initial assessment of a child or adult. Examples of this include the Integrated Service for Children with Additional Needs (ISCAN) (see boxed text).

The Gwent ISCAN Service

The Gwent ISCAN service provides a single point of access to services for children and young people aged 0-18 years who have two or more developmental needs and those with suspected ASD or ADHD.

The service developed in response to concerns that referrals were being made to different services 'resulting in a fragmented and siloed approach' where 'children were placed on multiple waiting lists, underwent several different assessment processes resulting in numerous plans, appointments in different places.' For example, if an OT identified other needs in the course of their work with a child, they could bring it back to the panel, rather than having to go back to make a fresh referral into another service such as SLT.

The weekly ISCAN referral meetings bring together paediatricians, psychiatrists, members of the children's ND team, therapy services, EP services, care co-ordination and social services, and facilitates effective communication, information sharing and decision making. The meetings determine how best to meet needs, including where appropriate a referral to the children's ND service, and have adopted a 'no bounce approach', so even if a child is not accepted for a statutory service, the family can be offered other options, such as referral to Families First or to Family Liaison who can help with practical and emotional support.

Adapted from: [IPC, 2019](#)

- 4.53. Models such as multi-agency panels are seen as important here in helping determine the service(s) best placed to provide support (see boxed text).

Gwent's SPACE-WB and SPACE-ND panels

The SPOA for Children's Emotional Well-being and Mental Health (SPACE) Panels, are a Gwent-wide initiative. Requests for support from schools and services are triaged by a multi-agency team which decides the best placed service(s) to meet a child's or young person's needs. A co-ordinator manages requests, going back for further information if required, and decisions are made by the panel about the most appropriate approach(es) to take and services to get involved to support the child or young person. The initiative aims to ensure that

children and young people can access the right help the first time and that there is no duplication of support across services.

There are currently two 'front doors': one for referrals for ND assessments (SPACE-ND) and one for emotional health and wellbeing needs (SPACE-WB). While both professionals and families can refer to the SPACE-WB panel, only professionals can make a referral to the SPACE-ND panel. As an interviewee from the service explained, if a referral is made to the 'wrong' panel, they will pass it onto the other panel, to ensure there is 'no bounce' (as they put it) and will also try to educate the referrer to reduce the risk of it happening again. They also explained that they accept re-referrals, for example after a referral has been rejected and (following this) an intervention has been tried and demonstrated to fail to address the child's need.

ND referrals are assessed by a community embedded/ND triage team. This multi-disciplinary triage team includes nursing, therapies and medical staff from paediatrics and the ND team. They review referrals and determine the most appropriate outcome to meet the needs of the child or young person and their family. This could include referrals to the Community Embedded Team, ND Assessment Team, Integrated Services for Children with Additional Needs (ISCAN) Panel, the SPACE-WB panel and other services.

Families referred for an ND assessment can still access support through the SPACE-WB panel with, for example, behaviour that can challenge, helping ensure that waiting for an ND assessment does not delay access to support. The Community Embedded Team and co-coordinator have a role in helping 'think outside the box' as one interviewee from the service put it, to identify support for families who need it. This includes 'complex' cases, where multiple referrals have been made to the ND service, but not accepted. In these cases, the team has a role in exploring potential support, for example for attachment or trauma, which might mean an ND assessment is not warranted. They explained that the relationships they had developed with other agencies, and the ways in which access to other agencies was facilitated through the SPACE-WB panel, was vital

to support this. It also helped to sever some of the links between a diagnosis and access to support, and facilitated earlier intervention and preventative work.

Panels such as these offer a number of potential benefits. For example, they can help referrers, who do not need to choose which service to refer to; they can help highlight systemic gaps in provision; and they can build relationships between, and mutual understanding of, different partners, which can help collaborative work.

This was supported by interviewees from ND services who reported that the panel meant services could pass referrals between each other more readily and had also reduced the number of inappropriate referrals to the service from referrers (who previously did not know where best to refer some clients).

Adapted from data gathered through interviews and also [WG, 2021d](#); [NHS Collaborative, 2021c](#)

- 4.54. In contrast, structures for adults are less developed than the panels that are developing in many areas for children and young people with emotional, mental health and/or ND difficulties. It was reported by a contributor from an IAS that adults tend to go through social services and IAA services. Therefore, they identified a need to establish better working relationships with IAA teams and to increase awareness and skills at the point of contact (e.g. through training and access to expertise) which could help ensure swifter access to support. There was also discussion in the Working Group meetings about the potential to develop models analogous to those developed for children and young people, such as multi-agency panels, to support swifter identification of the most appropriate support (but no firm decision was reached on this).
- 4.55. This approach, to further develop single points of access for adults and to enhance the capacity of those undertaking initial assessments, to identify where best to signpost or refer people, is consistent with the vision for ND services identified by the review. However, there is a need to better understand how and where adults seek support or are identified by services; for example, as one member of the Working Group commented: 'it's useful to think about where people initially go to access support. To what degree is it primary care? If it is, what is the opportunity to

explore open access to professionals linked with the third sector who can offer early help and support?’ Although likely ‘gatekeepers’ such as GPs and IAA teams can be identified, a comprehensive assessment was beyond the scope of this review. Understanding where adults initially seek support will be important in identifying where capacity and confidence needs to be built; for example, data from IASs suggests that around half of those adults (51 per cent) referred to IASs are referred by professionals, but the type of professional is not recorded (with 43 per cent of adults self-referring to the IAS).

- 4.56. As table 4.3 illustrates, data from IASs on the other services currently working with adults who are referred, suggests that a substantial number of autistic adults supported by the IAS are also supported by MH services, with a smaller number supported by social services.⁵⁴ This highlights the key role MH services have to play in providing access to support for adults.

Table 4.3. The number of autistic adults supported by the IAS who are currently supported by other services*

	Total No.
Primary Mental Health Services	495
Community Mental Health Team	467
Social Care	104
Forensic Services	25
Joint Diagnosis	18
Adult Learning Disability Service	11
Adult Physical Disability Service	4
Other	630

**It is possible that adults can be supported by more than one service. Source: NAT*

Collaboration between services working together rather than in sequence

- 4.57. Collaboration between services for children or for adults is also identified as critical to ensure that they do not work in sequence, for example, where a child or adult has to wait to be diagnosed by a children’s ND service or IAS before MH services

⁵⁴ This data has some gaps; for example, no data was recorded by Gwent.

will work with them (which, as outlined in section 3, sometimes occurs⁵⁵). This is particularly important where there are co-occurring difficulties, and people need to access expertise from more than one specialist service. For example, joint assessments for people with complex presentations should improve patients' experiences and help share skills. Moreover, as an interviewee working with the NAT put it, although it is 'expensive to collaborate, not doing so, is expensive...you spend a lot of time and energy to divert cases' from one service to another.

Dealing with complexity through collaboration

As one of the contributors to the Working Group described it: 'the IAS deals with complexity on a daily basis' and with a fully staffed Multi-Disciplinary Team (MDT) and good relationships with MH and other specialist services, such as personality disorder services, they 'can handle complexity'. They stressed that this requires good relationships with other services, which take time to nurture and sustain and also requires partner services to be willing to collaborate, but gaps in, for example, provision for adults with ADHD undermine this model. This contributor to the Working Group suggested that if ASD and ADHD assessments could be considered concurrently, this would ensure that people are not 'sat on two separate waiting lists'.

Other examples of collaboration to better manage complexity included:

- joint work between the IAS and AMHS, to manage what are seen as inappropriate referrals to the IAS and to upskill staff, although this is not without its challenges. As an interviewee from AMHS explained, they see people who have a mental health condition (such as self-harming or challenging behaviour) but also have an autism diagnosis, so he has asked someone from the IAS to sit in with him. They reported that this joined up approach allowed them to tackle the mental health condition more effectively.
- Powys IAS reported working with the adult psychology service to help that service structure their assessment process so that they can do ASD

⁵⁵ The Code of Practice on the Delivery of Autism Services outlines that autistic people with a mental health condition should not be excluded from either CAMHS or AMHS ([WG, 2021a](#)).

assessments. People then do not have to join the IAS waiting list as they have already been assessed (by the psychology service).

- in Hywel Dda, as an interviewee from AMHS explained, co-location of the IAS with the MH and LD services helps with joint working. They noted, for example, that the crisis teams often seek help from the IAS when they are looking at a joint diagnosis and the 'preciousness' that can exist within services is reduced.

- 4.58. So called 'softer' models of integration, such as joint working and co-ordination, can be cheaper and swifter to implement than so called 'hard' models of integration, such as establishing new integrated services ([Ham and Curry, 2011](#)). For example, it is reported that in Hywel Dda, co-location of the children's ND service and IAS, and bringing management of the two services together under a single manager, has helped strengthen links and collaboration between the two services. This has, for example, eased tensions about where young people aged 17 and over should be assessed, without formally integrating the two services into an all-age service.
- 4.59. Blurring the boundaries between services through greater collaboration is seen as important, because, as an interviewee from a children's ND service observed, the requirement to refer a child into other services to access expertise (rather than, for example, being able to jointly assess a child) created barriers to collaboration, and often added multiple additional steps. This slowed and complicated the process, making it more service-centred than person-centred.
- 4.60. Effective collaboration requires different services and the third sector to build rapport and understanding and to appreciate and acknowledge each other, including their respective strengths, but also their limitations and weaknesses ([Timmins, 2015](#); [Cooper et al., 2016](#)). Specific actions identified by the review include:
- action to address demand-capacity gaps. Collaboration takes time and, as one contributor to the working group put it: 'if services are chronically underfunded it's hard to look outwards';

- steps to enhance communication between services, such as co-location of services⁵⁶, joint training and forums, such as multi-agency panels, which provide opportunities and time to talk to partners, to discuss, understand and respect each other's positions, strengths and challenges; and
- ensuring that targets, protocols and performance management structures encourage collaboration (see also e.g., [Cooper et al., 2016](#)).

Barriers to collaboration

The barriers to collaboration are typically the obverse of the factors that facilitate it; they include, for example:

- limited capacity in the system, outlined in section 3; for example, as a contributor to the Working Group put it, the key challenge is the 'lack of services' which ND services could collaborate with to ensure access to early help and support and, as many interviewees reflected, the pressure upon their service and that of potential partners had led many to turn inward; and
- difficulties exercising systems leadership and co-ordinating the work of different organisations, due to:
 - cultural and organisational differences which can impede collaboration, including, for example, differences in goals, ways of working and Information Technology (IT) systems and, in the case of children's ND teams, their somewhat uneasy 'fit' within LHB structures which may hamper collaboration with other services, such as mental health or paediatric services⁵⁷ and may suppress the profile of ND services within LHBs; and
 - human factors; for example, as one contributor to the Working Group put it: 'empire building' and/or a fear of losing status and/or power could

⁵⁶ For example, as one interviewee from a children's ND service (because the service was spread across different sites) remarked: 'you've got to wait, you've got to send an email, can't just ask' whereas co-location with CAMHS means 'people talk to each other, things work better'.

⁵⁷ Children's ND services may, for example, sit within Mental Health directorates, which can aid links to CAMHS or within Women's and Children's Directorates, which can aid links to Paediatrics.

impede collaboration (while more open and collaborative outlooks could encourage it). Similarly, a reliance upon key individuals to act as the link or bridge between services can create a fragility in relationships that is vulnerable to key people moving on.

This is borne out by the difficulties many young people experience transitioning from children's to adults' services, such as CAMHS to AMHS ([WG, 2020b](#)), and the children's ND services to IAS, discussed above.

4.61. Current policies that support collaboration include, for example:

- The Social Services and Well-being (Wales) Act 2014, which aims to improve the well-being of people who need care and support, and carers who need support, and which includes, for example, requirements for LAs, health boards and NHS trusts to work together to ensure better integration of health and social care, for example, through Regional Partnership Boards (RPBs) ([WG, 2019a](#));
- The Health and Social Care Regional Integration Fund, which supports the effective delivery of integrated services in Wales ([WG, 2022b](#));
- [The Well-being of Future Generations \(Wales\) Act 2015](#), with its focus upon on collaboration, prevention and early intervention;
- A Healthier Wales: Our plan for Health and Social Care ([WG, 2021b](#)), with its vision of a 'whole system approach to health and social care' and 'new models of seamless local health and social care ... with support tailored to the needs and preferences of that person, even if it is made up of services delivered by several different providers' (ibid., p.10).

Barriers to ensuring swifter access to support

4.62. Opening up access to more targeted and specialist services by, for example, decoupling access to support from a diagnosis, poses challenges. There are fears that it could 'open the flood gates', meaning services could not cope with demand, potentially diluting support for those with diagnosed NDCs. There can be specific challenges, it was reported, when, for example, people who are not autistic join support groups for autistic adults. Moreover, although, as one interviewee from a

children's ND service put it: 'some techniques are not harmful whether there is a diagnosis or not', such as behaviour support, others should be informed by a diagnosis; in the case of ADHD, a diagnosis is required for medication. Provision of generic support, such as parenting advice, can also fuel families' frustration if they feel they are being 'blamed' for their child's difficulties and labelled as 'poor parents' (by being referred to a parenting course) ([WG, 2019b](#)).

- 4.63. Despite the progress made in raising awareness of NDCs, 'lack of awareness and stigma associated with the ADHD diagnosis' has been identified as the 'greatest barrier to services for people with ADHD'. It makes it harder for people to access treatment and support and contributes to the de-prioritisation of ADHD by service commissioners in the NHS ([Young et al., 2021](#), p. 11). Similar concerns were reported by interviewees from the third sector who described how, for example, scepticism and misconceptions about ADHD could make it hard for adults to access support.
- 4.64. More broadly, as a contributor to the Working Group put it: 'perhaps the biggest challenge [to realising the goals] is changing our whole philosophy/attitude to neurodiversity. There is a massive cultural shift [towards a more needs-led rather than diagnosis-led approach] needed'. This is a key part of the T4CYP's Vision for ND Support and Services ([NHS Collaborative, 2021a](#)). There was broad support for this aspiration, but much less clarity on how it could be achieved, and it was observed that existing service structures, such as the IAS, are condition specific.

Actions to ensure swifter access to a specialist ND assessment for those who would benefit from it

- 4.65. The review identified (and recommends) two key strategies to reduce demand:
- diffusing the demand for ND services across the system by increasing capacity elsewhere in the system to, for example, undertake formulations⁵⁸ in order to inform

⁵⁸ There are differing approaches to formulation. It may, for example, adopt a 'biopsychosocial' model that focuses upon identifying the range of factors contributing towards the child's or adult's presentation, such as an NDC, but also, for example, their home life and education, rather than determining the symptoms the individual has, how long the symptoms have persisted, and how their life is being affected, and then evaluating if those symptoms match the criteria outlined in, for example, the Diagnostic and Statistical Manual of Mental Disorders, in order to make a diagnosis.

decisions about support, rather than concentrating demand for assessments upon ND services (discussed in more detail below); and

- reducing demand for diagnostic assessments by enhancing access to help and support, irrespective of whether a child or adult has a diagnosis (discussed above).

4.66. However, the likely efficacy of either strategy to reduce demand for a diagnostic assessment from ND services is uncertain and monitoring and evaluating the impact of these strategies will therefore be important in assessing demand and capacity in the future. While both strategies may mean children and adults can access support more swiftly (and are therefore worthwhile), they do not guarantee that demand for an ND diagnostic assessment will decrease; as contributors to the Working Group observed or described some children and adults will still want, need and benefit from a diagnostic assessment, for example:

- An ND diagnostic assessment can help identify a child's or adult's strengths and difficulties and inform intervention, and in the case of ADHD, is required to enable the prescription of medication (to treat ADHD);
- 'having a formal diagnosis can be important for many people in regard to wider support that is dependent upon this, such as student support, protection in work under the Equality Act'; and
- 'until we remove diagnostic categories all together, people will still want a diagnostic assessment'.

4.67. In addition, the working group noted that evidence from practice is mixed. For example, one area (West Wales/Hywel Dda) has focused upon improving access to early help and support by developing an Early Help Team. They reported that this avoided people going into crisis and supported people to engage in their community, but people were still very keen to wait for their diagnosis.

4.68. Therefore, actions to decouple access to support from a diagnosis may, lessen demand for a diagnosis but are very unlikely to eliminate it. As one contributor to the Working Group summed it up: 'I don't think it's one or the other'. The problem, as outlined in section 3, is that demand for ND services far outstrips capacity, and taking steps to reduce demand and increase capacity are therefore important.

- 4.69. There was also discussion of a third strategy, gatekeeping, which received little support during both stakeholder workshops and the Working Group meetings (and which is not recommended). This was because the relatively open access to services like the IAS where, for example, people can self-refer, was seen as a real strength. In contrast, attempts to restrict access were seen as both unpopular and potentially futile or counter-productive, as they led to complaints from parents or carers who felt 'entitled', as one interviewee put it, to an assessment. In this respect, the more open access to the IAS was generally seen as a strength of the service, compared to children's ND services, which do not all accept self-referrals.
- 4.70. Nevertheless, there was discussion about screening and services were clear that while they should accept referrals where the evidence was suggestive of autism (in line with NICE guidelines⁵⁹), screening was important to determine if this was the case or not. Data provided by four children's ND services (Betsi Cadwaladr, Cardiff and Vale, Swansea Bay and Powys) suggests that somewhere between around 30-45 per cent of referrals are not accepted. Although some of these may be accepted later with, for example, additional information, it illustrates the importance of screening in managing demand (and this is recommended by the review). Given the dangers of excluding those who would meet diagnostic thresholds, it was observed that screening required experienced clinicians and therefore reduced capacity elsewhere in services. It also illustrates the need for signposting to alternative services for those not accepted by ND services and the potential role of multi-agency panels in identifying which service(s) will be best placed to help in these cases (which is also recommended by the review).
- 4.71. There was also some discussion in the Working Group about whether screening could also be used to streamline assessments where the evidence was clear cut. This approach is used by ND services where appropriate ([WG, 2019b](#)), but the scope to do so is limited. Clinicians who contributed to the review were clear that a

⁵⁹ NICE guidelines for autism suggest a referral 'on the basis of reported or observed features suggesting possible autism' ([NICE, 2017](#)) and the Standards for Children's ND Services require 'adequate information to support concern' before a referral is accepted ([1000LivesPlus, 2016](#)). The difficulty, as one interviewee from an ND service put it, was that they 'screen out [those where the evidence is not suggestive of autism] if we can, but it is sometimes difficult to get enough information', so they err on the side of caution, rather than rejecting a referral. It was also noted that screening drew clinical time away from diagnostic assessments.

quality assessment takes time, especially for 'complex' cases and the NICE guidelines limit how far the process can be streamlined. Therefore, an elongation of the process, where cases were considered more complex, was much more common than examples of shortening the process. This (streamlining assessment) is therefore recommended where appropriate.

Diffusing demand for a diagnostic assessment across the system

- 4.72. A diagnostic assessment of NDC is a specialist task which should only be carried out in line with NICE guidelines. However, a diagnostic assessment is not always required and may not always be the best way to identify a person's strengths and strategies to target their difficulties ([NHS Collaborative 2021a](#)). Developing capacity elsewhere in the system to, for example, undertake formulations of a child's strengths and needs and identify possible interventions and support strategies (e.g. through training, workshops and consultations) may help lessen the demand for, and need to undertake, an ND diagnostic assessment. In Aneurin Bevan UHB it is reported, for example, that an ND nurse is undertaking 'upstream' work which aims to 'provide support without the need for full ND assessment' and also to identify support for those on waiting lists. This can include exploring the causes of behavioural issues and identifying interventions which could be supported by the community embedded team and providing support to schools (such as strategies that might be useful on a whole class basis) and families in areas such as behaviour management. This can both enable earlier intervention and mitigate the frustration associated with long waiting times for diagnostic assessments (and is therefore recommended by the review). If it means that needs are met without needing a full ND assessment, it may also lessen demand from families.
- 4.73. The Evelina service in Lambeth (see boxed text on the next page) and models such as the CAMHS In-Reach Pilot Programme provide examples of how specialist services can support staff in, for example, schools, to develop formulations of the causes of a child's difficulties.

Lambeth Paediatric Service (Evelina)

The Evelina paediatric service works with children up to the age of 11 and provides a holistic assessment considering a range of different possible NDCs within the wider psychological, biological and family context. 'This assessment is not driven by diagnosis; instead, the end result is an individual profile and formulation of the child's strengths and difficulties.' Following the assessment, the child is, if required, referred for a diagnostic assessment of potential NDCs highlighted by the assessment.

Adapted from: [Embracing Complexity, 2020](#)

Increasing the capacity of ND services

- 4.74. The findings of the review and conclusions of the Working Group are both clear: there is no simple, swift or inexpensive way to increase the capacity of ND services in Wales. Nevertheless, as table 4.4. outlines, a range of actions were identified and discussed by the Working Group.

Table 4.4. Appraisal of options to increase the capacity of ND services

Action	Potential benefits identified by the review and the Working Group	Potential challenges identified by the review and the Working Group
<p>Improving the quality of information that informs an ND assessment through, for example, the new digital Neurodiversity Wales Shared Platform</p>	<p>The review identifies problems getting the information required for an assessment in a timely way as a constraint. Addressing this should help increase the efficiency of assessments, by making it easier to make decisions and minimising delays (e.g. where information is not available).</p>	<p>It will be several years before the Neurodiversity Wales Shared Platform, which is currently being piloted in Cardiff and Vale University Health Board, could be rolled out.</p> <p>Likely to generate marginal, rather than transformational increase in efficiency.</p>
<p>Investing in ND services to address constraints such as shortages of administrative support and inadequate accommodation or IT equipment.</p>	<p>The review identified a number of issues, bottlenecks, constraints and gaps in ND services; these include: a shortage of administrative support (which means that clinical staff have to undertake administrative tasks); problems with accommodation (which can, for example make scheduling assessments difficult); problems with IT (which can hamper moves to work online). Addressing these</p>	<p>Likely to generate marginal, rather than transformational, increases in efficiency (although this could be a relatively 'quick win' that would help improve staff morale).</p>

	would increase efficiency and could address some factors that undermine staff morale / cause stress.	
<p>Exploring the potential to restructure ND teams to help increase capacity in relation to both diagnostic assessments and pre- and post-diagnostic support, without increasing staffing costs; for example, where specialist nurses take on tasks from medics.</p> <p>Strengthening 'core' teams⁶⁰ and reviewing the pay of support workers⁶¹</p>	<p>ND service structures should not be 'set in stone', as one contributor to the Working Group put it.</p> <p>Restructuring staff could help increase capacity without increasing staffing costs. It could also ease problems with the recruitment and retention of staff, make teams more diverse and multi-disciplinary (and therefore potentially more confident working with neurodiversity), increase opportunities for progression within services, and address bottlenecks in services (e.g. by bringing in non-medical prescribers to free up psychiatrists' time where prescribing ADHD medication causes bottlenecks).</p>	<p>Risks diluting ND teams with less skilled and experienced staff. There are shortages of trained staff in some of the professions who could contribute (e.g. EPs). More diverse teams create challenges around corporate governance and management and would, for example, require approval by LHB clinical directors.</p> <p>Increasing salaries of support workers would put additional strain upon IAS budgets.</p>

⁶⁰ The structure of some children's ND teams causes challenges; for example, the reliance upon 'virtual' members of the team, who contribute to ND assessments but who are not formally part of the ND service, can make it harder to manage the process and teams, and may mean staff face conflicting priorities

⁶¹ The pay for support workers within the IAS was also reported not to be commensurate with their responsibilities.

<p>is also likely to be important.</p>		
<p>Drawing upon expertise in the wider system, including professionals who are not part of ND teams but who may know more about the child, who can add breadth to the multi-disciplinary assessment, which should increase the quality of a diagnostic assessment.</p>	<p>Could increase capacity, by increasing the number of professionals who can contribute to ND assessments (without requiring the expansion of ND services) and make teams more diverse and multi-disciplinary (and therefore potentially more confident working with neurodiversity).</p>	<p>Appropriately skilled professionals, such as SLTs can contribute but they need training and experience to ensure compliance with NICE guidelines (Mullis, 2021) and the capacity of professionals, such as EPs, is limited, given demand-capacity gaps facing EP services</p> <p>Health Boards would want quality assurance around changes to the diagnostic process, such as bringing new professionals into the process, and they would look to ND services for this, which would increase demands upon ND services (and it was noted that demand created by non-NHS assessments is already very time consuming and difficult for ND services to manage). It was also felt that the quality assurance process could be very complex to manage (as one contributor put it: 'it would be a minefield').</p>

<p>Increasing funding to enable increases in the size of ND services.</p>	<p>The demand-capacity gap is large and unlikely to close without action to address it. Waiting times are unacceptably long and the current level of funding may not be sufficient to sustain services (given the risk of losing staff who will be difficult to replace).</p> <p>Offers a medium to long term solution to capacity, assuming new staff could be recruited, and clinical space expanded.</p> <p>Additional investment could provide opportunities to, for example, help restructure staff teams, develop capacity to support training for inexperienced staff and develop and extend their support offer to children, adults and families. As a member of the Working Group suggested, additional funding could be used by IAS to employ a social worker to consult with social care, and a training and liaison worker who could oversee the training needs across services and also be the point of liaison for the third sector.</p>	<p>Recruitment of skilled and experienced clinical staff is likely to be challenging (although recruitment of support staff is likely to be easier). Increasing funding for all services at the same time risks increasing competition between services and ‘poaching’ of clinical staff which could weaken some services further. Any expansion of ND services would therefore need to be underpinned by a workforce development strategy.</p> <p>The evidence of the impact of increased funding for CAMHS suggests that increasing funding will not necessarily close demand-capacity gaps, and that action in the wider system is therefore also required.</p>
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<p>Outsourcing assessments to private providers.</p>	<p>May be the only viable way to increase capacity in the short term to help clear backlogs.</p>	<p>It is costly (for example, one Health Board reported commissioning 75 diagnostic assessments from a private provider at a cost of £130,000) and questions have been raised (by interviewees from children's ND services and the IAS) about the quality of assessments done by private providers, so members of ND services expressed concern about this option.</p>
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Actions to ensure the sustainability of ND services

- 4.75. As outlined in section 3, at present children's ND services and IASs face unsustainable pressures, meaning too many are fragile. The risks of losing skilled and experienced staff, who will be very difficult to replace, is a key concern. Moreover, even short-term absences of staff due to illness (which can be linked to stress) add to the pressure upon services and the remaining staff. It also risks creating a vicious cycle in which the loss of staff (e.g. due to sickness or resignation) increases pressure upon services and staff, which increases the risks of losing further staff.
- 4.76. Action to strengthen early help and support and address demand and capacity gaps (outlined above) should help ensure that ND services are sustainable. These actions would, for example, contribute to helping ensure that demand does not routinely outstrip capacity; staff morale and well-being is good, or better; services can recruit and retain staff (reducing the turnover of staff which has destabilised some services); and stakeholders support, rather than criticise, services. Other specific actions that would enhance the sustainability of services include:
- more intelligent performance management of services to shift to a broader suite of measures that includes, but is not limited to, waiting times, as focusing too much upon waiting times as the only measure of performance can distort services' focus (as it draws resources to minimising waiting times and away from, for example, post-diagnostic support); waiting times can be perceived differently by children, families and adults waiting for a diagnostic assessment⁶²; and can demoralise services (as demand-capacity gaps mean the targets are unachievable, and can lead them to be judged as under-performing, obscuring their strengths and achievements). Use of a broader set of measures should increase understanding of the issues and constraints that ND services face;

⁶² For many of those interviewed, the time they feel they have waited starts when they first suspected that they or their child had difficulties, rather than the time their referral for assessment was accepted by ND services).

- creating more opportunities for progression within services, so that, for example, newly qualified staff could gain skills and experience. This could help strengthen and replenish ND services when other staff move on⁶³ and help address challenges around recruitment of highly skilled and experienced staff (by enabling initially less highly skilled and experienced staff to be recruited); and
- longer term funding and staffing commitments to ensure that, for example, staff are on permanent, rather than fixed term contracts, and their pay is commensurate with their roles and responsibilities⁶⁴.

Actions to ensure equity of access to services and support irrespective of age, gender, ethnicity or NDC

4.77. As outlined in section 3, at present access to a diagnostic assessment and/or support can depend upon an individual's characteristics, such as their age, gender, NDC, ethnicity or language preference. Overall, there is felt to be too much emphasis upon autism, to the detriment of other NDCs; for example, provision for children with autism or an NDC such as Tourette Syndrome differs, as does provision for children with trait disorders who fall short of a diagnostic threshold. Moreover, some groups, such as people from some Black, Asian and Minority Ethnic communities, appear to be under-represented in ND services and only a small number of services have an 'active offer' of Welsh.

4.78. Actions to address inequity need to focus upon the cause; as outlined above, these include:

- the structure of services and eligibility criteria, which can privilege access to some groups over others, depending upon a person's age or the nature of their difficulties. Problems linked to transitions between services are also pertinent here; and
- failures to identify and engage and reach out to some groups such as autistic girls, so they are missed by services, or some Black, Asian and

⁶³ For example, as a member of the Working Group put it: 'we need staff progression within the team - e.g., band 6 staff who can progress to band 7. Different levels of psychology staff.'

⁶⁴ Particular concerns were raised about the pay of support workers in some areas.

minority ethnic communities which children's ND services and IASs have been less effective at reaching.

4.79. Actions therefore need to focus upon:

- changing the structure and practice of services, for example, by:
 - moving away from separate pathways for ASD and ADHD (which can cause problems where children have co-occurring NDCs) and establishing SPOAs;
 - greater collaboration between services (e.g. where children or adults have co-occurring conditions or are making transitions between services);
- moving toward a more needs-led rather than diagnosis-led approach (discussed above), which can be important to help ensure that people do not fall in the gaps between services or get 'bounced' between services;
- raising awareness and understanding of neurodiversity, to reduce the risk that people's difficulties are missed; and
- actively reaching out to engage under-represented groups and ensuring that, for example, services have an active offer of Welsh.

4.80. The key Welsh Government policies supporting action in this area include:

- the Autism Code of Practice (CoP) ([WG, 2021a](#)), which, as one member of the Working Group put it: 'aims to ...improve the early help and support there will have to be clear pathways and clear support pathways and cannot be diagnosis driven.' However, it was noted that: 'the CoP only applies to autism' and some contributors to the review expressed concerns that it privileges autism over other NDCs;
- the Equality Act which safeguards those with 'protected characteristics'⁶⁵ 'from 'unlawful discrimination';
- The Rights of Children and Young Persons (Wales) Measure 2011, which enshrine children's rights in law, such as 'the right to special care and support if you have a disability so that you can lead a full and independent life'; and

⁶⁵ The protected characteristics are: age; disability; gender reassignment; marriage and civil partnership; pregnancy and maternity; race; religion and belief; sex; sexual orientation.

- [The Welsh Language Act 1993](#), the Welsh Language (Wales) Measure 2011, [More Than Just Words: The Follow-on Strategic Framework for Welsh Language Services in Health, Social Services and Social Care](#) (WG, 2016b), and [The More than Just Words Action Plan](#) (WG, 2019d).

4.81. Local health board policies and decisions about the service structure and provision are also important drivers of access to service and support.

ND services' Welsh language offer

4.82. As outlined in section 3, the ND service and IAS in only two areas reported having an active offer of Welsh language provision. It is therefore important that steps are taken to:

- identify the Welsh language requirements of the service and of individual posts within the service, given the language preferences of the local population;
- map capacity (in terms of Welsh language skills) to identify opportunities (e.g. to utilise existing skills or upskill existing staff) and identify the gaps in provision;
- set target(s) and produce an action plan to close gaps e.g. by adopting a language training programme for selected staff as part of their professional development; by seeking to recruit a Welsh speaker to a specific post when that post becomes vacant⁶⁶ or when a new post is created; and/or providing access to Welsh speaking staff (which could include drawing upon Welsh speaking staff in other services⁶⁷); and
- monitoring and evaluating progress in achieving targets and implementing the action plan ([Welsh Language Commissioner, 2021](#)).

4.83. Other actions include proactively asking service users about their language preferences and recording this to ensure that other staff are aware.

4.84. The issues are complex though, as an interviewee from an IAS described it: 'they cannot offer an assessment in Welsh, and none of the assessment tools are available in Welsh.' They went on to explain: 'it is not just a matter

⁶⁶ For example, if the ability to conduct ND assessments through the medium of English and Welsh and the ability to present written information in both languages is essential for this post.

⁶⁷ There is, for example, an informal agreement between IAS to enable this.

of taking the English language version and translating it – it needs to be adapted with nuances to meet the cultural experiences of Welsh speakers.’ They reported that the communication issues around autism mean that in assessment the clinician needs to have very good language skills and cultural awareness (e.g. to read body language) and so it is not just a matter of providing Welsh lessons to staff.

- 4.85. The interviewee’s response illustrates both the importance of Welsh language provision for those who need to access services in their first language (meaning ‘the Welsh language is not just a matter of choice but also a matter of need’ ([WG, 2016b](#), p.4) and the challenges this poses to services. Practical actions to address this are outlined above in paragraphs 4.81-4.82.

Actions to ensure a whole systems approach

- 4.86. The change envisaged by this review’s proposals will require strong systems leadership at multiple levels, ranging from ND services themselves, through LHBs, education and social care services, and bodies such as Public Service Boards (PSBs)⁶⁸ and RPBs⁶⁹, to national bodies such as the NAT and Welsh Government. The review identified the need for change across the system. This change cannot be dictated from the top down and it will be vital to bring different actors together and build support for a shared vision of change and the willingness and commitment to change practice. Given the cultural differences between, for example, health, education, social care and the third sector, which can impede collaboration, bringing different groups together so they can see and understand others’ positions and practices is likely to be important.
- 4.87. As outlined above, collaboration between services is critical to making a ‘whole systems’ approach work effectively and delivering the national support offer outlined in table 4.2. It is vital to ensure that, for example, referrals between services are appropriate and that people with NDC and

⁶⁸ Public Services Boards (PSBs) are intended to improve joint working across all public services in each local authority area in Wales.

⁶⁹ RPBs bring together health boards, local authorities and the third sector to meet the care and support needs of people in their area.

their families experience joined-up (co-ordinated) support, and to identify how improvements can be made (e.g. through training and capacity building and changes in practice) throughout the system. However, as a contributor from the NAT observed, encouraging greater collaboration has been a long-standing goal of policy. For example, as the 2001 CAMHS strategy Everybody's Business identified over twenty years ago, 'good joint working is the Holy Grail of all attempts to improve delivery of health, education and social services. It is easy to see its vital importance, but it has been very difficult to achieve' ([NAfW, 2001, p.23](#)). Too often, the review suggests this remains the case today.

4.88. Collaboration, particularly when the aim is to exercise 'systems leadership' and to inform and potentially change partners' practice, is challenging. It takes skill and time and the T4CYP programme has identified a 'triad' of factors that underpin systemic change:

- 'governance and delivery', such as a clear policy position and recognition of a mandate that spans different policy areas such as health, education and social care, and mobilises resources across different sectors to achieve shared goals. This will require strong leadership to define the vision (e.g. with strategic leadership from the Welsh Government and support from national bodies such as the NAT) and take decisions (e.g. through RPBs) underpinned by delivery plans that cover areas such as workforce planning and development⁷⁰;
- 'cultural shift' (or change) such as moves toward embracing neurodiversity, and more needs-based and strengths-based approaches across services; and
- 'enablers' that 'introduce innovation, quality and consistency' such as the NDWSP and networks of specialist practice (T4CYP, n.d.).

Identifying how help and support needs can best be met

4.89. NICE guidance for autism ([NICE, 2012](#); [NICE, 2021](#)) and ADHD ([NICE, 2018a](#)) recommend that local autism and local ADHD multi-agency strategy

⁷⁰ For example, delivery plans should cover areas such as workforce planning and development, including training, demand and capacity and performance standards.

groups should be responsible for developing, managing and evaluating local care pathways and have responsibilities in areas such as training and awareness, ensuring ‘the integrated delivery of services’ and ‘supporting the smooth transition to adult services’ ([NICE, 2012, p.10](#)).

4.90. RPB autism sub-groups currently fulfil some of the roles NICE suggests for strategy groups, and could be expanded to cover ADHD, and potentially oversee provision for other NDCs as well in the future. Given the remit and membership of RPBs (see para 4.80), it is recommended by this review that their role should also encompass overseeing the delivery of the national support offer for people with autism and ADHD (and potentially other NDCs) and their families at a regional level. Examples of the support that should be provided are outlined in table 4.2. and RPB sub-groups should have a key role in taking forward the actions identified in section 4 to ensure swift access to early help and support. This should include identifying who is best placed to deliver support and addressing gaps in provision⁷¹. This would require some sub-groups to make stronger links to education services, as although LAs are key partners, RPBs are focused primarily upon health and social care.

Actions to ensure an evidence-informed approach

4.91. This review forms part of the evidence base that should inform reforms, alongside evidence such as NICE guidelines, lessons from the establishment of the children’s ND service and IAS (see e.g. [WG 2018; 2019b](#)), and established and emerging evidence from developments in Wales, the UK and other OECD countries; this should include, for example:

- research into NDCs and, for example, the co-occurrence of conditions (see e.g. [Cleaton and Kirby, 2018](#) and forthcoming analysis of SAIL databank data); provision for people with ADHD (see e.g. [Young et al., 2021](#)); and the work of institutions such as the Wolfson Centre for Young People’s Mental Health on the co-occurrence of NDCs and mental health difficulties;

⁷¹ The Social Services and Well-being Act requires collaboration and action to develop services, including promoting social enterprises, co-operative organisations, co-operative arrangements and third sector organisations to provide care and support and preventative services in their area, if they do not exist ([WG, 2019a](#)).

- systematic literature reviews of practice in areas such as multi-agency collaboration (e.g. [Atkinson et al., 2007](#); [Cooper et al., 2016](#)⁷²) to identify what works (and what does not);
- piloting (and evaluating) new approaches before seeking to roll them out and evaluating new services such as the adult ADHD service in Hywel Dda UHB, Community Embedded Teams in Aneurin Bevan UHB, and the Dundee/Scottish ND pathway⁷³ to identify good practice which can be replicated and learning which can inform service development; and
- robust modelling of the likely demand for new services (such as adult ADHD or ND services, if chosen as the preferred model) and of the resources required to meet this demand. This should, for example, draw upon expected prevalence rates and evidence from existing services of levels of demand and the resources required to meet them.

4.92. The development of services should be done co-productively, working with service users and services. As the T4CYP programme identifies: ‘the phrase “nothing about me without me” is a powerful reminder of the priority this needs to be afforded if we are to create services that are relevant and effective for the people they serve.’ ([NHS Collaborative 2021c](#), p.31). The T4CYP’s two reference groups, the Parents and Carers Network and the National Youth Stakeholder Group, and the Welsh Government’s Autism Advisory Group, provide important structures for engaging stakeholders. However, they should be complemented by other ways to identify what is important to and about service users, including research and using digital solutions to reach out to more people through more dynamic and interactive ways ([WG, 2021c](#)).

4.93. Although there is urgency in areas such as demand and capacity, given the pressure upon ND services (outlined in section 3), as one contributor to the Working Group put it, there was a need ‘to stop knee jerk reactions and take the time to plan the future of ND services; do not change the service model of ND or the IAS until wider consultation and policy has been developed around the wider ND agenda.’ Broadening and diversifying the engagement of a

⁷² This review did not have the scope to systematically review the evidence, and these are just illustrative examples.

⁷³ Evaluations of these services have not yet, to our knowledge, been undertaken.

range of stakeholders drawn from ND services themselves, health, education, social care and third sector services, and service users themselves, will be important in co-producing reforms.

- 4.94. The Working Group endorsed the principle that ‘intelligent’ monitoring, evaluation and performance management is crucial to ensure that, for example, what is measured focuses upon what is important to service users (including both their experiences and outcomes⁷⁴) and to enable levels and trends in demand, and any gaps in capacity, to be understood by services and commissioners.
- 4.95. The review has highlighted the lack of data, other than data on waiting times, which is routinely collected and shared by children’s ND services. Children’s ND services collect a range of data on, for example, the number of referrals and activity levels, and this was used for this review, but accessing this data has taken time. The Demand and Capacity Tool that was developed by the NHS Collaborative to address this (by adapting an existing tool for CAMHS) has proven problematic, as the ND diagnostic process is not linear, and modelling both the time required, and capacity of services has proved challenging⁷⁵. The lack of consistent data on demand, activity, capacity and performance makes it difficult to assess the scale of challenge at service or national level and hinders benchmarking. It may also have contributed to the apparent breakdown in trust between policy makers and practitioners, and the situation that some children’s ND services reported, where they felt senior managers only criticised the service for failing to meet waiting time targets without understanding the challenges the services faced.
- 4.96. In contrast, the breadth of data collected by the NAT for each IAS is valuable and forms an important part of the evidence base for this report. Nevertheless,

⁷⁴ For example, as one contributor to the Working Group suggested: ‘meaningful outcome measures’ would include the ‘number of people that felt supported through the diagnostic process, number of people that feel they have a plan in place following their diagnosis, number of people that have a better understanding of themselves and are able to move forward’. As another put it: ‘start measuring ND services on the number of children/families who receive post-diagnostic support’. In a similar vein, Healthier Wales proposes: ‘measuring the health and wellbeing outcomes which matter to people and using that information to support improvement and better collaborative decision making.’ ([WG, 2021c, p.5](#)).

⁷⁵ It cannot easily be broken into discrete packages e.g. one hour for assessment, and staff have the capacity to undertake x assessments a week.

this review has identified some gaps and weaknesses which constrain its value⁷⁶ and it is not clear if the data is being used as fully as it could to, for example, help benchmark performance and to inform questions to explore why activity levels differ so much across different IASs (the data alone will not answer this, but it provides a starting point for asking questions).

4.97. The data on other services that undertake ND assessments is fragmented across multiple services and teams and therefore difficult to access. This means that assessing demand and activity levels in relation to diagnostic assessments for ADHD at either a regional (LHB) or national level, was not possible.

4.98. Given these weaknesses, as a contributor to the Working Group put it: 'there is a real need to develop more robust and meaningful data on ND services.'

Key actions include:

- continuing the ongoing work to develop a demand and capacity tool that is considered 'fit for purpose' by children's ND services and service commissioners and that offers consistency at a national level, of data on ND services' performance, capacity and activity. This will be required in order to inform decisions about the service model at a national level and service management, and development and benchmarking at a regional (LHB/RPB) level;
- reviewing the data collected by the NAT, to identify gaps (e.g. how adults seek support before accessing the IAS), ways in which the value could be enhanced (e.g. by disaggregating data on the characteristics of those seeking assessment from those seeking support) and data collection that may not be needed, as it has limited value;
- developing tools to measure demand, activity and capacity for any new services (such as an adults' ND or ADHD service);
- developing measures of services users' experiences and outcomes that reflect what is important to and for them, to cover children's, adults' and parents' and carers' experiences and outcomes; and

⁷⁶ For example, data on the age of those accessing the service is not disaggregated between those seeking a diagnosis and those seeking support.

- routinely publishing data on funding, referrals, activity and waiting times and, where available, experiences and outcomes, to provide greater transparency and accountability to stakeholders than the current arrangements.

ND Service Models

- 4.99. As outlined in section 2, one of the questions the review of ND services was asked to consider was the feasibility, as well as potential advantages and disadvantages of alternative structures and models of service delivery. The review identified that changing the design and structure of the current ND services was likely to increase demand, and therefore would not address the demand-capacity gaps facing existing services. Actions outlined above, underpinned by increased investment in ND services, were therefore recommended to address demand-capacity gaps. Nevertheless, the review identified there was still interest amongst stakeholders in developing new ND service models, such as adults ND service or all age ND service, as it was felt they might better meet the needs of some groups.

Appraisal of the current ND service models

- 4.100. A number of contributors to the stakeholder workshop for children concluded that, despite its strengths, such as examples of innovative practice within some children's ND services seeking to work with complexity and neurodiversity, the current model for children's ND services was 'broken'⁷⁷. This reflected a number of challenges including:
- the extent to which a diagnosis has become bound up with access to support, both in people's minds and in practice, meaning opportunities to intervene early and prevent children's and families' difficulties escalating and/or multiplying, are missed (given lengthy waiting times for ND diagnostic assessments) and that some children struggle to access support because, for example, they fall short of diagnostic thresholds, despite having very real needs;

⁷⁷ For example, as one contributor to the workshop put it: 'health cannot solve this alone, there is not enough money or staff to ever fix the current system [or model focused upon children's ND services]; [it] must be the whole system' that is reformed.

- the often very limited capacity of children’s ND services to offer support, coupled with weakness in the support offered by other services, which led some to question the value of a costly diagnostic assessment without also offering adequate support (in contrast, while the IAS also has lengthy waiting lists, it also has greater capacity to offer support); and
- the unsustainable pressure that ND services face as a result of persistent demand-capacity gaps.

4.101. In response, contributors to the stakeholder workshop for children, like the Working Group, advocated rethinking the role that diagnostic assessment plays and strengthening the wider system; a vision reflected in the actions outlined above, intended to enhance access to help and support, and decouple access to help and support from diagnostic assessments, alongside actions to ensure swifter access to a diagnostic assessment for those who would benefit from it.

4.102. Contributors to the stakeholder workshop for adults celebrated the establishment of the IAS but identified the need to address the unsustainable pressure ND services (like the IAS) face as a result of persistent demand-capacity gaps and to strengthen support. It was also noted that, while the IAS’s offer of post-diagnostic support was important (and much needed), it can struggle to provide longer term support that autistic people can ‘dip in and out of’ as one interviewee from the third sector put it. The workshop also considered the gaps in provision for, for example, adults with ADHD identified by the review. However, the overall view amongst contributors to the stakeholder workshop for adults was that the ‘system is struggling rather than broken’. As one put it: ‘whatever we decide on ND we must NOT break the IAS teams - we need to build upon the foundations - the IAS isn’t perfect, but it’s a start.’

Options for developing ND services and new service models

4.103. Given the appraisal of the current ND service model (outlined above) and gaps in provision, particularly for adults with ADHD, the review identified a number of different options, which as outlined in table 4.5. address different goals. The first option, increasing funding for existing ND services, would

help sustain the current service model, while the remaining options would change it, for adults (for example, by establishing an adult ADHD service) or for children and adults (in the case of all age services), in order to address key challenges highlighted by the review. As table 4.5. illustrates, the later options offer greater potential benefits, in terms of the groups intended to benefit, but also pose greater costs and risks.

Table 4.5. the goal each option addresses

Goals	Close demand-capacity facing current ND services*	Address gap in services for adults with ADHD	Improve services for people with co-occurring NDC	Address issues around transitions between services	Address gaps in provision for people with a range of NDC**	Address gaps in provision for people with a range of NDC** and/or needs
Options						
Increasing funding for existing ND services (such as the children's ND service and the IAS).	✓					
Building capacity in primary and secondary care services in undertaking diagnostic assessments and the management of adult ADHD.		✓				
Establish a national adult ADHD service		✓				
Establish a national adult ND service.		✓	✓		✓***	
Establish a national all-age, pan-NDC model.		✓	✓	✓	✓	
Developing needs-based rather than diagnosis-based services or approaches.		✓	✓	✓	✓	✓

* Increased funding would aim to increase capacity in existing services. The other options would reduce pressure upon AMHSs (who currently have responsibility for diagnostic assessments for adults suspected to have ADHD) but are also likely to increase demand for the (new) ND services established through each of these options.

** i.e. including NDC other than autism and/or ADHD.

*** Assuming the service was not limited to autism and ADHD.

4.104. The five options considered may appear weighted toward options for developing services for adults, despite greater concerns about children's ND services (outlined above). This apparent imbalance between options reflects three key factors:

- there is a clear gap in provision for adults with ADHD, which is not the case for children (and as table 4.5. outlines, options such as an adult ADHD or adult ND service would address this gap);
- although children's ND services have important weaknesses, and reform and restructuring of children's ND services is recommended, there was generally agreement that some sort of diagnostic service for children with NDCs was required; and
- given the weaknesses in provision before the children's ND service was established (see e.g. [WG, 2019b](#)), there was little interest in disbanding children's ND services and repatriating responsibilities for diagnostic assessment back to paediatrics and CAMHS.

Options appraisal

4.105. The options appraisal is presented in table 4.4. The original options appraisal shared with the review Working Group has been updated in light of the comments made by members of the Working Group, with the additional text highlighted in red.

Table 4.6. Developing ND services: options appraisal

Option	Description and rationale	Potential strengths	Potential challenges or weaknesses
<p>Increasing funding for existing ND services (such as the children’s ND service and the IAS).</p>	<p>The demand-capacity gap is large and unlikely to close (without action to close it). Waiting times are unacceptably long and the current level of funding may not be sufficient to sustain services (given the risk of losing staff who will be difficult to replace).</p>	<p>Offers a medium-term solution to address capacity (e.g. 1-2 years+), assuming new staff could be recruited, and clinical space expanded.</p> <p>ND services are currently underfunded (relative to demand). Additional investment provides opportunities to, for example, help restructure and strengthen services’ infrastructure and staff teams (so they are more sustainable and better able to handle complex cases); provide greater opportunities for progression within services and develop capacity to support training for inexperienced staff; streamline processes (e.g. by enhancing administrative support); adopt digital solutions; develop post-diagnostic support; and provide</p>	<p>Recruitment of skilled and experienced staff is likely to be challenging. Increasing funding for all services at the same time would also risk increasing competition between services and ‘poaching’ of staff which could weaken some services further. Therefore, increased investment would need to be accompanied by a strategy to develop the workforce. Actions such as increasing training places and/or commissioning training to upskill existing staff to increase supply, in addition to actions to support recruitment and retention of staff by ND services, such as enhancing progression</p>

		<p>greater scope to collaborate with service users and other services.</p>	<p>opportunities and improving staff well-being would also be needed.</p> <p>The evidence of the impact of increased funding for CAMHS suggests that increasing funding will not necessarily close demand-capacity gaps (so action in the wider system is also required).</p> <p>Moreover, the lack of robust data on demand and capacity makes it difficult to quantify the level of funding required (so action to address this is required) and there are concerns that funding intended for ND services might be diverted to address other health service priorities.</p> <p>Does not directly address weakness in the current service model, such as the difficulties some young people experience, or will</p>
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			<p>experience, while transitioning from children's to adults' services (there is no lifetime model); the lack of provision for adults with ADHD (so action to address these issues would also be required).</p> <p>Moreover, co-occurring difficulties such as multiple NDCs and / or mental health difficulties are common, but children and adults with co-occurring conditions do not always 'fit' into existing services, increasing the risks of sitting on multiple waiting lists or being 'bounced' between services (meaning action to address this would also be required).</p>
Building capacity in primary and	This would focus upon ensuring there are clear referral pathways and	ADHD is a common condition, affecting around 5% of children and 2.5% of adults, and a diagnostic assessment and treatment of	Primary health services are often stretched and lack the capacity to adequately take on these roles.

<p>secondary care services in undertaking diagnostic assessments and management of ADHD.</p>	<p>establishing new specialist services within primary care. Pilots in England suggest they can be run by appropriately trained (and qualified) assistant psychologists and specialist nurses who can diagnose non-complex cases and oversee titration and monitoring (with initiation of medication made by a specialist, such as a paediatrician or psychiatrist) (Young et al., 2021). In line with NICE guidelines (NICE, 2018a),</p>	<p>ADHD need not be costly or complex. Establishing ADHD hubs within primary care would help dissipate demand across the wider system and reduce demand for specialist ND services.</p> <p>ADHD often co-occurs with mental health difficulties so ensuring that clinicians currently diagnosing and treating conditions such as anxiety and depression also consider ADHD, should improve identification and outcomes (Young et al., 2021).</p> <p>Potentially simpler than establishing a new standalone service.</p>	<p>This would therefore require additional investment.</p> <p>Establishing condition specific services runs counter to the current vision for ND services in Wales (NHS Collaborative, 2021a).</p> <p>This model would not cater for adults with complex presentations (e.g. those with co-occurring difficulties, such as eating disorders or post-traumatic stress disorder) and there is no equivalent to the children's ND service which could deal with adults with complex conditions ⁷⁸. Therefore, expertise elsewhere (e.g. in specialist ADHD teams) would also be required.</p>
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⁷⁸ NICE guidelines suggest that 'mental health services for... adults... should form multidisciplinary specialist ADHD teams and/or clinics ' to 'provide diagnostic, treatment and consultation services for people with ADHD who have complex needs, or where general psychiatric services are in doubt about the diagnosis and/or management of ADHD' ([NICE, 2018a](#)).

	<p>complex cases would still be diagnosed by the children's ND service (or another multidisciplinary specialist team e.g. in CAMHS).</p>		
<p>Establish a national adult ADHD service.</p>	<p>Pathways and the capacity to undertake diagnostic assessment for adults with ADHD are weak and inconsistent across Wales. Waiting times are reported to be long and post-diagnostic support is often limited to medication.</p>	<p>Addresses a clear need (for diagnostic assessment and support for adults with ADHD) in the medium term (e.g. 2 years+) and the IAS offers a proven model for developing an equivalent service for ADHD.</p> <p>Establishing a new service, rather than integrating ADHD into an existing service like the IAS is likely to be less disruptive to existing services.</p> <p>Potential to develop and then share expertise around ADHD (through collaboration and joint work with other services).</p> <p>Should ease the transition for young people with ADHD supported by children's services</p>	<p>There are NICE guidelines which suggest multidisciplinary specialist ADHD teams and/or clinics for adults. However, there are few examples of services in the UK (and the impact of these services upon service user experiences and outcomes has not yet been evaluated). Furthermore, there is no agreed or proven template for developing an adults' ADHD service (although there are initiatives like the adult ADHD service in Hywel Dda which could be treated as pilots and evaluated,</p>

		<p>(e.g. CAMHS or an ND service) by ensuring that there is a service for adults in every area.</p> <p>One UHB, Hywel Dda, has already developed an adults' service and two other health boards are considering trying to develop one.</p>	<p>and models such as the IAS which could be adapted).</p> <p>Given the demand-capacity gaps existing services such as the IAS and AMHS face, establishing a new service would require additional funding (or it would risk undermining existing services, if money were reallocated from them).</p> <p>Recruitment of skilled and experienced staff is likely to be challenging (and might therefore require actions to support workforce development).</p> <p>Co-occurrence of difficulties is common and creating new condition specific services runs against the vision for more needs-led approaches and risks adults</p>
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			<p>sitting on multiple waiting lists or being 'bounced' between services; for example, it would exclude those with developmental trauma, which was described as leading to ADHD-type difficulties.</p> <p>A stand-alone service would need to collaborate with, for example, AMHS and/or the IAS, where ASD and ADHD co-occurred, and other services, like substance misuse services, where there is co-occurrence with ADHD.</p> <p>Increasing diagnosis of ADHD would require an increase in prescribing capacity (and increase demand upon GPs, which might require new staff, such as specialist pharmacy posts or advanced nurse practitioners, and which might</p>
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			require actions to support workforce development.
Establish a national adult ND service.	NDCs are not distinct from each other and often overlap (Cleaton and Kirby, 2018). Pathways for ADHD are often unclear and the capacity to undertake diagnostic assessments for adults with ADHD is weak and inconsistent across Wales. Waiting times are reported to be long and post-diagnostic support is often limited to medication.	A medium to long term solution (3+ years) that addresses a clear need for diagnostic assessment and support for adults with ADHD and/or other NDCs such as Tourette Syndrome. Elements of IAS's current support offer, such as support workers, may be helpful for adults with ADHD or other NDCs. A national ND service ought to ease transitions as there should be greater alignment of children's and adults' ND services (improving experiences and outcomes for young people and their families). Although a transition from a children's to an adults' ND service at 18 may come at a difficult time in many young people's lives, establishing a new adult service aligned to the children's service, may provide the opportunity to ensure greater flexibility about the age at	There are NICE guidelines which suggest multidisciplinary specialist teams for autism and ADHD, but few examples of adult ND services in the UK and no template for developing an adults' ND service. Given its weaknesses, the children's ND service does not yet offer a model or template for an adults' ND service and aspects of the IAS model, such as its collaboration with other services, may offer a better template. Potentially disruptive for the IAS (and it will be important to ensure that current provision is not compromised while new services are established) and risks diverting

		<p>which young people transition to adult services.</p> <p>A national adults' ND service should be better able to deal with co-occurrence of ASD and ADHD than a standalone adult ADHD service and offers the potential to address NDCs other than ASD and ADHD in adults (although assessing the need for this is beyond the scope of this study). Support from a single service is likely to be preferable for service users with co-occurring NDCs (rather than support from multiple different services like the IAS and an adult ADHD service).</p> <p>It could create potential to create economies of scale and develop and deepen expertise in services through the creation of larger ND teams. This could offer opportunities for progression within services and more diverse roles for staff, which could be more rewarding.</p>	<p>resources from IAS / autism services and diluting services' focus upon ASD.</p> <p>The experience of establishing both the children's ND services and the IAS (see WG, 2018, 2019b) highlighted the costs and challenges inherent in creating new integrated services (and the lengthy period of development before services are fully operational and able to help children or adults). Although this needs to be weighed up against the potential benefits.</p> <p>The implications for diagnostic assessments of NDCs currently undertaken by AMHS or ALD services are unclear.</p> <p>Creates a larger 'silo' which should be better able to cope with the co-</p>
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		<p>Innovative and would make Wales a pioneer in this area.</p>	<p>occurrence of ASD and ADHD, although co-occurrence and complexity challenges some children's ND services. Despite co-occurrence, some interviewees from IASs reported that it is not efficient to routinely assess for ADHD and ASD at the same time, as the criteria are different.</p> <p>Evidence from children's ND services suggest more holistic assessments are more time consuming but are more beneficial and reduce the risk that multiple assessments for different NDCs are undertaken.</p> <p>Recruitment of skilled and experienced staff is likely to be challenging (given the dearth of ADHD provision for adults) and may therefore require actions to</p>
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			<p>support workforce development. Increasing diagnosis of ADHD would require an increase in prescribing capacity (and, for example, staff able to prescribe and monitor ADHD medication, which IASs may not have and/or involvement of GPs, (which may also require actions to support workforce development)).</p> <p>Existing staff in IASs would need training if they were also going to assess for ADHD and although service design should not be driven by the preferences of staff, it was reported that many joined the IAS because of their interest in autism, not ADHD.</p>
Establish a national all-	NDCs are not distinct from each other and often	A medium to long term solution (3+ years) that addresses a clear need for (i) diagnostic	There are NICE guidelines which suggest multidisciplinary specialist

<p>age, pan-NDC model.</p>	<p>overlap (Cleaton and Kirby, 2018). Wales's national children's ND service was pioneering, and this represents a logical next step that would help reduce friction between children's ND services and the IAS.</p> <p>It would also help address a key gap: pathways from ND services to adult ADHD support are often unclear and the capacity to undertake diagnostic assessment for adults with ADHD is weak and inconsistent across Wales. Waiting times are reported to be long and post-diagnostic support is</p>	<p>assessment and support for adults with ADHD and (ii) children and adults with NDCs other than autism or ADHD, (such as Tourette Syndrome).</p> <p>Elements of IAS's current support offer, such as support workers, may be helpful for adults with ADHD and for children and adults with NDCs other than autism or ADHD, and their families.</p> <p>Offers a lifetime model of support and care that should, for example, address issues around diagnostic assessment for young people aged 16-18, which causes friction between some children's ND services and the IAS. It also eliminates the need for the transitions from children's ND services or CAMHS to AMHS (although there might still need to be handovers between staff within services, given the tendency of staff to</p>	<p>teams for autism and ADHD, but the review did not identify any examples of an all-age ND service in the UK and no template for developing an all-age ND service.</p> <p>Potentially disruptive for existing services (and it will be important to ensure that current provision is not compromised while new services are established), although this needs to be weighed up against the potential benefits.</p> <p>It risks diverting resources from the IAS / autism services, to other NDCs and/or from services for adults to children (e.g. it is feared that statutory responsibilities to children would mean they were prioritised over adults).</p>
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	<p>often limited to medication.</p>	<p>specialise in work with either children or adults).</p> <p>A national all age pan ND service should also be better able to deal with co-occurrence of ASD and ADHD than a standalone adult ADHD service and offers the potential to address NDCs other than ASD and ADHD (although assessing the need for this is beyond the scope of this study).</p> <p>Support from a single service is likely to be preferable for service users.</p> <p>Potential to focus upon families (where multiple family members have NDCs, rather than individuals and, for example, make a shift from children being seen by the children's ND service and their parents by the IAS). This is important as whole family solutions may be more effective than support from separate children and adult services.</p>	<p>The experience of establishing both the children's ND services and the IAS highlights the costs and challenges inherent in creating new integrated services (and the lengthy period of development before services are fully operational and able to help children or adults).</p> <p>Equally, this should be a long term (e.g. 10 year) project that cannot be realised in the short term.</p> <p>The implications for diagnostic assessments of NDCs currently undertaken by AMH or ALD services are unclear.</p> <p>Creates a larger 'silo', which should be better able to cope with the co-occurrence of ASD and ADHD, although co-occurrence and complexity challenges some children's ND services and the</p>
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		<p>It could create potential for economies of scale and develop and deepen expertise in services through the creation of larger ND teams. This could create new opportunities for progression within services and more diverse roles for staff, which could be more rewarding.</p> <p>Innovative and would make Wales a pioneer in this area.</p>	<p>IAS's model of collaboration with other services may offer a better template. Maintaining and strengthening links with CAMHS and AMHS (and other services) would be vital, but could become more challenging for an all-age service, which might not easily fit into LHB structures.</p> <p>Despite co-occurrence, some interviewees from IASs reported that it is not efficient to routinely assess for ADHD and ASD at the same time, as the criteria are different. However, interviewees from children's ND services suggested that more holistic assessments of children are more time consuming but are more beneficial and reduce the risk that</p>
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			<p>multiple assessments for different NDCs are undertaken.</p> <p>Clinicians currently specialising in children's or adults' services would need additional training to create a true 'all-age service'.</p> <p>Recruitment of skilled and experienced staff is likely to be challenging (given the dearth of ADHD provision for adults, clinicians who typically specialise in work with either children or adults, and the difficulties existing services have experienced in recruiting staff) and therefore this might require actions to support workforce development. Existing staff in IASs and some children's ND services would need training if they were</p>
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			<p>also going to assess for a range of NDCs.</p> <p>Although service design should not be driven by the preferences of staff, it was reported that many joined the IAS because of their interest in autism, rather than ADHD (or other NDCs).</p> <p>May not be a true 'all-age' service, as many all-age services are, in effect, a children's and adults' service bolted together, given the tendency for clinicians to specialise in work with either children or adults. Work with both children and adults may also create risks in areas like safeguarding.</p> <p>An all-age service would not align with policies for children and young people (0-25), such as the ALN</p>
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			Transformation Programme; alternative models, like a young people's (11-25) or children's and young people's (0-25) service, might fit better with existing policies.
Developing needs-based rather than diagnosis-based services or approaches.	Not all neurodiverse children or adults, or children or adults with other needs, 'fit' into existing services, and needs-based services or approaches are considered best practice by some.	A long-term solution (5-10 years) intended to build services better able to manage complexity linked to co-occurring conditions or support those who have needs but fall short of diagnostic thresholds. It could address the needs of a much broader cohort of children and young people (such as the 20 per cent estimated to have an NDC or ALN) than current ND services which only work with those with autism (1-2 per cent) and ADHD (5 per cent). This ought to reduce the risk that people fall through the gaps between or below different services (where they fall short of	Requires restructuring of services, and a significant expansion of capacity to deal with a much larger number of children and adults with needs, which would be costly and disruptive. It will be important to ensure that current provision is not compromised while new services are established and would require a significant cultural change, which could delay much needed reform of ND services. Softer models of integration, such as greater collaboration between existing

		<p>thresholds for eligibility) or are bounced between services.</p> <p>Consistent with ‘neurodiverse’ approaches which are needs-led rather than diagnosis-led.</p> <p>This would support efforts to decouple a diagnosis from access to support and specialist services (with access to support determined by need, rather than a diagnosis, and would be more like a social care than a medical assessment). It would also support moves to ensure there is ‘no wrong’ door to services.</p> <p>More holistic assessments can be more time consuming but are reported to be more beneficial and reduce the risk that multiple assessments are required/undertaken.</p> <p>Assuming an all-age model was adopted⁷⁹, it should offer a lifetime model of support and care that, for example, addresses problems</p>	<p>services, may be less disruptive and more cost-effective.</p> <p>However, the potential cost and disruption needs to be weighed up against the potential benefits including cost savings elsewhere (for example, reducing the risk of problems linked to unmet needs in education, training and employment, family breakdown, substance misuse and mental health difficulties). Moreover, like other more transformative options (such as an all-age ND service), this would be a long-term project that would rightly take time to realise and would require actions to support workforce development.</p>
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⁷⁹ Other options would include for example a needs based service for children and young people (0-25), for young people (aged 11-15) or for adults 18+ (see e.g. [WG, 2020b](#)).

		<p>linked to transitions from children's to adults' services. Support from a single service is likely to be preferable for service users.</p> <p>This new structure could offer more diverse roles for staff, which could be more rewarding.</p> <p>Innovative and would make Wales a pioneer in this area.</p>	<p>There would still need to be a defined diagnostic service (as a diagnosis will remain important for both informing some interventions and for providing people with a sense of identity).</p> <p>Would need a strong multidisciplinary team at the 'front door' in order to assess the needs of individuals, which would be resource intensive, although also valuable in helping people access the right support more swiftly.</p> <p>The evidence on the effectiveness of needs-based services in meeting the needs of people with NDC is limited. There is no NICE guidance that could underpin this service structure (in contrast to, for example, guidance around autism or ADHD services) and few</p>
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			<p>examples of needs-led services in the UK, and most are focused upon young people. Evaluations of these services find support in principle for the models, but substantial challenges in establishing and operating services. They have often struggled to meet demand, although the high level of demand is also an indication of previously unmet need. Furthermore, there have been substantial organisational challenges associated with developing new services and partnerships between services, which have caused delays and disruption; and there have been problems with staff recruitment, skills, retention and morale</p>
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			<p>(WG, 2020b), although there is potential to learn from this and seek to mitigate the risks.</p> <p>An all-age service would not align with policies for children and young people (0-25), such as the ALN Transformation Programme.</p> <p>Alternative models, like a young people's (11-25) or children and young people's (0-25) service, might fit better with existing policies.</p> <p>Potentially unpopular with some groups, such as autistic adults accessing existing services, as it could be perceived as diluting the focus upon NDCs such as autism.</p> <p>Building support from adults and families, who may be distrustful, given negative experiences of services in the past, and who often</p>
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			view a diagnosis as the key to accessing services and support, and a guarantee of support in the future, may be challenging.
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- 4.106. The appraisal of the options prepared by the review team was shared with the Working Group, but the group did not have enough time to properly discuss it in the second workshop. As it was clearly an area where opinions differed, and as outlined in table 4.6., each option has different strengths and weaknesses, members of the Working Group were invited to comment (through an online form) on the appraisal of five options for developing ND services:
1. Increasing funding for existing ND services (like the IAS)
 2. Establishing a national adult ADHD service
 3. Establishing a national adult ND service
 4. Establishing a national all-age pan NDC service
 5. Developing needs-based rather than diagnosis-based services or approaches.
- 4.107. Members of the Working Group were asked if they felt the appraisal of each of these options was 'fair' (that it was accurate and balanced) and invited to add comments if, for example, they disagreed or felt important points were missed. They were also asked to rank the options. Ten members of the Working Group responded. Written comments were also provided by a member of the Children's Commissioner for Wales's team and a representative from Cardiff and Vale UHB.
- 4.108. As table 4.7. illustrates, the majority of respondents agreed that the appraisal of each of the five options was 'fair', although a number made additional comments (discussed further below).

Table 4.7. The Working Group’s judgments on the options appraisal

The appraisal of the potential strengths and weakness of the option to....	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
...increase funding for existing ND services (like the IAS) for adults is fair	2	6	1	1	1
...establish a national adult ADHD service is fair	2	5	1	2	1
... establish a national adult ND service is fair	3	5	2	2	
... establish a national all-age pan NDC service is fair	3	5	2		1
.... establish needs rather than diagnosis- based services is fair	3	7		1	

4.109. As noted above, the options appraisal presented in table 4.4., was updated in light of the comments made by members of the Working Group (e.g. where they felt the appraisal was not fair), with the additional text highlighted in red. This additional material focuses upon the key points made in comments by members of the Working Group that were consistent with other evidence gathered by the review. An additional option, building capacity in primary and secondary care services in undertaking diagnostic assessments and the management of adult ADHD, which was identified after the Working Group concluded, has also been included.

4.110. When asked to rank the five options initially presented, from the most to least preferred, opinions amongst the 12 people who responded to this question were split, with option 1, Increasing funding for existing ND services; option 3, Establishing a national adult ND service; option 4, Establishing a national all-age pan NDC service; and option 5, Developing needs-based rather than diagnosis-based services or approaches, each receiving over half of respondents’ first or second preferences. In part this reflected the difficulty of ranking options that were not necessarily mutually exclusive, with some, for example, advocating (in written comments) additional investment in children’s ND services and the IAS in the short

term and consideration of models like an adult ND service in the longer term. However, there were also clear differences of opinion about the desirability of options like replacing the IAS with an adult ND service (with some in favour and others opposed). Some respondents also expressed an interest in exploring other options, such as a young person's ND service; transition workers to aid transitions between services⁸⁰; and regional adult ND clinics that could complement an adult ND service (or IAS and adult ADHD service) by developing expertise to undertake diagnostic assessments for adults with NDCs other than autism or ADHD such as Tourette's syndrome, which have a lower prevalence than either autism or ADHD in adults.

⁸⁰ This proposal is partially addressed by the role of a named transition and handover worker in the new guidance on Transition and Handover ([WG, 2022a](#)).

5. Conclusions

Demand for, and ND services' capacity to undertake, diagnostic assessments

- 5.1. As section 3 outlines, Welsh Government investment in children's ND services and the IAS helped establish clear pathways, national standards and a designated service in each LHB ([WG, 2019b](#)). However, the demand for diagnostic assessment for autism and ADHD continues to outstrip the capacity of ND services. 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. The increasing demand reflects increased awareness and recognition of NDCs, a broadening of diagnostic criteria and also the establishment of new services, which are to be celebrated, but:
- waiting times for children, young people, adults and families have increased, delaying support (which is too often linked to assessment), which can mean problems multiply and/or escalate, and children's, adults' and families' distress increases;
 - staff within services face unsustainable pressures which contributes to the risk of losing staff and the fragility of many ND services; and
 - in children's ND services particularly, attention is driven towards waiting time targets, rather than the needs of children, young people and families.
- 5.2. The review identifies a number of issues and constraints, such as a lack of administrative support, lack of adequate IT equipment or clinical space and the structure of some teams, that limit capacity. 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 the demand-capacity gap facing ND services.
- 5.3. The review identifies that the fundamental problem has been the small size of services relative to demand over many years, rather than issues and constraints in the diagnostic assessment process or the design and structure of ND services. Indeed, options which involve redesigning services are likely to increase demand, rather than address existing demand-capacity gaps. The purpose of redesigning services should therefore be to address gaps in provision (e.g. for adults with ADHD), rather than trying to close the demand-capacity gaps which have resulted in long

waiting lists for those currently eligible for ND services. Action to restructure and expand ND services will be required to increase capacity.

- 5.4. The review also identifies that, in part, the demand for diagnostic assessment is because (as section 3 outlines) a diagnosis is either needed, or believed to be needed, to access support and/or is believed 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, and ties too much support to a diagnosis rather than need. This is despite the longstanding policy aspiration that support should not depend upon a diagnosis (e.g. [WAG, 2008](#)). The review endorses this aspiration and outlines ways to realise it through a systems wide approach to addressing demand-capacity issues outlined in section 4, with a focus upon both enhancing access to help and support (with or without a diagnosis) and ensuring swifter access to a diagnostic assessment for those who need one.
- 5.5. Nevertheless, there are some caveats to the principle that a diagnosis should not be required to access support; for example, in relation to ADHD (unlike autism) pharmacological treatment is an option (alongside other non-pharmacological interventions⁸¹) but this requires a diagnosis. In addition, access to some specialist provision, such as special school placements, may require a diagnosis. Moreover, the review identifies that access to support is not the only reason people seek a diagnosis and a diagnosis may be important to provide explanation and understanding of why some people experience the world differently. Therefore, while important given its potential to improve people's lives, decoupling access to support from a diagnosis will not necessarily reduce demand for diagnostic assessments (and cannot therefore be relied upon as a strategy to close the demand-capacity gap).
- 5.6. Looking beyond children's ND services and the IAS, the evidence from the review 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. This is a key barrier because 'ADHD can only be diagnosed and treated as quickly as the

⁸¹ Both NICE guidelines (NICE, 2018a) and interviewees from the third sector advocate interventions such as psychosocial education alongside medication (where medication is appropriate).

condition is identified in the community' ([Young et al., 2021, p.4](#)). Moreover, the current model of relying upon secondary MH services to assess and diagnose ADHD in adults is not working well. Access to diagnostic assessments is reported to be patchy and too dependent upon the skills and interest of individual clinicians and demand is reported to outstrip capacity.

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

- 5.7. 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 provide support, the support varies across Wales and can often be disjointed (uncoordinated). Many families also reported what they describe as a 'battle' with services to access the support they feel they and their children need before and after a diagnostic assessment. The ALN Transformation Programme is intended to address this adversarial relationship in education, but it is too early to judge how effective it will be in creating a simpler and less adversarial system⁸² and it will not, for example, improve access to social care.
- 5.8. In contrast, the IAS has greater capacity to provide post-diagnostic support to autistic adults eligible for the service⁸³ 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, which is generally limited to short term interventions, does not always meet people's hopes and expectations.
- 5.9. 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

⁸² The new system started in September 2021 for children up to and including year 10, newly identified as having an ALN, while those covered by the existing SEN system will move to the new system over the next three years.

⁸³ The IAS is intended to support adults who are not eligible for support from statutory services such as MH or LD services ([Autism Wales, 2020](#)).

the IAS and the third sector, but there are very few equivalent services for adults with ADHD.

The impact of demand-capacity gaps

- 5.10. The review is clear that no change is not an option. Demand-capacity gaps in relation to diagnostic assessments increase waiting times for children, young people, adults and families 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' as a consequence of long waits before they felt their, or their children's, difficulties were properly understood. The pressure upon services also exacerbates the difficulties ND services face in relation to workforce retention and recruitment, and the risk of losing skilled and experienced staff was reported to be a threat to the sustainability of services.
- 5.11. 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 – or in some cases battle – to access support. Weaknesses in support reduce the value of a costly ND diagnostic assessment. It also means that, even if waiting times for a diagnostic assessment were improved, the impact of this upon the experiences of adults and families and outcomes for children and, to a lesser degree, adults (where opportunities for early intervention have often been lost) might be limited.
- 5.12. Finally, it is important to bear in mind that, although the review includes the experiences of those accessing services, much less is known about the experiences and outcomes of those who are not identified or referred to services. The review identifies that 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 are reported to be under-represented in services. This is important because there are reported (by autistic adults interviewed for the review and interviewees from ND services, the T4CYP(2) programme and the third sector) to be substantial human, social and financial costs associated with undiagnosed and/or unsupported NDCs. This is illustrated by the experiences of adults diagnosed in middle age or older, whose experiences provide an insight into

living without a diagnosis or understanding of problems (see e.g. Stuart-Hamilton, et al, 2009). However, other than the experiences of those where diagnosis or support was delayed (where outcomes and experiences worsened as a consequence of delays), the review did not have the scope to directly explore the experiences of those not accessing services.

The design of ND services

- 5.13. 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](#)). As noted above, these have helped address gaps in diagnostic assessment services and in post-diagnostic support for adults ([WG, 2019b](#), [2019c](#)).
- 5.14. Nevertheless, as sections 3 and 4 outline, 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.
- 5.15. The review identified that neither the children's ND service nor the IAS offer the perfect model, with both exhibiting strengths and weaknesses as the following examples demonstrate:
- 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 can 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 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; and

- 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 autism and ADHD are done sequentially by different services.

5.16. The review identifies a need for change and stakeholder workshops and Working Group discussions suggest that there is an appetite and interest in developing new ND services for both children and adults, but also that there is 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 (and service models) 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.

5.17. Moreover, although there was a fair degree of consensus in the Working Group about the goals of reform, outlined below, and a range of actions needed to underpin changes to the wider system (outlined in section 4), judgments were divided over the merits of different ND service model options, which (as outlined in section 4) offer different combinations of potential benefits, costs and risks.

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

5.18. Given the impact of demand-capacity gaps and limitations in the design of ND services (outlined above), 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.

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

- a whole systems approach with a focus upon early help and enhanced support to help improve people and their families' well-being and to help reduce demand for specialist services; the active involvement of a range of sectors, including health, education, social care and the third sector, to maximise capacity and better address what is important to and for people; 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 is better able to handle both complexity, where, for example, people have co-occurring difficulties or fall short of diagnostic thresholds and also the diversity of strengths and difficulties people with NDC experience, and which has 'no wrong door'; and
- reform of ND services and the wider system should be informed by evidence, done co-productively, working with service users as well as services, and be subject to 'intelligent' monitoring and evaluation that focuses upon what is important to service users and offers greater transparency and accountability to stakeholders than the current arrangements.

5.20. Realising these goals in line with these principles will require investment and reform of ND services and the wider system, and the review's recommendations are outlined in the following sections.

Recommendations for developing ND service models

5.21. Although, as outlined in section 4, the working group was unable to reach a consensus on a preferred model for ND services, the evidence from the review as a whole suggests that many of the options considered by the review (and the Working Group) may be considered complementary. Some offer short or medium term

options, which would address some of the key issues and weaknesses identified by the review, while others offer choices between more ambitious long term options that have both greater potential benefits and risks, and over which opinion is divided.

Therefore, 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.

5.22. 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, to inform further development of services. Figure 5.1. provides a roadmap, outlining short and medium term actions to address the distressing experiences of too many children and adults with NDCs and their families and the unsustainable pressures ND services face, while also providing the foundations for future decisions about the future design and structure of ND services. These actions are discussed in more detail below, focusing upon recommendations for:

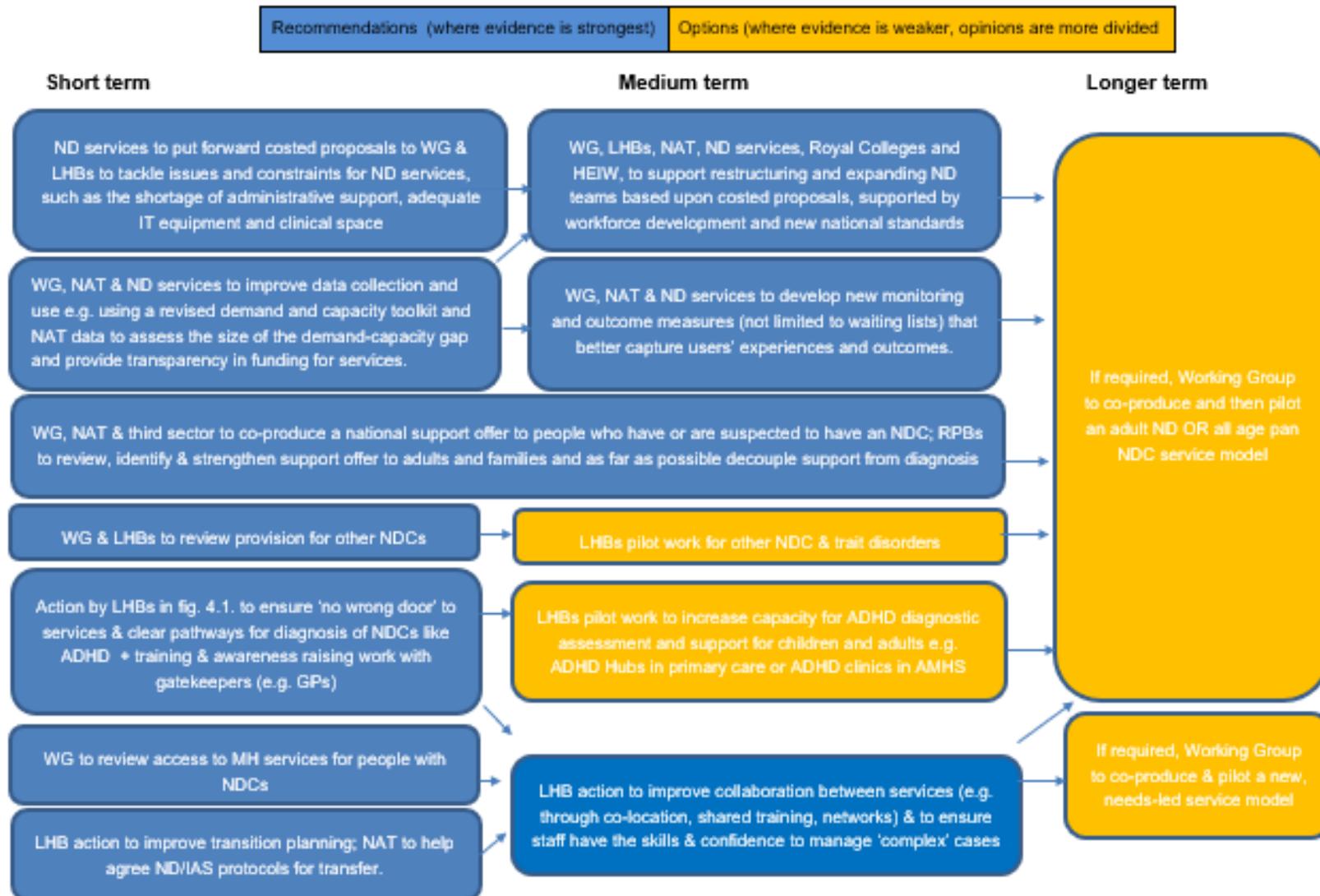
- developing children's ND services and the IAS;
- addressing gaps in provision for adults with ADHD;
- enhancing assessment and support for those with co-occurring conditions or who fall short of diagnostic thresholds; and
- improving transitions between services.

5.23. 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.

5.24. 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 is 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 is also strongly advocated by the Working Group).

Figure 5.1. ND review roadmap for action



Recommendations for developing children's ND services in the short, medium and long term

- 5.25. In the short term, the review identifies opportunities to 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.
- 5.26. In the medium term, because it is reported (by interviewees) to be particularly difficult to recruit some types of clinicians, such as psychiatrists and clinical psychologists, the review identifies opportunities to address recruitment challenges and increase the capacity and diversity of teams. For example, recruiting more therapists and specialist nurse practitioners could ease recruitment challenges in some areas 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 ND conditions. This is likely to require joint work between the Welsh Government, LHBs, ND services, a number of Royal Colleges, such as the RCPsych, RCSLT and the Royal College of Nursing (RCN) and Health Education Improvement Wales (HEIW) to consider the training, structure and workforce implications of a reshaped ND service for children. Bringing different professionals, such as specialist nurse practitioners and more therapists, into ND services would have implications for corporate governance and quality assurance. This could potentially be considered at a national level through a new working group to develop new standards and guidance for children's ND services.
- 5.27. The problems reported with virtual team structures (where a number of different staff who are not part of the ND service contribute to diagnostic assessments) suggest that, while it is appropriate and beneficial for teams to draw upon expertise from beyond the core (or dedicated) team when needed, a reliance upon virtual team members for routine work creates challenges in areas like communication, planning and management of the diagnostic assessment process. Expanding core ND teams with staff who are dedicated to the service is therefore important.
- 5.28. While it is clear that ND services are currently underfunded, gaps in the data make it difficult to quantify the size of services required to meet demand now, or in the future,

or to understand the impact of investment in services. Improving the comprehensiveness of data on demand for services, their performance and funding will be critical in better understanding the challenges services face, and their performance. This will be important to enable ND services to put forward costed proposals to Welsh Government and LHBs, for additional investment to expand and restructure ND services to ensure that capacity matches demand.

- 5.29. More intelligent monitoring and evaluation, 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. This is likely to require joint work between the Welsh Government, LHBs, the NAT, NHS services (e.g. the National Collaborative Commissioning Unit, the Delivery Unit), and ND services themselves, to develop new measures and tools. This should help increase transparency and build trust and understanding of the effectiveness of services in meeting needs (providing a stronger basis for identifying action to, for example, address weakness and under-performance, while also celebrating success) and help inform decisions about the future design and development of services. A nationally agreed approach would help strengthen this and enable benchmarking. However, the scope to develop this will depend, in part, upon actions to close the demand-capacity gaps ND services experience, as gathering and using data to inform practice takes time and this type of activity can be deprioritised when, for example, services experience high levels of demand.
- 5.30. In the medium term, if the capacity of children's ND services is increased, their role providing advice, support and, potentially, training to education settings and other services, such as special 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, as in Gwent, could help ensure that appropriate support is put in place in schools and at home and reinforce signposting to other support, such as third sector services. Sharing practice and reviewing what is working will be important in identifying and then rolling out good practice across children's ND services in Wales. Consideration should also be given by the Welsh Government, the NAT, RPBs, ND services and IASs, to whether responsibilities for providing advice and support for parents or carers of children with NDCs in areas such as sleeping and behaviour, should rest with children's ND services. At present, IASs provide some limited support, such as advice on, for example, sleep or

behaviour, or drop-in sessions (open to parents and carers of autistic children, as well as autistic adults); access to training courses such as Cygnet and EarlyBird and EarlyBird+ and signposting (e.g. to the third sector). However, the capacity of the IAS to provide post-diagnostic support to parents and carers has been squeezed by the high levels of demand from adults; the support offer differs markedly between IASs; and there is no equivalent service for the parents or carers of children with other NDCs, such as ADHD.

- 5.31. Given the small size of children's ND services, in the medium term consideration could also be given by LHBs to developing capacity to diagnose ADHD beyond children's ND services. Models such as ADHD Hubs in primary care, which could diagnose non-complex cases, could offer a cheaper way to expand capacity. However, there are a number of issues that also need to be considered (when weighing up this option). For example, the development of separate pathways for ADHD and ASD, runs counter to efforts to create services better able to manage neurodiversity and more complex cases, and therefore would not be consistent with the current vision for ND services in Wales ([NHS Collaborative, 2021a](#)). Moreover, the clinical time needed for a diagnostic assessment for ADHD (approximately 3 hours) is much less than the clinical time needed for a diagnostic assessment for ASD (approximately 10-15 hours), meaning the additional capacity freed up by diverting routine ADHD diagnostic assessments to ADHD hubs would be modest.
- 5.32. In the medium to long term, 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. This would require further research to assess demand, the extent to which current provision is adequate, and to identify appropriate service models (if required).
- 5.33. Over the long term, if actions to improve transitions between 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, 2022a), 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 (outlined above) will be important in providing evidence to inform these decisions.

Recommendations for developing the IAS in the short, medium and long term

- 5.34. In the short term, the review identifies opportunities to 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 Welsh Government, the NAT, LHBs and RPBs for additional investment to increase efficiency.
- 5.35. In the medium term, the review identifies opportunities to 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. This is likely to require joint work between the Welsh Government, NAT, LHBs, IASs, a number of Royal Colleges, such as the RCPsych, RCSLT, and RCN, and HEIW to consider the training, structure and workforce implications of a reshaped IAS. Data collected by services and collated by the NAT should be used to inform decisions about the need to increase funding for each IAS (as levels of demand and capacity differ). 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). Longer term funding and staffing commitments, to ensure that, for example, staff are on permanent, rather than fixed term contracts, and their pay is commensurate with their roles and responsibilities are also important.
- 5.36. The IAS's integrated model, which brings together clinical staff and support workers, is seen as effective. Nevertheless, different IASs' support offers vary considerably. Given differences in the size and distribution of the populations they serve, ranging from large, often sparsely populated regions such as Powys, to more densely populated and more urban regions, such as Cardiff and Vale, coupled with differences in the local support offer of partners, adaptation of the offer to local contexts is appropriate. Nevertheless, a thorough review (commissioned by the Welsh Government and/or NAT) of the rationale for differences in the support offered

by each IAS would be appropriate. The support offer is discussed in table 4.2. and it is recommended that RPBs determine who can best provide it.

- 5.37. In addition, in the medium term, if, as outlined below, adult ADHD services were established, collaboration between IASs and ADHD services would be required to ensure a joined-up response, where it was suspected that an adult might have both autism and ADHD. Models such as co-location of services, joint training and shared support services could all contribute to this.
- 5.38. In the longer term, as outlined above, if actions to improve transitions between services failed, or did not go far enough, an alternative strategy would be required, and consideration could be given to establishing a national working group to consider the feasibility of developing all-age services. Similarly, if actions to improve access to a diagnostic assessment and support for adults with (or suspected to have) co-occurring NDCs failed, an alternative strategy would be required. 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 will be important in providing evidence to inform these decisions. Focusing evaluation upon new services and models, such as the adults' ADHD service and co-location of the children's ND service and the IAS in Hywel Dda, would enable these innovations to be used, in effect, as pilots which could help inform future decisions about the development of national services.

Recommendations for addressing gaps in provision for adults with ADHD

- 5.39. In the short term, ensuring 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 will be important. The review suggests that 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). Although important, in order to ensure that people suspected to have ADHD are identified and referred, these actions may increase demand, and therefore exacerbate the pressure upon existing services and clinicians. Action to increase capacity, outlined below, is therefore also vital.
- 5.40. In the medium term there is a need to increase capacity to undertake diagnostic assessment for adults identified as potentially having ADHD, but no agreement on

the optimal model. The NICE guidelines ([NICE, 2018a](#)) recommend establishing multidisciplinary specialist ADHD teams to 'provide diagnostic, treatment and consultation services for people with ADHD who have complex needs, or where general psychiatric services are in doubt about the diagnosis and/or management of ADHD'. The NICE National Attention Deficit Hyperactivity Disorder (ADHD) Implementation Working Group has been reviewing the current NICE guidance, including examining recommendations for service structures such as specialist services and alternative delivery models, like ADHD clinics or hubs centred upon primary care discussed above in relation to children's services (see e.g. [Young et al., 2021](#)). Within Wales, a number of LHBs are already either developing or considering developing ADHD services either as a stand-alone service or as a service linked to the IAS. Whichever model to build capacity is chosen by LHBs, GPs are likely to have a key role in supporting monitoring of medication, although this poses challenges in terms of capacity, particularly if rates of diagnosis increase.

- 5.41. Therefore, the review recommends LHBs pilot new models (to increase capacity) and monitor and evaluate the new service models developed in Wales, including assessment of costs, demand, capacity and service users' experiences and outcomes. Furthermore, it is recommended they monitor developments of services and evaluations in other parts of the UK. This, together with any updates to the NICE guidance, should be used to help inform decisions by the Welsh Government and others about a national model and the implications for workforce development, such as expanding training and/or upskilling staff, to increase the supply of suitably skilled and experienced staff.
- 5.42. The parents and carers of children with ADHD may need advice and support in areas such as sleep and behaviour. As outlined above, if the capacity of children's ND services can be increased in the medium term, it may be appropriate for RPBs to support children's ND services to offer this in partnership with, for example, schools and/or the third sector.
- 5.43. In the medium term there is also a need to increase the capacity to support adults with ADHD. Interviewees reported that, in addition to medication (which is currently offered), adults with ADHD may need support with executive functioning difficulties, sleep and/or relationships. In order to provide 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. Both options would require additional funding (IAS support workers do not have 'spare' capacity) and a choice would need to be made about whether to invest in condition specific teams (i.e. the IAS and an ADHD service) or a support service better able to support neurodiversity. The third sector could also play a role. However, the third sector's capacity to support adults with ADHD is currently much less developed compared to the sector's capacity to support adults with ASD, and the sector would therefore require additional funding to expand its role. Monitoring and evaluation to learn from and inform the development of new support services for adults with ADHD, will be important.

Recommendations to enhance assessment and support for those with co-occurring conditions (such as co-occurring NDCs and/or mental health conditions) or who fall short of diagnostic thresholds

- 5.44. In the short term, there is a need to better understand why people with NDC, who also have mental health difficulties, can struggle to access MH services (e.g. what the barriers are and how they could be addressed). It is recommended that the Welsh Government commission an independent review to consider this.
- 5.45. In the medium term, actions outlined above to strengthen and diversify children's ND services staff 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. This would help maximise the value of having a children's ND service, rather than condition specific services.
- 5.46. In the medium term, actions outlined above to improve access to diagnostic assessments for adults with ADHD, coupled with collaboration between secondary MH services and/or adult ADHD services and the IAS, should improve outcomes and experiences for adults with (or suspected to have) ADHD and autism. The IAS's model of working with MH services where autism co-occurs with mental health conditions may provide a template for LHBs to develop this between secondary MH services and/or adult ADHD services and the IAS.
- 5.47. In the medium term, LHB actions to strengthen collaboration between children's ND services, the IAS and MH services, such as co-location, joint training and joint management, will be important to ensure those with an NDC and co-occurring mental

health condition experience a joined-up service and ensure that an NDC is not a barrier to accessing MH services. Similarly, LHB services, such as drug and alcohol misuse and eating disorder services, are also likely to be important providers of support where children or adults have other co-occurring conditions and action to strengthen collaboration between them and children's ND services and the IAS will also be important.

- 5.48. In the medium term, it is also recommended that the Welsh Government and LHBs review provision for people with other NDCs and those who fall short of diagnostic thresholds, and if appropriate, develop and pilot new models.
- 5.49. As outlined above, 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. Consideration could be given to establishing a national working group to consider the feasibility of developing alternative service models, such as an adults' ND or needs-led service.
- 5.50. In the longer term, enhancing collaboration between existing services should also help ensure that if, for example, the decision was made to develop an adults' ND or an all-age ND service in the future, integration of existing services (such as the IAS and new adults' ADHD services) into a new ND service should be easier.

Recommendations to improve transitions between services

- 5.51. Research (e.g. [WG, 2020b](#); [Asherson et al., 2022](#)) consistently identifies a range of factors that support transitions from children's to adults' services; they include:
- supporting the transition to adult services where appropriate and available and identifying alternative services where this is not possible (to help ensure continuity of care)
 - providing information and support for young people and their families before and during the transition process so they know what to expect and can plan for the change and involving them in decisions about the transition process;
 - collaboration between child and adult services including starting transition planning early, preparing young people and their families for transition, and where appropriate, joint working between child and adult services to support young people and their families during the transition process and provide greater continuity of care;

- flexibility that enables person-centred, rather than service-centred approaches to transitions and care (and that, for example, enables transitions to start when the patient is ready);
- ensuring that both child and adult services get ‘the simple things right’ and are, for example, ‘welcoming, friendly and warm’ and that staff have the skills and time ‘to develop a relationship and sense of trust and respect’ with the young person (CQC, 2017, p.58 cited in WG, 2020b); and
- effective quality assurance, monitoring and evaluation, covering users’ experiences and outcomes (WG, 2020b).

5.52. These are reflected in the new guidance on Transition and Handover ([WG, 2022a](#)) and will be important for LHBs in improving transitions from CAMHS to AMHS (e.g. for children with ADHD) and also from children’s ND services to the IAS and/or adults’ ADHD services (if children were being supported by children’s ND services) in the short and medium term.

5.53. In addition, in the short term, agreeing protocols for the transition of young people awaiting diagnostic assessment and approaching their 18th birthday from children’s ND services to the IAS will be important, particularly while ND services have large demand-capacity gaps. These should be agreed between children’s ND services and the IAS, rather than imposed, and be part of broader work to improve communication, collaboration and links between children’s ND services and the IAS (for example, through co-location of services and joint training).

Recommendations for enhancing access to early help and support and ensuring equity of access

5.54. Alongside actions to develop ND service models, the review recommends decoupling a diagnosis from access to support (where appropriate) and enhancing access to early help and support. This reflects the importance of intervening as early as possible to help prevent difficulties escalating or multiplying and the often limited value of a costly diagnostic assessment without also offering adequate ongoing support. The provision of access to early help and support could potentially reduce the demand for diagnostic assessments. However, actions to actively reach out to engage under-represented groups (such as children and adults from Black, Asian and minority ethnic communities), could also potentially increase demand.

- 5.55. Although ND services have (as outlined above) an important role to play in providing support, they cannot (and should not) be expected to meet the range of support needs people with autism or ADHD and their families have. MH services, education, social care, the third sector and others will all often have key roles to play. It is recommended that the Welsh Government, working with partners such as the NAT and third sector, define a national support offer, based upon the current NICE guidance and standards such as the ALN and Autism Codes of Practice (as outlined in table 4.2). This would outline the support that should be offered across Wales and also identify which types of support would require a diagnostic assessment to confirm that someone had autism and/or ADHD, and which could be accessed without a formal diagnosis. This would aim to provide a degree of consistency in access to support, just as the national standards for ND services provide a degree of consistency in access to diagnostic assessments across Wales.
- 5.56. Given differences in local services (including the third sector), it is recommended that there be regional – or local – determination of who (which services) would deliver and how a national support offer would be delivered, to ensure access to early help and support and how they would ensure equity of access to services and support. A key challenge here will be striking the balance between (i) developing services like the IAS, which were intended to provide a range of support, to minimise the number of support services and organisations involved (as the involvement of multiple services can increase the risk that care and support feels disjointed); and (ii) maximising different services' and organisations' comparative advantages (as different services, including the third sector, offer differing levels of value for money, flexibility, expertise and strengths). A further consideration is the diversity of people's strengths and needs. This may mean that a one size fits all solution, such as a single service trying to cater for needs ranging from independent living and life skills, health, behaviour and diet, through employment and relationships, to parenting and aging, may struggle to meet everyone's expectations. Listening to service users and learning from the experience of the IAS, which has important strengths, but which has also sometimes struggled to meet everyone's expectations, will be important in informing decisions about how best to support children and adults with autism and/or ADHD, and their families, in the future.
- 5.57. RPBs, which bring together health boards, LAs and the third sector to meet the care and support needs of people in their area, 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. This could, for example, involve expanding the role and remit of existing RPB autism sub-groups to cover autism and ADHD, and access to diagnostic assessments and to early help and support. This role should include monitoring and evaluating the effectiveness of regional and local action to ensure:

- access to early help and support when people who have, or who are suspected to have, an NDC, and/or their families, need it;
- access to a specialist ND assessment for those who would benefit from one; and
- equity of access to services and support irrespective of age, gender, ethnicity, NDC or language preference (Welsh or English).

The potential to transform experiences and outcomes

5.58. 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. 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.

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6. Annex: demand for neurodevelopmental services

- 6.1. Establishing the demand for ND services and, in particular, children's ND services and adult services such as AMHS and LD services which diagnose NDCs such as autism and ADHD, is challenging. This is because the Demand and Capacity Tool that was developed for children's ND services was judged not fit for purpose, no consistent data collection process exists (see 6.6 below), and data on referrals to adult services such as AMHS and LD services is fragmented across services.
- 6.2. Given the gaps, data from PLASC⁸⁴ was analysed to identify trends in the numbers of pupils identified as having ASD or ADHD and data on the number of referrals accepted by ND services was collected.

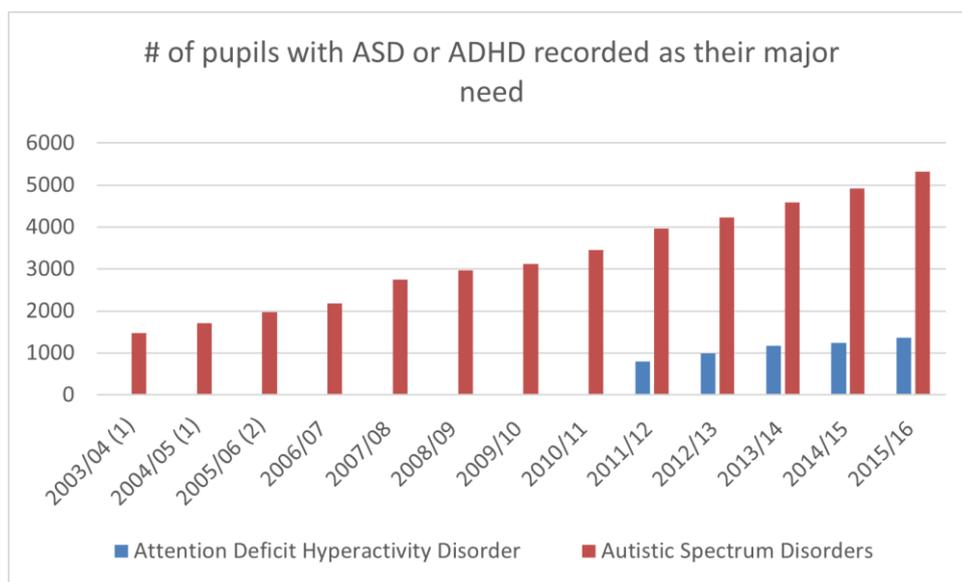
Historical trends in the numbers of pupils with ASD or ADHD

- 6.3. Data from 2003/04 to 2015/16 is available on the number of pupils whose 'major' special educational need (SEN) was autism or ADHD. The data is not available beyond 2015/16 as, from January 2017, maintained schools were allowed to report as many types of SEN for a pupil as required. As illustrated by graph 6.1., the data shows the long term increases in the number of pupils identified by schools as having ASD or ADHD⁸⁵. The increase in the numbers cannot be explained by changes in the total number of pupils, which has remained relatively stable, and is an increase also observed in the other UK nations ([McConkey, 2020](#)).
- 6.4. However, there are some concerns about the accuracy of PLASC SEN data and, for example, a formal diagnosis of ASD or ADHD would be expected if a pupil is recorded as having ASD or ADHD as a SEN, but this is not verified. This also means that those who choose not to seek a diagnosis are not included.

⁸⁴ The PLASC collects data on pupils in all maintained sector primary, middle, secondary, nursery and special schools in January each year. This includes data on pupils' special educational needs (SEN).

⁸⁵ Data on the number of pupils with ADHD as their major SEN was only collected from 2011/12 onwards.

Graph 6.1. Pupils with ASD or ADHD recorded as their major special educational need 2003/04-2015/16



Notes: 1. Nursery school data is incomplete for 2003/04 and 2004/05; 2. Rockfield (6801002) & Fair oak (6801005) Nursery Schools submitted a combined return for 2005/06; 3. ADHD was only introduced as a category in 2011/12

Source: [StatsWales](#) pupils with special educational needs by major need and year, to January 2016.

The prevalence of ADHD and ASD in the pupil population

6.5. Data on the number of pupils recorded as having ADHD or ASD as a SEN can be used to calculate the prevalence of ADHD or ASD (reported by schools) in the pupil population. Given the changes in the way the data is collected (noted above), this is only presented for the last three years. It illustrates that rates for ASD are higher than around the 1 per cent that would be expected, but rates for ADHD are markedly lower than around the 1.6-5 per cent that would be expected⁸⁶ if all children with the condition were identified and diagnosed ([NICE, 2020a](#); [NICE, 2021](#)).

⁸⁶The higher rate is based upon US studies, where rates of diagnosis are higher ([NICE, 2021](#)).

Table 6.1. The number of pupils reported by schools to have ADHD as a SEN, the total pupil population and the percentage of pupils reported to have ADHD as a SEN, in the pupil population

Year	# of pupils with ADHD	Total # of pupils	Prevalence (%)
2018/19	3,105	468,398	0.7
2017/18	2,830	467,112	0.7
2016/17	2,585	466,508	0.6

Source: [StatsWales](#)

Table 6.2. The number of pupils reported by schools to have ASD as a SEN, the total pupil population and the percentage of pupils reported to have ASD as a SEN, in the pupil population

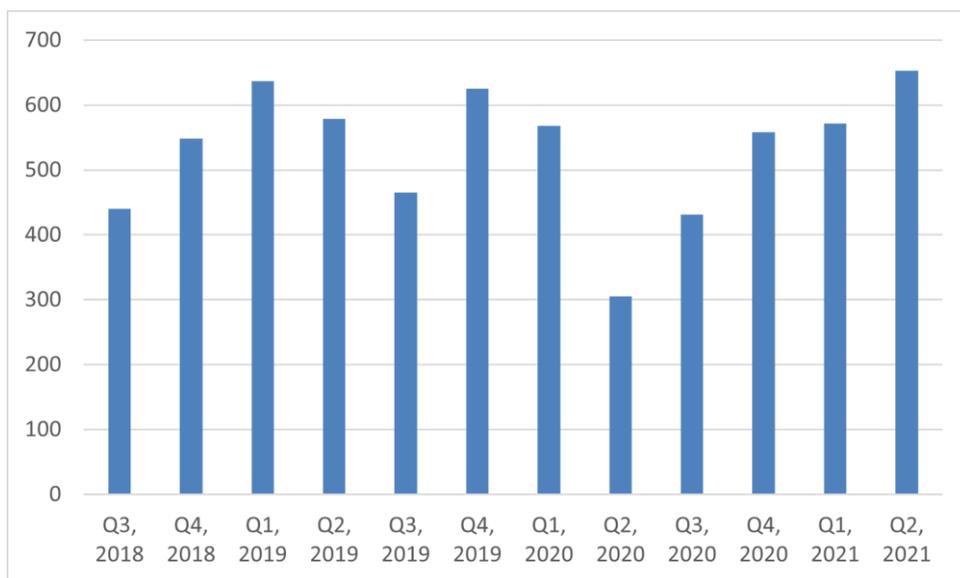
Year	# of pupils with ASD	Total # of pupils	Prevalence (%)
2018/19	9,095	468,398	1.9%
2017/18	7,655	467,112	1.6%
2016/17	6,910	466,508	1.5%

Source: [StatsWales](#)

The numbers of children referred to children’s ND services and accepted onto waiting lists

6.6. Children’s ND services were asked for the number of referrals (for diagnostic assessment) accepted by the service, to provide a measure of demand. Data was provided by four services: Aneurin Bevan University Health Board (ABUHB), Cardiff and Vale University Health Board (CVUHB), Hywel Dda University Health Board (H DUHB) and Powys Teaching Health Board. This data, illustrated in graph 6.2., suggests a high and steady level of demand, aside from the decline in referrals during the first COVID-19 lockdown in quarter 2 of 2020. This is a somewhat crude measure of demand, and, for example, it was observed that the complexity of cases was also important, as more complex cases take longer and absorb more resources.

Graph 6.2. The numbers of children referred for diagnostic assessment in each quarter of 2019/20 and 2020/21 (total for Aneurin Bevan, Cardiff and Vale and Hywel Dda University Health Boards and Powys Teaching Health Board)

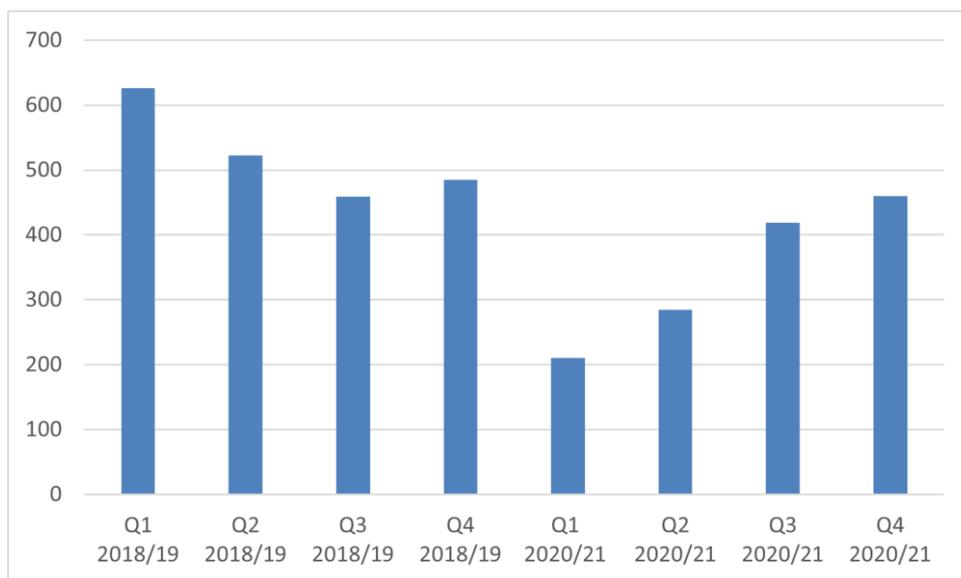


Source: Aneurin Bevan, Cardiff and Vale and Hywel Dda University Health Boards and Powys Teaching Health Board

The numbers of adults referred to IAS and accepted onto waiting lists

6.7. The NAT provided data on the number of referrals (for diagnostic assessment) accepted by IASs, to provide a measure of demand. This data suggests a high and steady level of demand, aside from the decline in referrals during the first COVID-19 lockdown in quarter 2 of 2020. This is presented in graph 6.3. This is a somewhat crude measure of demand, and, for example, it was observed that the complexity of cases was also important, as more complex cases take longer and absorb more resources.

Graph 6.3. The numbers of adults seeking diagnostic assessment in each quarter of 2019/20 and 2020/21 (total for all seven IASs)



Source: NAT

The number of adults referred to adult mental health services for an ADHD assessment

6.8. The number of adults referred to AMHS for an ADHD assessment is not known, because data is fragmented across multiple services. However, some indication is provided by the adults' ADHD service in Hywel Dda which reports that they have 600-700 people on their waiting list, and that demand is increasing, with 74 new referrals in the month of July 2021. Written comments made by psychiatrists in the online survey of RCPsych members also highlighted, for example, what one described as the 'exponential' increase in demand for ADHD assessments that their CMHT was experiencing.

7. Annex: ND services' capacity to undertake diagnostic assessments

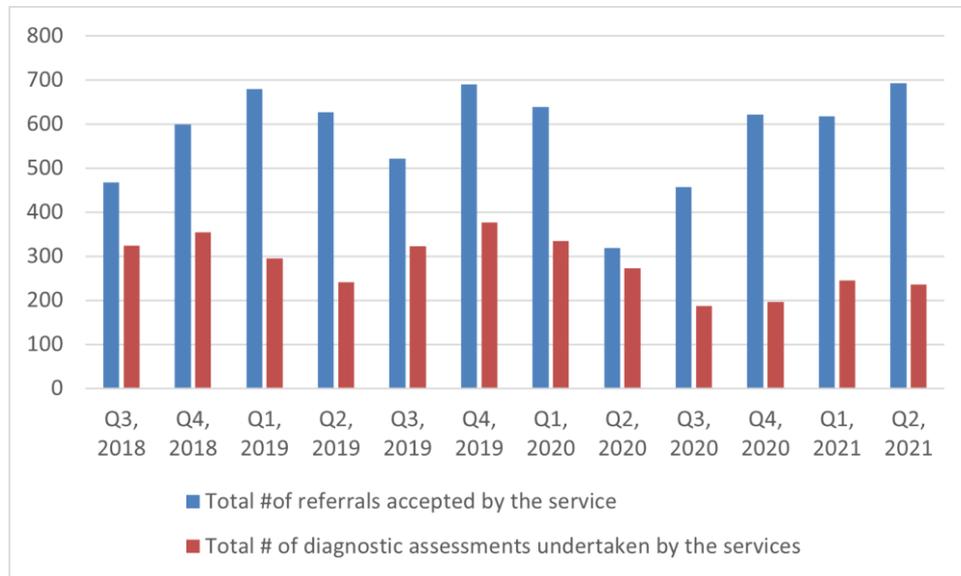
Introduction

- 7.1. Establishing the capacity of ND services and specifically children's ND services and those adult services such as AMHS and LD services which diagnose NDCs such as autism and ADHD, is challenging. As outlined in section 4, the Demand and Capacity Tool that was developed for children's ND services was judged not fit for purpose. Data on capacity in adult services, such as AMHS and LD services, is fragmented across services.
- 7.2. Given the gaps, data on activity (in terms of the number of diagnostic assessments undertaken) was requested from each children's ND service, and provided by Aneurin Bevan, Cardiff and Vale, Hywel Dda and Powys Health Boards, and provided by the NAT for the IASs, to provide an approximate measure of capacity.

The size of the demand-capacity gap facing ND services

- 7.3. As graph 7.1 illustrates, the number of children seeking diagnostic assessment has consistently been higher than the number of diagnostic assessments undertaken in the four health boards that provided data. Both demand and activity fell during lockdown, but activity remains lower than it did pre-pandemic, while demand has increased again. Over the period (quarter 3 2018 to quarter 2 2021) 6,381 children were referred for an assessment and 3,160 assessments were undertaken, meaning that, for roughly every two children seeking an assessment, one assessment was undertaken.

Graph 7.1. The numbers of children referred for diagnostic assessment and the number of children assessed in each quarter of 2019/20 and 2020/21 (total for Aneurin Bevan, Cardiff and Vale, and Hywel Dda University Health Boards and Powys Teaching Health Board)



Source: Aneurin Bevan, Cardiff and Vale, and Hywel Dda University Health Boards, and Powys Teaching Health Board

7.4. As tables 7.1-7.3 illustrate, the consistent gap between demand and capacity has created an ever-growing backlog and ever-lengthening waiting lists in the three LHBs ND services that were able to provide this information.⁸⁷

⁸⁷ In addition, Hywel Dda ND service provided data on the total number of new referrals each year, but could not easily provide data on the total number of children on the waiting list in any one year, so the data was not directly comparable and has not been included in table 7.1..

Table 7.1. The number of children on the waiting list in Aneurin Bevan and Cardiff and Vale University Health Boards and Powys Teaching Health Board

	2019	2020	2021
ABUHB	234	410	336
CVUHB	423	676	818
PTHB	174	143	203

Source: ABUHB, CVUHB, and PTHB

Table 7.2. The average referral to assessment waiting time in Aneurin Bevan and Hywel Dda University Health Boards and Powys Teaching Health Board (weeks)

	2019	2020	2021
ABUHB	27	28	32
HDUHB	54	55	70
PTHB	N/A	53*	30

**It was noted that waiting times increased sharply in 2020 due to the impact of COVID-19 upon activity*

Source: ABUHB, HDUHB and PTHB

Table 7.3. The longest referral to assessment waiting time in Cardiff and Vale University Health Board (weeks)

	2019	2020	2021
CVUHB	35	60	109

Source: CVUHB

Constraints upon capacity in ND services

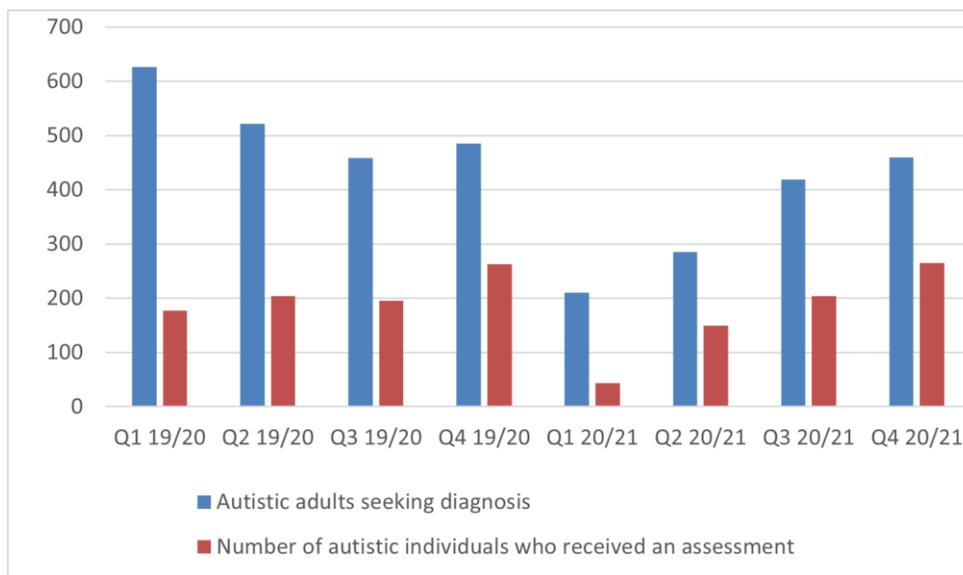
7.5. As outlined in section 3, it was reported by interviewees from both children's ND services and IASs that their capacity was constrained by the following three factors, each of which is discussed in further detail from paragraph 7.9:

- compliance with NICE guidelines;
- the small size of teams; and
- a range of more specific constraints, issues or bottlenecks that limited teams' ability to use staff time as efficiently or effectively as they wished.

The size of the demand-capacity gap facing IASs

7.6. As graph 7.2 illustrates, the number of adults seeking diagnostic assessment has consistently been higher than the number of diagnostic assessments undertaken⁸⁸. Both demand and activity fell during lockdown. While demand remains lower than it was before the pandemic, activity has now returned to peak pre-pandemic levels. Over the period (April 2019-March 2020 and April 2020-March 2021) 3,466 adults sought an assessment, and 1,502 assessments were undertaken, meaning that for just over every two adults seeking an assessment, one assessment was undertaken (the ratio of adults seeking an assessment to assessments undertaken was 2.3:1).

Graph 7.2. The numbers of adults seeking diagnostic assessment and the number of adults who received an assessment in each quarter of 2019/20 and 2020/21 (total for all seven IASs)

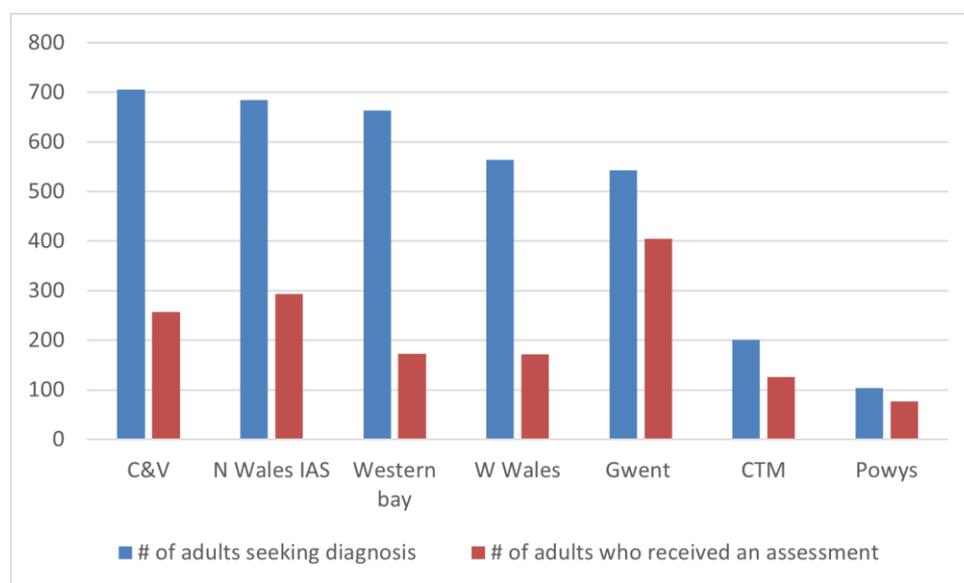


Source: NAT

7.7. As graph 7.3 illustrates, the national data masks considerable variation across IASs in terms of both demand and activity.

⁸⁸ The data has limitations; for example, some of those adults seeking a diagnostic assessment will not be accepted by an IAS, although the numbers are reported to be small. They may, for example, live in a different health board area or may not provide sufficient information. However, data on the numbers of adults seeking a diagnostic assessment who are accepted by each IAS is not currently available. The impact of COVID-19 upon both demand and capacity also makes it difficult to extrapolate future trends based upon the historical data.

Graph 7.3. The number of adults seeking diagnostic assessment and the number of adults who received an assessment in 2019/20 and 2020/21 in each IAS



Source: NAT

7.8. As table 7.4. illustrates, differences in demand and capacity mean the average waiting time from a referral being accepted to intervention varies considerably across IASs.

Table 7.4. Average weeks from referral accepted to start of intervention (2019/2020) for each IAS

IAS	Weeks
Cardiff and Vale	38.5
Cwm Taf Morgannwg	62
Gwent	45
North Wales	37
Powys	52
West Wales	95
Western Bay	17.3

Source: NAT

NICE guidelines

- 7.9. Striking the balance between quality, by ensuring compliance with NICE guidelines, and streamlining the diagnostic assessment process, was seen as a challenge for both children's ND services and IASs. Although the guidelines helped dictate services' capacity (in terms of the numbers of assessments that could be undertaken) and different judgments were made about how much the process could be streamlined, they were consistently reported to be important. It was observed by interviewees from both children's ND services and IASs, that if 'streamlining' was taken too far, the quality of assessments was likely to fall, as they would, for example, provide less information on a person's strengths and difficulties, which is vital to inform support strategies, and the risk of misdiagnosis was felt likely to increase.
- 7.10. There was some scepticism within both children's ND services and IASs as to whether diagnostic assessments conducted elsewhere met this 'gold standard'. In particular, the quality of assessments in AMHS and in private practice were questioned.

ND services' staffing: size and structure

- 7.11. The small size of ND teams necessarily limits their capacity, as a diagnostic assessment, particular for autism, is a complex and lengthy, multi-disciplinary process, with a number of different elements⁸⁹.
- 7.12. The structure and skill mix of teams and the time each team member can devote to diagnostic assessments are further constraints upon each service's capacity. As a complex multi-disciplinary process, bottlenecks can develop where the time of specific staff who must be part of the process (given their expertise or role prescribing and monitoring ADHD medication) is limited. The 'virtual' structure of some children's ND services, with staff who contribute to ND assessments but who are not formally part of the ND service, can also

⁸⁹ Data from children's ND services and the IAS suggests that a diagnostic assessment of autism typically requires around 10-15 hours of clinical time, but may take longer when the case is complex. In contrast, a diagnostic assessment for ADHD can be done by a single clinician and takes much less time (around 3 hours).

contribute to this, as virtual staff can face conflicting demands upon their time, which can mean they cannot contribute to an ND assessment as planned.

7.13. Recruitment of staff was reported to be a challenge for many (although not all) children's ND services and IASs. As one interviewee from a children's ND service summed it up: 'we can't recruit more staff; there's not the people out there'. A member of the NAT reported how ND services and IASs were often in effect competing to recruit the same staff, and examples where staff had left one service to move to another were given. Recruiting experienced staff was seen as a particular challenge.

7.14. Retention of staff was also a challenge in some areas and the loss of experienced staff was a particular concern. This reflected the heavy emotional demands of the role which were highlighted by interviewees from both children's ND services and IASs; these were linked to:

- the nature of the work, which could be dominated by diagnostic assessments, crowding out potentially more rewarding work and which could be very upsetting given, for example, the difficulties some patients and/or families experienced due to the effects of NDCs, difficulties accessing a diagnostic assessment and/or support – frustration that was sometimes taken out on staff;
- the small size of teams, which increased their fragility or vulnerability to staff absences (e.g., due to maternity leave or sickness); and
- limited capacity relative to the level of demand services experienced, which increased the pressure upon services from LHBs and adults or families.

7.15. These challenges could become mutually reinforcing; as an interviewee from a children's ND service observed, recruitment and retention 'became harder' as waiting lists increased and staff absence increased (e.g. due to sickness).

Other constraints upon staff activity and capacity

7.16. A number of other factors which constrained how efficiently staff time could be used were identified by children's ND services and IASs; they included:

- problems with accommodation⁹⁰; as one interviewee from an IAS asked (rhetorically): ‘how can you plan assessments over a three-month block if you don’t know what rooms are available?’ as they did not have dedicated space
- delays in completing any stage of the diagnostic assessment process, which could have knock on effects. These included problems with referrals, particularly for children’s ND services, where, for example, there was a lack of supporting documentation⁹¹, delays accessing reports or patients missing appointments, although the latter was generally not seen as a major constraint;
- difficulty in accessing equipment such as laptops that complied with data security requirements, which was a particular problem when staff were trying to work from home during the COVID-19 lockdown;
- other demands upon their time, such as dealing with requests for advice or support could be ‘very time consuming’, as one interviewee from children’s ND services put it. The time needed to build and maintain relationships with other services⁹², which was important to, for example, help manage inappropriate referrals from other services, responding to complaints and managing staff, with the integrated structure of IASs, was reported to cause some problems⁹³; and
- the lack of administrative support which meant that, for example, clinicians were undertaking tasks that could be done by administrative staff.

⁹⁰ As one ND service reported: ‘there is a problem with finding clinical space for assessments. There is no special space. They try to do ADOS [Autism Diagnostic Observation Schedule] and assess at the same time to avoid families having to come twice but this means they need a room all day. The teams cover a large area and if you cannot find a room you have to ask families to travel a long way on public transport which is not very frequent’.

⁹¹ This was a particular concern as one interviewee from a children’s ND service observed: ‘the clock [measuring compliance with the waiting time target] does not stop even if documents were missing’. Examples were given where referrals were not received (lost in the post or sent to the wrong email address) or not made by professionals and it was reported that chasing them up takes time.

⁹² The IAS also offers advice and, as one interviewee from an IAS put it: ‘requests for support from professionals increased during the pandemic because of increase in distress and anxiety, so requests for advice and consultation’ tripled. Fortunately, they were able to meet this demand, because the demand for diagnostic assessments fell.

⁹³ For example, as one interviewee from an IAS explained, IAS support staff managed complex cases, so they needed supervision to ensure safe practice. The management of support staff who were employed by the LA, by IAS staff who were employed by the LHB, was also reported to have caused difficulties in some areas.

- 7.17. COVID-19 increased the challenges linked to accommodation, as some services found it difficult to find clinical spaces that were COVID safe⁹⁴, and moves to home working and online assessments increased the importance of access to effective and secure IT equipment.
- 7.18. It was also reported by children's ND services that COVID-19 limited activities like observations by specialist nurses, which were delayed while nurseries and educational settings were closed during lockdowns, and when they re-opened, constrained by rules on class bubbles, which limited the number of pupils they could observe during each visit.

Staff skills and confidence

- 7.19. The speed with which staff could complete each stage of the process depended in part upon their skills and experience (with more skilled and experienced staff swifter than those with fewer skills and less experience). Matching patients to the right staff (and skills) through an effective triage process was therefore seen as important, but also took time.
- 7.20. In addition, as noted, a lack of skills and confidence beyond interviewees' core areas of expertise (such as autism or ADHD) limited their capacity to identify and diagnose other types of NDC or handle complex cases.

Constraints upon capacity in AMHS and LD services

- 7.21. For psychiatrists in CMHTs or LD services who were currently undertaking diagnostic assessment of ASD, who responded to the online survey (n=10), the main barrier was 'lack of time to undertake a diagnostic assessment'. This is consistent with feedback from interviewees from AMHS and LD services; other barriers were reported to be:
- delays or problems accessing reports or information required to complete a diagnostic assessment;
 - delays or problems securing the involvement of other professionals in the diagnostic assessment; and

⁹⁴ As one interviewee from an IAS put it, 'rooms had to be big enough to be COVID safe', so 'spent a lot of time searching for venues'.

- complex presentations (e.g. where there are suspected to be co-occurring conditions).

7.22. For psychiatrists in CMHTs or LD services who were currently undertaking diagnostic assessment of ADHD, who responded to the online survey (n=13), the main barrier was 'lack of time to undertake a diagnostic assessment', and for those in LD services, 'complex presentations'; for example, as one respondent put it in a written comment:

'There is no current diagnosis service for adult ADHD in [LHB], which has been an unacceptable unmet need for some time. This is mainly because of very high caseloads of adult psychiatrists and not having time to do proper assessments and also due to lack of resources to safely initiate treatment and monitor. There should be a dedicated neurodevelopment service for adults in [LHB].'

Similarly, as another respondent put it in a written comment:

'Adult ADHD diagnosis and treatment initiation and monitoring is needed. ...We have had an explosion of new referrals for diagnosis and treatment of ADHD such that these outnumber referrals for all other conditions combined. Furthermore, we have only one doctor qualified to make diagnostic assessments in our Health Board, and his waiting list is now five years.'

7.23. Other barriers included:

- delays or problems securing the involvement of other professionals in the diagnostic assessment; and
- complex presentations (where there are suspected to be co-occurring conditions).

7.24. Lack of training or experience in relation to autism or ADHD was not seen as a barrier for psychiatrists in CMHTs, although it was reported to be a barrier for some psychiatrists in LD services⁹⁵. Written comments suggest that this

⁹⁵ Although it should be noted that this was only asked of those currently undertaking diagnostic assessments of autism, so may exclude those who do not undertake them because they lack training and/or experience.

may have been interpreted as a barrier for the whole service, rather than the individual respondent. One respondent commented that, in their view, there needed to be 'more training in diagnostic assessments across wider MDTs so one discipline is not completing all the assessments.' This is consistent with feedback from interviewees from AMHS and LD services which highlighted the reliance upon individual clinicians with an interest and expertise in autism and/or ADHD.

- 7.25. Given these barriers and the small number of clinicians undertaking diagnostic assessments for ADHD, there was also a strong view amongst respondents that there was not sufficient capacity to meet the demand for diagnostic assessments for ADHD or to provide post-diagnostic support for adults in the health board they worked in; for example, one of the written comments described the 'exponential increase in referrals' they experienced.