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Scoping Study for the Alignment and Development of Autism and Neurodevelopmental Services

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Views expressed in this report are those of the researcher and not necessarily those of the Welsh Government

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Glossary

Acronym Definition

ADHD	Attention Deficit Hyperactivity Disorder ADHD is a neurodevelopmental disorder associated with inattention and/or hyperactivity/impulsivity.
ADOS	Autism Diagnostic Observation Schedule
ALN	Additional Learning Needs Learners are defined as having additional learning needs when they have a learning difficulty or disability, which means they need additional learning provision.
ALNET	Additional Learning Needs and Education Tribunal [Act] The ALNET is the new legal framework to support children and young people with additional learning needs.
ASCC	Autism Spectrum Connections Cymru
ASD	Autistic Spectrum Disorder Autism is a lifelong developmental condition that affects how people think and experience the world. It can affect people's communication, understanding of others and their behaviour.
BIU	Brief Intervention Unit
CAMH	Centre for Addiction and Mental Health
CAMHS	Child and Adolescent Mental Health Service CAHMS assesses and treats children and young people with emotional, behavioural or mental health difficulties.
CAPA	Choice and Partnership Approach
CCH	Community Child Health
CMHT	Community Mental Health Team CMHTs support people living in the community who have complex or serious mental health problems.
DISCO	Diagnostic Interview for Social and Communication Disorders
IAS	Integrated Autism Service
ICF	Integrated Care Fund
GP	General Practitioner

LA	Local Authority/Authorities
LD	Learning Disability
LHB	Local Health Board
MH	Mental Health
NAS	National Autistic Society
ND	Neurodevelopmental
	Neurodevelopmental disorders are disabilities that affect the functioning of the brain such as behaviour or the ability to learn.
NICE	National Institute for Health and Care Excellence
OECD	Organisation of Economic Co-operation and Development
PHW	Public Health Wales
PSB	Public Service Board
RCP	Royal College of Psychiatrists
RPB	Regional Partnership Board
RPS	Royal Psychological Society
SAP	Strategic Action Plan
SCAIT	Social Communication Assessment and Intervention Teams
SEN	Special Educational Needs
SLT	Speech and Language Therapy
SSWBA	The Social Services and Wellbeing (Wales) Act
	The act provides the legal framework for improving the well-being of children and adults who need care and support, and their carers, and for transforming the way care and support is provided.
T4CYP	Together for Children and Young People
	The T4CYP programme was launched in February 2015 to reshape and refocus emotional and mental health services for children and young people. One of its work streams focuses upon developing neurodevelopmental services for children and young people.
WG	Welsh Government
WLGA	Welsh Local Government Association

Describing autism, ADHD, regions and health board areas

The language to best describe autism is difficult, as different people prefer different terms. There is some evidence that there has been a shift toward more assertive language, such as “autistic adults”, rather than “adults with autism” (NAS, no date.) and we have chosen to use this where appropriate in this report. However, where, for example, we directly quote someone or a report that uses other descriptions, such as “adults with autism”, we use those. There is less evidence on the preferences of adults with ADHD and we have chosen to use the language “adults with ADHD”.

In the report we refer to children and young people’s neurodevelopmental (ND) services by Local Health Board (LHB) area and the Integrated Autism Service (IAS) by region, to reflect the differences in their management.

We refer in the report to Abertawe Bro Morgannwg and Cwm Taf Health Boards. After the report was completed, but before publication, these boards changed to Swansea Bay and Cwm Taf Morgannwg Health Boards respectively.

Summary

In February 2015, the Welsh Government launched the Together for Children and Young People (T4CYP) Programme. The programme included a focus upon addressing the needs of children and young people with neurodevelopmental (ND) disorders, such as Attention Deficit Hyperactivity Disorder (ADHD) and autism, and led to the establishment of a national “assessment pathway” (a description of how children can access ND services and how they should be assessed) and ND teams in each Local Health Board (LHB).

In March 2016, as part of the refreshed Autistic Spectrum Disorder Strategic Action Plan (ASD SAP), the Welsh Government announced that it would be funding a new national Integrated Autism Service (IAS) to help fill gaps in assessment and diagnostic services for adults and in post-diagnostic support for adults and support for parents and carers.

Children and young people’s ND services and the IAS were developed in parallel, and this study was commissioned to review the alignment of children and young people’s ND services and the IAS services, and to explore evidence-based options for improving services, including action to address waiting times for assessment and diagnosis.

Approach and methodology

This review draws upon in depth interviews with children’s and young people’s ND services and IASs in each of the seven LHBs/regions; mental health (MH) services in six LHBs/regions (Abertawe Bro Morgannwg/Western Bay, Betsi Cadwaladr/North Wales, Cardiff and Vale, Cwm Taf, Hywel Dda/West Wales and Powys)¹; the Welsh Local Government Association (WLGA), the National Autism Team, the Welsh

¹ The evaluation team had spoken to representatives of MH services in Aneurin Bevan/Gwent before the extension to the work was agreed. Therefore, the opportunity to explore questions about the alignment and development of autism and ND services with MH services in Aneurin Bevan/Gwent was missed.

Government and also voluntary sector organisations representing autistic people or children and adults with ADHD, and their families. The review also draws upon data gathered from autistic adults and families interviewed as part of the evaluation of the IAS and refreshed ASD SAP (WG, 2019a). A small number of interviews with adults with ADHD or parents/carers were undertaken where opportunities arose. Interviews were complemented and strengthened by a systematic desk-based review of autism, ADHD and/or ND services, both within the UK and internationally.

Emerging findings from interviews and the desk-based literature review were discussed at two workshops, bringing together representatives from five ND services and five IASs, and representatives from Public Health Wales (PHW) and the Welsh Government to consider, develop and validate findings and recommendations.

The study was commissioned as an extension to the evaluation of the ASD SAP. As a result, the scope to review provision for autistic individuals and their families was much greater than the scope to review provision for individuals with ADHD and their families. Most of the data on provision and the experiences of individuals with ADHD and their families came from interviews with staff from ND, IAS and MH services and the literature review. Therefore, as outlined in the report, further research to explore provision for adults with ADHD, and the experiences of families of children with ADHD, is warranted.

Demand, capacity and waiting times for assessment and diagnosis

Waiting times can be measured in different ways. These include measuring the length of time:

- from a referral to the ND service/IAS being accepted to the first appointment, which is the basis of the 26 week (six month) waiting time target for children and young people's ND services, and the measure used in this report; or
- from a concern about a child or young person first being raised, such as a school identifying the possibility that a child or young person may be autistic,

to the time of diagnosis. The time this takes can mean it can be over a year before a diagnosis is made, even if the waiting time target is met. This may capture the length of time that many parents or carers feel they have waited for answers and support, often at a critical time in their child's development. However, it would be difficult to measure consistently and is not currently measured or routinely reported on.

- from a referral to the ND service/IAS being accepted to completion of the assessment and diagnosis (and this being communicated to families or adults), which is also not currently measured or routinely reported on.

Children and young people's ND services and, at the time of the evaluation, those IASs that were fully operational (Cardiff and Vale, Cwm Taf, Gwent and Powys) were all struggling with higher than anticipated demand. Waiting times for referral to initial assessment in children and young people's ND services ranged from around six months (which is in line with the statutory target) to up to two years. Waiting times from referral to initial assessment in IASs range from around six to twelve months.

The data collected for this study indicate that there is no single cause for this level of demand, and instead a combination of different factors have had a large cumulative impact upon demand. The four key drivers of demand are:

- increasing awareness amongst families and professionals of both autism and ADHD and also the new services, which increases the likelihood that individuals will be identified and referred to other services;
- changes in thresholds for referral and diagnostic criteria;
- families' and schools' expectations of the need and value of diagnosis in order to access services and also to provide an explanation of the challenges autistic people or people with ADHD face; and
- the legacy of assessment and diagnostic services in the past, which often lacked the capacity to meet demand, creating a backlog of cases for new services.

Action to address waiting times

Action to address waiting times can focus upon reducing demand and/or increasing capacity. In order to manage demand, ND services and the IAS have adopted three key strategies:

- prevention, where services have sought to reduce the need or demand for assessment and diagnosis that comes from people needing a diagnosis in order to access support or services;
- gatekeeping, where services have sought to regulate who can be referred to services, by for example prescribing how referrals must be made and what information is needed before a referral can be accepted; and
- mitigation, where services have sought to minimise the impact of lengthy waiting times upon children, adults and families, by for example, providing information and access to support while children, adults and families are waiting.

The scope for prevention by ND services and the IAS has been limited, as the causes of increasing demand, such as the expectation that a diagnosis is necessary to access support, are largely beyond individual services' control. Gatekeeping has helped improve the quality of referrals, but for ND services this may only defer demand, as there are few other services to which they can refer children or adults. In contrast, gatekeeping is a key strategy for the IASs, which can refer some adults to MH and Learning Disability (LD) services for diagnostic assessments. Mitigation has not reduced demand, but may improve the experiences of children, adults and families while waiting.

Action to increase capacity can focus upon:

- making better use of the available resources through efficiencies, such as streamlining assessments; and
- increasing the total size of the resources, either by diverting other resources, as children and young people's ND services have done by reducing post-diagnostic support, or by accessing additional funding.

There is considerable variation in practice, particularly across ND services, and benchmarking across services may enable individual services to identify further marginal efficiencies. However, the scope to further streamline the assessment process in ND services and IASs is likely to be limited by:

- staffing, including the size of staff teams, their skills and confidence, which can be limited by difficulties with recruitment or absence (e.g. due to maternity leave or sickness);
- differing views on quality, compliance with NICE guidelines and consequently what is robust enough, and therefore how far the process can be streamlined by, for example, involving fewer clinicians and reducing the time spent on different stages of the process;
- the difficulties many services have found in securing adequate accommodation (or premises), which can make it difficult to schedule assessments (delaying the assessment process) or, for example, offer single contact assessments and which can lead to clinicians travelling between sites (which takes time);
- the size and rurality of some regions which means clinicians and/or families have to travel long distances, and which can compound difficulties finding suitable clinical space and accessing IT systems; and
- limitations in IT and administrative support, which can make booking, managing, and monitoring the process more difficult and also lead to difficulties in accessing clinical records, which can delay assessments.

Both children and young people's ND services and IASs were clear that there had to be, as one interviewee from an ND service put it, an "honest discussion about capacity", because "a quality assessment takes time"; a sentiment shared by many interviewees from ND services and IASs.

There is little scope to divert additional resources from services' existing budgets. ND services have either not offered or cut back post-diagnostic support to the minimum in order to maximise the resources available for assessment. IASs are very reluctant to cut post-diagnostic support, questioning the value of offering a diagnosis without support or intervention.

Neurodevelopmental service models in the UK and OECD

There are three broad types of service delivery model for ND disorders:

- no formal pathway or designated service for assessment and diagnosis of ND disorders;
- a formal pathway with multiple secondary services, such as Children and Adolescent Mental Health Services (CAMHS) or Community Mental Health Teams (CMHTs) designated to undertake assessment and diagnosis of some or all ND disorders. Provision for adults with ADHD in parts of Wales is an example of this; or
- a formal pathway with a specialist multidisciplinary service or services, established either within existing services (e.g. CAMHS or CMHTs) or as a separate service (e.g. Children and young people's ND services and the IAS), designated to undertake assessment and diagnosis of some or all ND disorders. There are also examples of adult ADHD and autism and adult ND services in other parts of the UK and the Organisation for Economic Co-operation and Development (OECD)². There are also examples of services that

² The OECD is a membership organisation of 36 mostly advanced industrialised market economies. The literature review focused upon OECD countries, as services in these countries were likely to be comparable to the UK, and it ensured that the search was not limited to European countries (which could have been an alternative focus for the literature review), and could for example, include practice in North America.

describe themselves as “all age” ND services, but in practice, pathways and provision for children and adults are separate/different.

There are a number of variations on these three basic models. These include differences in:

- pathways and services for people of differing ages (such as different pathways for younger and older children/young people);
- pathways depending on the complexity of presentation and/or ND disorder (such as different pathways for autism and ADHD); and
- levels of post-diagnostic support.

The alignment and development of autism and neurodevelopmental services

Development of children’s and young people’s ND services started before the IAS. Efforts were made to align the two services, but stalled and opportunities to integrate the services were felt by some stakeholders from ND services and IASs to have been missed. However, as children and young people do not make a transition from ND services to the IAS, the main interface between the two services is around post-diagnostic support for parents or carers of children with autism. Good working relationships have been established between children and young people’s ND services, IASs and local authorities (LAs) in the three regions where the IAS was first established (Cardiff and Vale, Gwent and Powys) (WG, 2019a).

The development of services is a more complex issue. There is asymmetry in the current configuration of services, with a service for children and young people that deals with a range of ND issues, but offers very little post-diagnostic support, and a service for autistic adults and families (the IAS), but not for other ND disorders.

This study could not undertake a comprehensive assessment of the needs of children and adults with ND disorders other than autism (and their family members), or of service provision. Nevertheless, the available evidence suggests a plausible, but not yet proven (*prima facie*) case for strengthening support for adults with ND disorders, such as ADHD, and also for parents or carers of children with ADHD, just as the IAS and action supported by the ASD SAPs have helped strengthen support for autistic children, adults and their families over the last ten years. The gaps in relation to ND disorders (other than autism), include:

- a lack of clarity about referral pathways for adults, and potential difficulties where there are co-occurring conditions, so an adult might be assessed for ADHD by one team and for autism by another team;
- limited capacity in assessment and diagnosis for adults, given the small size of teams and, in some cases, a lack of training and expertise, which contributes to differences depending on where you live in provision and waiting times (sometimes described as “post code lotteries”), gaps in provision and fragility of services; and
- limited post-diagnostic support, beyond medication and observation, for children and adults, and very limited support for families.

In many ways, the context appears to be similar to the position for autistic adults before the All Wales Adults Clinical Network and Community Monitoring and Support projects and later the IAS were established.

Conclusions and options for the alignment and development of neurodevelopmental and autism services in Wales

The reason for long waiting times for diagnostic assessments for children and adults is a mismatch between demand and capacity. Demand for assessment by both ND services and also the IAS has been higher than anticipated and the scope to increase capacity has been limited. Differences in the level of demand and in the capacity of different services causes variations in waiting times in different regions.

The scope to reduce demand or increase capacity further is constrained, and additional resources will be needed to increase capacity (e.g. by expanding the size of teams and/or funding waiting list initiatives).

There is no clear consensus amongst children and young people's ND services or IASs on a preferred service model, such as an adult ADHD service or ND service or an all age ND service. In general staff from children and young people's ND services support the idea of establishing an adults' ND or an all age ND service, whilst staff from IASs are concerned about the potential impact on existing services of such a move.

There appear to be gaps in services, particularly in relation to neurodevelopmental disorders other than autism, like ADHD, which have not benefited from the attention and resources devoted to autism. Therefore, there is a plausible, but not yet proven (*prima facie*) case for developing services for adults and parents and carers. However, the evidence base for the cost effectiveness of different service models is limited. For example, as the NICE Guidance ([2012, updated in 2016](#)) on autism notes "There is little evidence to guide the establishment and development of these teams". Moreover, the evidence, including the lessons from the establishment of ND services and the IAS in Wales, is clear that integrating existing services or developing new integrated services is difficult, costly and takes time. It would also potentially disrupt existing services which are already fragile, given high levels of demand and, particularly in the case of the IAS, still establishing themselves. Therefore, while there are potential gains, the case for further development and, if appropriate, integration of existing services to create, for example, an adult ND service needs to be very well founded.

Recommendations

Recommendation 1: The T4CYP National Steering Group, PHW, the National Autism Team and the IAS Community of Practice should support benchmarking of practice across services in order to identify potential efficiencies and improvement to assessment processes.

Recommendation 2. Children and young people's ND services and IASs should provide a strategic plan setting out the number of assessments that they can do in a year; identifying what this means for their waiting lists and making costed proposals on how to increase capacity so it matches demand. LHBs will need to consider the impact of this upon other services.

Recommendation 3. The Welsh Government, LHBs and LAs should review the funding for children and young people's ND services and the IAS to ensure it is commensurate with the demand they face. Consideration will need to be given to the impact of this upon funding for other services.

Recommendation 4. The T4CYP National Steering Group, Public Health Wales (PHW) and the National Autism Team should continue to support the further alignment of services through, for example, joint meetings and training.

Recommendation 5. Service leaders in children and young people's ND services and IASs should continue to collaborate and ensure that where alignment is needed (e.g. around post-diagnostic support for the families of autistic children) the interface between the two services is well managed, and that opportunities for the services to share practice and expertise and improve alignment (e.g. through collocation of services) are taken.

Recommendation 6. Regional Partnership Boards (RPBs), PHW and the National Autism Team, should monitor how effective the alignment and interface between the two services is. This should focus upon the key points of alignment: post-diagnostic support for parents or carers of autistic children and assessment and diagnosis for young people approaching adulthood (where an assessment by the IAS may be more appropriate). This could include, for example, services reporting on joint working in these areas as part of their service monitoring.

Recommendation 7. Further work to inform the development of services for individuals with ADHD, and/or ND disorders other than autism, and their families, is undertaken. This should focus upon identifying needs and gaps in service provision. This could be taken forward at a national level (for example, led by the Welsh Government and/or PHW) and at a regional level (for example, led by LHBs and/or RPBs).

Recommendation 8. Any proposed development of services should be done co-productively, involving individuals with ND disorders, their families and also existing services, such as children and young people's ND services, IASs and CMHTs. This could include, for example, the involvement of "experts by experience" (people with experience of ADHD or autism or of caring for someone with ADHD or autism) and the voluntary sector in national and regional working and steering groups tasked with developing services.

Recommendation 9. ND and IAS service leaders should ensure that any steps to further align ND services and the IAS do not unduly compromise or undermine steps to align and manage the interface of the children and young people's ND service and IAS with other services, such as education and mental health and social care.

Recommendation 10. Given the weakness of the evidential base for the cost-effectiveness of specialist integrated services like the IAS and children and young people's ND services, further evaluation is warranted to inform the future development of services. This should be undertaken by services themselves (self-evaluation) and also feature in evaluations commissioned at a national level by the Welsh Government, National Autism Team and/or Public Health Wales and at a regional level, by for example, RPBs and/or LHBs.

1. Introduction

Neurodevelopmental disorders

1.1. Neurodevelopmental (ND) disorders are disabilities that affect the functioning of the brain such as behaviour or the ability to learn. Autism and Attention Deficit Hyperactivity Disorder (ADHD) are the most common ND disorders (PHW, 2016). Wales's ND pathway for children and young people was initially established for Autism and ADHD and this report focuses primarily upon these two conditions. Other disorders include language and communication impairments and moderate learning disabilities.

Autism and ADHD

1.2. Autism is a lifelong developmental condition that affects: "how a person communicates with and relates to other people, and how they experience the world around them"³. Around one per cent of children and just over one per cent of adults are estimated to have autism⁴, although many adults, in particular, are likely to be undiagnosed (Baron-Cohen, 2008).

1.3. ADHD is a neurodevelopmental disorder associated with inattention and/or hyperactivity/impulsivity. The core defining features of ADHD tend to decline with age, with around a third of children diagnosed no longer meeting the full criteria for a diagnosis of ADHD in adulthood (PHW, 2016). Around three to nine per cent of children and three to four per cent of adults are estimated to have ADHD (NICE, 2018, 2011).

³ See: [What is Autism?](#)

⁴ The prevalence rate is based on two studies: one of children (Baird G. et al., 2006), which focused upon a sample of children in the South Thames area, and one of adults (Brugha, et al, 2009 and Brugha, et al, 2012) (BPS and RCP, 2012).

- 1.4. Like other complex medical and psychiatric disorders, both autism and ADHD are associated with a wide range of symptoms, skills and levels of disability. The impacts of autism and ADHD depend on the nature and severity of the disorder and are also affected by individual, family and social factors. The combination of both determines levels of disability (PHW, 2016).
- 1.5. Co-occurrence of different ND disorders, including ADHD, autism and learning disabilities, is common (NICE 2018, 2011); for example, some research argues that it: “will be rare to find an individual who presents with so-called uncomplicated ADHD, even if full diagnostic criteria for other co-morbid disorders are not met.” (Thapar & Cooper, 2015).

Assessment and diagnosis

- 1.6. Timely access to assessment and diagnostic services can help ensure that an individual’s needs are understood and appropriate services are put in place to support them to lead fulfilling lives. It can also help people, and their families and friends, better understand their lives and experiences (WG, 2016a). Although ND disorders like autism and ADHD can (and should) be identified and diagnosed at a young age, some people do not receive a diagnosis until adulthood.

Children and young people’s ND services

- 1.7. The T4CYP was launched in February 2015 to reshape and refocus emotional and 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. In some instances, families were waiting years to access assessment and support” (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 those with ADHD (ibid.).

The Integrated Autism Service

- 1.8. The IAS was launched in 2016 to: “address weaknesses and inconsistencies in the provision of assessment, diagnosis and post-diagnostic support for adults without either a moderate or severe learning disability or mental health difficulty” (WG, 2016a, p.18). Adults with a moderate to severe learning disability or mental health condition continue to be seen by LD and MH services⁵. The service also provides post-diagnostic support for the families of autistic children.
- 1.9. The IAS and the ND work stream of the T4CYP programme are intended to ensure that good practice is implemented consistently across Wales and increase the sustainability of services through new national standards and increased funding (£2m for ND services and £13m for the IAS). The new standards for ND services⁶ (underpinned by investment) are intended to: “reduce the time from referral to diagnostic assessment”, ensure there is a “child centred assessment” and “timely and multidisciplinary discussion of those involved in the assessment”, “improved communication and feedback of the outcome with follow up with the family and, where appropriate, the child to support delivery of the action plan” (PHW, no date). Similarly, standards for the IAS are intended to ensure compliance with NICE guidelines (NICE, 2012) and ensure consistent diagnostic pathways across Wales (WG, 2016b). A new 26 week referral to assessment waiting time standard for children and young people with ND disorders has been introduced and there are plans to introduce an equivalent target for adults.

⁵ As the revised guidance makes clear: “the service has been developed to meet the needs of autistic individuals (and their family and carers) who do not meet the eligibility criteria for statutory services due to the absence of a moderate to severe mental health need or moderate to severe learning disability. Those who do meet eligibility criteria for statutory services should be supported by the service that addresses the most significant need and not the Integrated Autism Service” (WLGA, n.d., p.5).

⁶ See [Guidance on the Delivery of Neurodevelopmental Services in Wales](#) and the [All Wales children and young people’s Neurodevelopmental Diagnostic and Assessment Pathway](#)

The alignment and development of neurodevelopmental and autism services

- 1.10. The children and young people's ND service and IAS were developed in parallel and the Welsh Government commissioned this study to review the provision of children and young people's ND services and the IAS in Wales and explore evidence-based options for improving services.
- 1.11. Initial scoping work undertaken by PHW identified that: "local alignment between ND and IAS services is very positive and relationships continue to develop" (PHW, n.d., p.4). However, it also highlighted the variation in the staffing and structure of ND services, some of which have been developed from CAMHS services and others from child health or disability services, and have gaps in service provision, including:
- "a lack of direct clinical intervention for young people, particularly between the ages of 12-15 years, without a formal diagnosis of autism/Attention Deficit Hyperactivity Disorder (ADHD)";
 - "limited service/interventions available for Children and Young People (CYP) with ADHD";
 - "waiting lists developing with some concerns about how these could be addressed";
 - "no formal pathways between ND, IAS and across other services e.g. Child and Adolescent Mental Health Services (CAMHS), Mental Health (MH) and LD services";
 - "limited evidence of, or/and agreed model developed for, alignment of ND/IAS services". (ibid, pp. 4-5).

1.12. The main recommendation was to undertake further scoping work around other ND services, both within the UK and internationally, and develop proposals for Wales. This reflects a number of considerations including:

- providing continuity for families and individuals, particularly when transitioning from one service to another;
- the potential for sharing expertise and knowledge;
- the case for an integrated ND service to address co-occurring ND disorders; and
- the potential to achieve economies of scale (*personal communication, Andrea Gray*).

1.13. However, the report also cautioned that: “attempting to integrate teams more closely when they have only just been established may lead to role confusion and frustration” (PHW, n.d., p.6).

Aim and objectives of the scoping study

1.14. Given this context, the aim of the study was:

- “to undertake a mapping exercise to identify evidence-based examples of other neurodevelopmental services that are NICE compliant”;
- “draw conclusions from ...[the first aim]...and provide options for developing aligned neurodevelopmental services in Wales for the Welsh Ministers to consider”;
- “to investigate the reasons for continued long waiting times for diagnostic assessments for children and adults in each health board and the reasons for any regional disparity, including identifying examples of effective practice”; and

- “draw together conclusions from ...[the third aim]... and develop recommendations for solutions to long waiting times both regionally and nationally”.

1.15. The review has three main objectives. The first objective was to identify existing evidence-based services, including those where alignment is closer than that currently provided in Wales, and included:

- scoping different models of providing services for children and adults who have ND disorders in the UK and abroad; and
- providing evidence-based and NICE compliant proposals and options for all age aligned ND services in Wales.

1.16. The second objective was to undertake a review of waiting times for assessment and diagnosis and the reasons for long waiting lists and included:

- establishing the reasons for, and current demand for, children and young people’s ND services and IAS services and how demand is currently managed;
- an assessment of waiting times in each region, the reasons for long waiting times and any regional disparities for children and adults;
- reviewing conversion rates between referral, assessment and diagnosis, including reasons for long waits between stages of assessment;
- identifying any blockages in the system that impact upon waiting times, the ability of children and young people’s ND services to comply with the 26 week waiting time standard and the anticipated ability of adult services to meet a 26 week waiting time standard;
- how regions are interpreting and applying the 26 week waiting time standard for children’s ND services;

- issues with co-existing conditions; whether the current lack of alignment creates a blockage in the system for those with co-existing conditions such as ADHD, and an assessment of whether aligned services would reduce these blockages; and
- providing solutions to reduce waiting time lists, i.e. preventative work and recruitment initiatives.

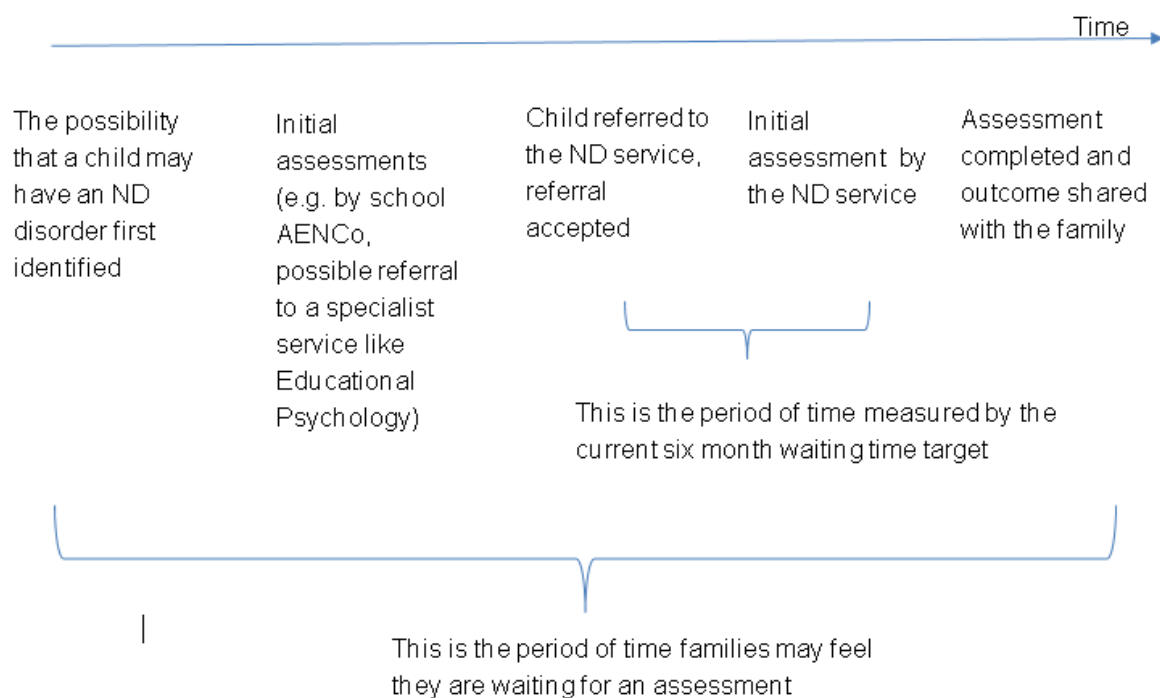
1.17. The third objective was to use the findings from the first two objectives to provide evidence-based options for an all age aligned ND service which also includes solutions to address longer diagnostic assessment waiting times.

Measuring waiting times

1.18. As illustrated by figure 1, waiting times can be measured in different ways. These include measuring the length of time:

- from a concern about a child or young person first being raised, such as a school identifying the possibility that a child or young person may be autistic, to the time of diagnosis;
- from referral to the ND service/IAS being accepted to first appointment; and/or
- from referral to the ND service/IAS being accepted to completion of the assessment and diagnosis (and this being communicated to families or adults).

Figure 1. Different measures of waiting times



1.19. The first of these metrics or measures (the time from concern to diagnosis) may capture the length of time that many parents or carers feel they have waited. It may help explain why some parents and carers have in the past reported waiting more than five years for a diagnosis in parts of Wales. However, in trying to measure waiting time in this way, services would need to determine when, for example, a concern was first raised. They would also need to include aspects of the process that are beyond their control, such as the responsiveness of a school or GP. This measure is not currently used by services. Therefore, although we note examples where there may be delays from a concern first being raised to a referral being made, we do not use this measure in the report.

1.20. The second metric (the time from referral to first appointment) is more precise than the first and measures aspects of the assessment and diagnosis process that services have control over. It is the measure that the current ND service target of 26 weeks (six months) is based upon and

it is also the measure IASs are reporting on. Therefore, it is the main metric used in this report to assess waiting times.

- 1.21. The third metric (the time from referral to diagnosis) is also more precise than the first measure and measures aspects of the assessment and diagnosis process that services have control over. However, it is not routinely used by services. Therefore, we report examples where there can be delays before an assessment is completed, but we do not use this metric in the report.
- 1.22. For each of these metrics, the longest waiting time can be reported (as IASs do in the Integrated Care Fund (ICF) returns) or the average wait can be reported (as ND services do in relation to the 26-week waiting time target). We have opted to focus upon the average wait as the best indication of typical waiting times.

2. Approach and methodology

2.1. A primarily qualitative approach was taken to explore waiting times and views on the alignment and development of services. Questions about the alignment and development of services were included in interviews with services conducted primarily for the evaluation of the IAS (WG, 2019), including the IASs themselves. Data collected through these interviews were enriched by additional interviews, with, for example, staff from adult MH services involved in the assessment and diagnosis of ADHD, which focused primarily upon scoping the alignment and development of services (rather than evaluation of the IAS). The report therefore draws upon semi-structured interviews and discussions with:

- staff involved in developing and delivering each of the seven IASs (n=30 interviewees);
- staff involved in managing and delivering ND services in each LHB (n=11 interviewees);
- staff from adult MH services in six LHBs/regions (Abertawe Bro Morgannwg/Western Bay; Betsi Cadwaladr/North Wales; Cardiff and Vale, Cwm Taf, Hywel Dda/West Wales and Powys⁷ (n=13 interviewees);
- staff from the National Autism Team (n=2 interviewees);
- staff from the Welsh Government Mental Health Division (n=3 interviewees); and
- representatives from NAS Cymru and ADHD Connections Cymru, key voluntary sector organisations (n=3 interviewees).

2.2. Interviews and discussions were used to explore and identify:

⁷ The evaluation team had spoken to representatives of MH services in Aneurin Bevan/Gwent before the extension to the work was agreed. Therefore, the opportunity to explore questions about the alignment and development of autism and ND services with MH services in Aneurin Bevan/Gwent was missed.

- the reasons, and current demand, for assessment and diagnosis and waiting times;
- how demand and waiting lists/times are currently managed, blockages in the system and how this impacts on services;
- potential solutions to reduce waiting lists/times; and
- views on the extent to which existing service configurations meet the needs of service users, and the potential benefits and costs of greater alignment, including full integration of services.

2.3. This scoping study also draws upon data gathered from autistic adults and families interviewed as part of the evaluation of the IAS and refreshed ASD SAP (WG, 2019a). A small number of interviews with adults with ADHD or their parents/carers (n=3) were undertaken where opportunities arose.

2.4. Interviews were complemented and enhanced by a systematic desk-based review of autism, ADHD and/or ND services, both within the UK and internationally. Full details of the review methodology are included in the appendix.

2.5. Emerging findings from interviews and the desk-based literature review were discussed at two workshops in March 2019, bringing together five ND services (Abertawe Bro Morgannwg, Aneurin Bevan, Cwm Taf, Cardiff and Vale and Powys) and five IASs (Cardiff and Vale, Gwent, Powys, Western Bay and West Wales) and representatives from PHW and the Welsh Government to consider, develop and validate findings and recommendations.

Limitations of the study

- 2.6. As a scoping study commissioned as part of the evaluation of the ASD SAP, the scope to comprehensively review provision for individuals with ADHD and their families was more limited than the scope to review provision for autistic individuals and their families. Most of the data on provision and the experiences of individuals with ADHD and their families came from services and the literature review and, as outlined in the report, further research to explore provision for adults with ADHD or parents/carers is warranted.
- 2.7. Data on waiting times were provided by services and services were invited to confirm the data. As outlined in the introduction, there are a number of different metrics, which could be used, and the chosen measure – average waiting times from referral to first (initial) appointment – should be reasonably robust. However, it may not capture or reflect the length of time families or adults feel they are waiting. The focus upon average (mean) waiting times helps smooth out the impact of changes in demand and capacity of services, which mean waiting times can change from month to month. However, it causes problems when waiting times are not stable and, for example, increasing, as the current longer waiting times will not be fully reflected in average waiting times.
- 2.8. There are differences in the way data are collected and reported by services. For example, some services calculate the waiting time from the time a referral is made to the service and others from the time the referral is accepted by the service. There can also be grey areas, where services will accept some referrals that are incomplete (e.g. where a signature is missing) but reject others (e.g. where there is judged to be inadequate supporting information). The differences in practice are important, as it means that there can be delays between a referral being made and accepted by a service when, for example, the initial referral contains insufficient information. Taken together, these factors make it difficult to directly compare waiting time across different services.

3. Context for the alignment and development of autism and children and young people’s ND services

Health and care services

- 3.1. Health and social care services face a very challenging context, with rising demand as a result of demographic changes and increasing expectations, alongside cuts or freezes in their budgets. A focus upon co-production, prevention and integration of services is seen as a key part of the response to this challenge (see e.g. the Well-being of Future Generations (Wales) Act and Social Services, Well-being (Wales) Act and A Healthier Wales: Plan for Health and Social Care). RPBs⁸ and the Integrated Care Fund (ICF)⁹ are key vehicles for advancing this agenda.

- 3.2. The focus upon co-production and prevention is expected to help improve effectiveness and reduce demand (e.g. by preventing escalation of needs) and integration is expected to help increase effectiveness, by services working together (creating synergies) and create more seamless services for users/citizens (Parliamentary Review, 2017; Williams, 2014). However, evidence of the impact and efficiencies generated by integration remains weak (Cameron et al., 2012).

⁸ Regional Partnership Boards (RPBs) were established in response to the Social Services and Well-being (Wales) Act 2014. They bring together health, social services, the third sector and other partners to take forward the effective delivery of integrated services in Wales. RPBs administer the ICF, which supports delivery of the Social Services and Well-Being Act (2014).

⁹Established in 2014 as the Intermediate Care Fund to: “support initiatives which prevent unnecessary hospital admission, inappropriate admission to residential care, and delayed discharges from hospital”, in April 2017 it was rebranded as the Integrated Care Fund to better reflect an expanded scope (WG, 2017).

NICE Guidelines

Autism

- 3.3. In 2012, the National Institute for Health and Care Excellence (NICE) published clinical guidelines on: “autism spectrum disorder in adults: diagnosis and management” ([NICE, 2012](#)), outlining best practice advice on the care of autistic adults. The guideline recommendations included establishing a local autism multiagency strategy group and a specialist community-based multidisciplinary team for autistic adults (the Specialist Autism Team¹⁰) (ibid., p.14). However, the guidance (which was updated in 2016) also identifies that:

There is little evidence to guide the establishment and development of these teams. There is uncertainty about the precise nature of the population to be served (all people with autism or only those who have an IQ of 70 or above), the composition of the team, the extent of the team's role (for example, diagnosis and assessment only, a primarily advisory role or a substantial care coordination role), the interventions provided by the team, and the team's role and relationship with regard to non-statutory care providers. Therefore, it is likely that in the near future a number of different models will be developed, which are likely to have varying degrees of success in meeting the needs of people with autism (ibid., p.40).

¹⁰The membership should include: clinical psychologists, nurses, occupational therapists, psychiatrists, social workers, speech and language therapists, support staff (for example, staff supporting access to housing, educational and employment services, financial advice, and personal and community safety skills).

3.4. The latest NICE guidelines ([2019](#)) on the diagnostic assessment of autism outlines that:

A comprehensive assessment should:

- be undertaken by professionals who are trained and competent
- be team-based and draw on a range of professions and skills
- where possible involve a family member, partner, carer or other informant or use documentary evidence (such as school reports) of current and past behaviour and early development (NICE, 2019, p.5).

ADHD

3.5. In March 2018 NICE published clinical guidelines on: “attention deficit hyperactivity disorder: its diagnosis and management” ([NICE, 2018](#)). The guidelines include recommendations for establishing a multiagency group to oversee services, and multidisciplinary specialist ADHD teams and/or clinics for children and young people, and separate teams and/or clinics for adults. These services’ roles should include:

- provid[ing] 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; and
- ensur[ing] age-appropriate psychological services are available for children, young people and adults with ADHD, and for parents or carers (NICE, 2018, p.6).

3.6. The guidelines for ADHD are somewhat less stringent than those for autism (e.g. because they only require assessment by a ADHD *specialist* rather than assessment by an autism *team*) and outline that:

A diagnosis of ADHD should only be made by a specialist psychiatrist, paediatrician or other appropriately qualified healthcare professional with training and expertise in the diagnosis of ADHD, on the basis of:

- a full clinical and psychosocial assessment of the person; this should include discussion about behaviour and symptoms in the different domains and settings of the person's everyday life;
- a full developmental and psychiatric history; and
- observer reports and assessment of the person's mental state. (NICE, 2018, p.511).

4. Waiting times for assessment and diagnosis: children and young people's ND services

Services' compliance with the 26 week (six month) waiting time target

- 4.1. As outlined in the introduction, the assessment of waiting times focuses upon the existing waiting time target for ND services of 26 weeks (6 months) from referral to initial assessment.¹¹
- 4.2. Children's and young people's ND services in all seven areas are struggling to meet the waiting time target. Waiting times for referral to initial assessment range from:
- Around 6 months (26 weeks) on average¹² in Aneurin Bevan, Cardiff and Vale Cwm Taf and Powys¹³;
 - 10-12 months in Abertawe Bro Morgannwg;
 - 20 and 24 months respectively in two of the three ND services in Betsi Cadwaladr¹⁴; and
 - up to 24 months in Hywel Dda.
- 4.3. Waiting times can fluctuate over the course of a year, as demand and capacity changes, and the longest waiting times are longer than the average (mean) waiting times. Moreover, even where services are able

¹¹ The available data lack precision as, for example, waiting times can increase at some times of the year and fall at others, but provide an indication of the range of average waiting times in each area.

¹² This represents the mean waiting time. In Cardiff and Vale, this is calculated as the mean waiting time for 80 per cent of cases.

¹³ Powys ND service reported that the referral to initial assessment wait time was continuing to slowly rise as demand overtakes current capacity and the mean wait was 30 weeks as of end of May 2019.

¹⁴ In Betsi Cadwaladr East the waiting times have been increasing, making it difficult to calculate a meaningful average, and in June 2019 the wait for routine referrals was around 24 months. The average wait in this area, based upon all waits for the service up until the end of April 2019 was 47 weeks.

to meet the 6 month (26 week) target, as we outline below in the discussion of “gatekeeping”, there can be delays before a referral is made and accepted by the service. It can also take weeks or months to complete an assessment. This reflects the time needed to arrange for the collection of information (such as a developmental history); different assessments, often undertaken by different professionals, operating on different sites; and for a decision about the outcome of assessment to be made. This means that even if the target is met, families can feel they are waiting much longer than 6 months.

- 4.4. In one area, in rare cases, it was reported that it can take up to a year to complete an assessment, when, for example, there is a period of “watchful waiting” of active observation, to see if, for example, the symptoms that are first reported are stable or if they change (e.g. increase or decrease in severity). This can also allow additional information to be gathered and may be particularly important, when, for example, a child or young person is making a transition, such as moving from primary to secondary school, which can make it more difficult to assess the permanency of symptoms¹⁵.

Demand

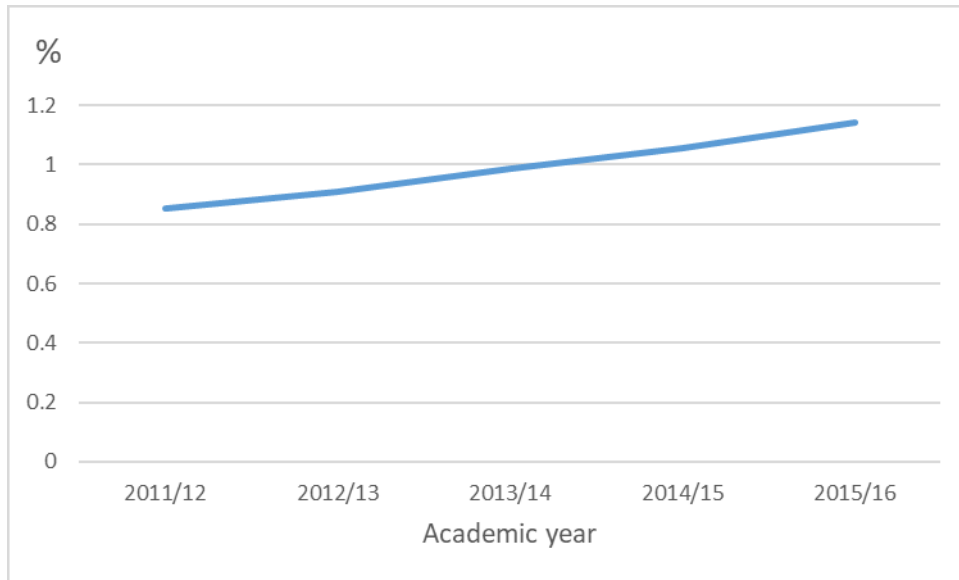
- 4.5. All seven ND services report large increases in demand for assessment and diagnosis; for example, Cardiff and Vale forecast 300-350 referrals and experienced almost three times as many. Two services (Abertawe Bro Morgannwg and Betsi Cadwaladr) reported that referrals were continuing to increase, meaning waiting lists and waiting times were likely to grow. Four services (Betsi Cadwaladr, Cwm Taf, Hywel Dda and Powys) were dealing with a large backlog of cases due

¹⁵ “Watchful waiting” This is a feature of the NICE guidelines, albeit as a potential step to help determine if a referral or assessment is warranted, rather than as part of the assessment process.

to waiting lists they had inherited, as well as an initial spike in demand after the service was established, but both Hywel Dda and Cwm Taf were hopeful that demand was now starting to plateau (i.e. slow and stabilise rather than continuing to increase).

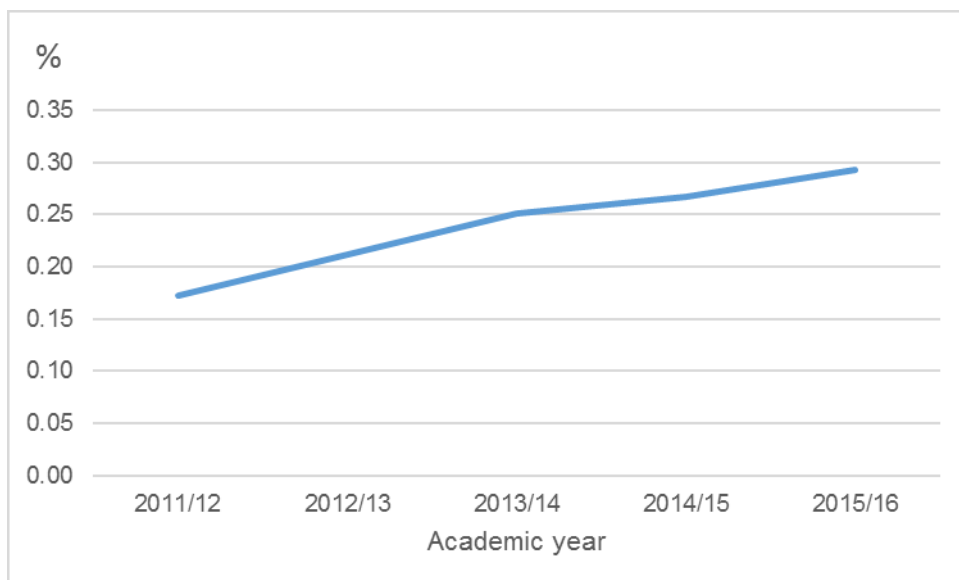
- 4.6. This anecdotal evidence that demand was much higher than expected, and in some cases continuing to increase, is consistent across ND services. It is also in line with increases in demand reported by other services, such as CAMHS, for assessment and diagnosis. However, it is difficult to quantify or independently verify whether demand has increased, as assessment and diagnosis takes place across a range of clinical specialities, and robust historical data on the number of assessments and diagnoses undertaken in each year are not available (PHW, 2016).
- 4.7. Analysis of the SEN data collected through the Pupil Level School Age Census (PLASC) have some weaknesses; for example, it is possible that some of those recorded as having autism or ADHD as their primary SEN, may not have had a formal diagnosis. Subject to these caveats, as figures 2 and 3 illustrate, the PLASC data suggest that rates have increased consistently.

Figure 2. The proportion of pupils recorded as having autism as their major SEN, 2011/12-2015/16



Source: Stats Wales

Figure 3. The proportion of pupils recorded as having ADHD as their major SEN, 2011/12-2015/16



Source: Stats Wales

- 4.8. Changes in the way data were collected in 2016/17¹⁶ mean that it is not possible to continue the trend line shown in figures 1 and 2 to include data for 2016/17 and 2017/18. The rates based upon the latest data (2017/18) show autism at 1.6 per cent of the school population and ADHD at 0.6 per cent.
- 4.9. Rates for autism are therefore now considerably higher than expected; prevalence rates of around one per cent of the total population (Levy, 2009). In contrast, rates for ADHD appear to be lower than expected; prevalence rates of around three-nine per cent of children and young people (NICE, 2018). This reflects wider European trends of under-diagnosis of ADHD (Thapar & Cooper, 2015).
- 4.10. Several ND services also reported that the complexity of presentations was increasing. There is even less data available to assess long-term trends here, but like the overall increase, these data are often reported by a range of services.
- 4.11. The data collected for this study indicate that there is no single cause for this increase, instead a combination of different factors. The four key drivers of demand, which we discuss in more detail below, are:
- increasing awareness of ND disorders amongst families and professionals;
 - changes in thresholds for referral and diagnostic criteria;
 - families' and schools' expectations and the continuing need for a diagnosis in order to access services, particularly given the impact of austerity upon access to services; and

¹⁶ Previous to the 2016/17 academic year only the main need of the pupil was recorded (entitled "major need") therefore there would be those who had more than one need e.g. ASD and a learning disability. However, only one of these would be recorded (the main one). The system changed in 2017/18 to record all needs. This means it is not possible to compare data between these two periods.

- the legacy left by the limited capacity of assessment and diagnostic services in the past.

Increasing awareness

- 4.12. Increasing awareness of ND disorders amongst families and professionals is widely reported, although difficult to quantify. This is seen as increasing the chances that potential cases of ADHD or autism will be identified and referred for assessment and diagnosis. The evidence from this study (including interviews and evidence from the literature review) suggests that this is probably the most important factor in creating rising levels of demand.

Changes in thresholds for referral and diagnostic criteria

- 4.13. Stakeholders reported that thresholds for referral had become lower. Stakeholders and the literature also highlight how diagnostic criteria, particularly for autism, has become broader, as the “categorical view” of autism has been superseded by a spectrum view and more sub-groups, such as Asperger’s syndrome, are included (Baron-Cohen, 2008). There are debates about whether ADHD should also be considered as a categorical, or spectrum or continuum condition (McLennan, 2016).

Families' and schools'; expectations and the impact of austerity upon access to services

- 4.14. Services reported that families and schools often sought an assessment and diagnosis, because:
- they wanted “answers”, or an explanation of why they were struggling with a child’s behaviour and/or their child was struggling at school; and/or
 - they felt that a diagnosis, particularly of autism, would enable them and their child to access extra support, and in some cases, welfare benefits.
- 4.15. There was debate about how well founded these expectations were, but agreement that these expectations (whether well or ill founded) were driving demand.
- 4.16. Interviews with families of autistic children undertaken for the evaluation of the IAS (WG, 2019a) confirm the continuing value of diagnosis for families. Diagnosis was described as improving access to support, particularly around education; providing access to services, such as children’s disability services, voluntary sector provision, including support groups; and providing understanding and an explanation of the child’s needs and behaviour.
- 4.17. It was also reported by families and some ND services that cuts, as a result of austerity, had made it harder to access services and support, increasing the need for a diagnosis to access what remained. It was also reported that because schools had less access to support from SEN specialist services, such as educational psychology and speech and language therapy services, they found it more difficult to meet children’s needs. It was therefore reported that schools sometimes

encouraged parents or carers to seek a diagnosis, in order to unlock additional resources. Some children and young people's ND services felt they were becoming a "default" service for other services that had run out of options, and did not know what to do and/or could not meet the needs of children with, for example, "challenging behaviour".

- 4.18. As a consequence, while there is a longstanding aspiration that diagnosis should not be needed to access services or support, in practice¹⁷, for many children, it is still important; for example, it can be an important element in a statutory assessment of SEN (which can lead to a Statement of SEN) and a diagnosis of autism is often required to access special schools or SEN units in schools for autistic children. It is also required if parents are to access support from the IAS.
- 4.19. Moreover, ND services also highlighted the value of a comprehensive child centred assessment to create a profile of the child's or young person's needs, irrespective of whether it led to a diagnosis or not. This is likely to mean that even after the ALN reforms, (see boxed text) take effect, there may still be demand for a neurodevelopmental assessment, even if the 'need' for a diagnosis to access services and support declines.

¹⁷ For example, as the 2008 Strategic Action Plan states: "...formal diagnosis of autism should be neither a prerequisite for a full-assessment of each person's wider needs nor should it be a reason for not intervening in a timely manner" (WAG, 2008, p.16).

The ALN Transformation Programme

The Additional Learning Needs And Education Tribunal (ALNET) Act is a central part of the ALN transformation programme. The Act replaces the existing legislation around SEN and the assessment of children and young people with learning difficulties and/or disabilities (LDD) in post-16 education and training. For example, the existing statutory and non-statutory plans for learners in schools, including Individual Education Plans and Statements of SEN, will be replaced with a single statutory plan called the individual development plan

The programme aims:

- To provide a unified legislative framework to support children and young people aged 0-25 with ALN in schools and colleges;
- To promote an integrated, collaborative process of assessment, planning and monitoring which facilitates early, timely and effective interventions; and
- To have a fair and transparent system for providing information and advice for resolving concerns and making appeals to for example the new education tribunal.

The act is being phased in and will not be fully rolled out until 2023.

Other key elements of the ALN transformation programme include:

- Workforce development, including the roll out of person-centred approaches, the development of the additional learning needs coordinator (ALNCO) role, and additional investment in specialist SEN Services, such as educational psychologists;
- Awareness raising to ensure that staff better understand the evidence base for interventions, including a rapid evidence assessment (REA) of educational interventions to support learners with autism and the Learning With Autism Programme; and
- additional support for transformation, including grants, guides and the work of ALN transformation leads.

Adapted From Estyn (2018) And WG (2018)

- 4.20. In contrast, as we outline in section 8, while there can be an expectation that a diagnosis of ADHD will unlock access to resources, it is reported by services and parents interviewed that post-diagnostic support for children with ADHD is often limited to medication. Although the validity of an ADHD diagnosis is not uniformly accepted, it can still be very valuable for parents and carers for the explanation it gives to them and others of their child's difficulties and behaviour.
- 4.21. The value placed upon diagnosis also fuelled some parents' frustration when their child did not meet diagnostic thresholds or was diagnosed as having ADHD, rather than autism, given the differing impact upon access to services and support.

The legacy of past services

- 4.22. The limited capacity of the assessment and diagnostic services that preceded the ND service meant that in areas like Betsi Cadwaladr, Hywel Dda and Powys, ND services inherited waiting lists. The newly formed ND services also had referrals, which had not been made before, because of a lack of services and/or long waiting lists. It was also reported that other services, experiencing high levels of demand, and sometimes struggling to meet children's needs, could be incentivised to try to refer children to the ND services (to reduce demand for their own services). *Social, environmental and demographic factors*
- 4.23. In addition to these sociological factors, it was suggested by some stakeholders that demographic and environmental factors may be an important factor in explaining the increase in demand. ND disorders are thought to be linked to "complex interactions between genetic and social factors" (PHW, 2016). Risk factors for ND disorders include:

- premature birth;
- gender, with more boys affected than girls;
- socio-economic disadvantage; and
- some parental behaviours like smoking and alcohol intake in pregnancy (ibid.).

4.24. Changes in these risk factors are likely to impact upon prevalence rates. They may also affect the complexity of presentations. As we discuss below, where, for example, a child may have attachment difficulties¹⁸ and also ADHD, assessments take longer, because the symptoms of attachment and neurodevelopmental disorders, such as difficulties with social interaction and communication, can be similar. Socio-economic disadvantage is itself a risk factor and many of the other risk factors associated with mental health difficulties smoking, are correlated with socio-economic disadvantage (Allen and Donkin, 2015). Differences in socio-economic profiles of different regions may therefore be important (with higher levels expected in more socio-economically deprived areas).

4.25. Differences in population sizes, ranging from around 20,000 children aged 0-16 in Powys to over 120,000 children aged 0-16 in North Wales (Betsi Cadwaladr)¹⁹ (Stats Wales, 2018) will also have an effect on individual services. Changes in the size of the population are likely to have had a minimal impact on increasing demand nationally though, as the number of children in Wales has declined since the mid- 2000s and is only now starting to increase again.

¹⁸ Attachment difficulties describe disorders caused by a failure to form normal attachments to primary caregivers in early childhood (e.g. because of neglect or separation) (NICE, 2015).

¹⁹ Data on children aged 0-17 were not readily available, so 0-16 data are used to indicate differences in the population size of each region.

4.26. It was also suggested by one professional stakeholder that societal changes, such as changes in the structure and culture of schools with, for example, reductions in structure and routine, could also mean that the impact of ND disorders on people's ability to fully participate in society, sometimes described as people's "functioning", was greater. Conversely, it was argued by other professional stakeholders that as schools became more autism friendly this could reduce the impact upon functioning, and therefore the need for diagnosis. However, this suggests that this might simply defer the need for a diagnosis until a young person made the transition from school to a potentially less autism-friendly environment.

Managing demand

4.27. In order to manage demand, ND services have adopted four key strategies, which we discuss in more depth below:

- Prevention, so that assessment and diagnosis is not needed;
- Gatekeeping, regulating when and how children and young people can access services;
- Mitigation to try to minimise the impact of long waiting times upon children, young people and their families; and
- Focusing upon what is measured, to reduce external pressure upon services.

Prevention

There was some discussion among services about reducing exposure to social and environmental risk factors (see above) but this was seen as a long-term strategy and beyond the scope of individual ND services. As outlined above, societal changes, like making schools more autism friendly, were also felt to have potential, but were seen as

a longer-term challenge that ND services could support, but that were beyond the scope of individual ND services to control.

4.28. There was frequent discussion about ensuring that a diagnosis is not needed to access support and, for some stakeholders, frustration that having a diagnosis remained so important and/or was seen as important by so many families and schools. There was agreement that ensuring that a diagnosis is not needed in order for appropriate support to be provided, was desirable. Although there were hopes that the Additional Learning Needs and Educational Tribunal (ALNET) Act (discussed above) would help, the hopes remained largely aspirational and the increasing need to “ration” services, as a result of austerity, was seen as working against open access to support based on need rather than diagnosis.

4.29. As the evaluation of the IAS identifies, it is “too early to judge its impact”, and that:

Although the early indications are encouraging....^[20]... there is also recognition that the programme is “not a silver bullet”. The cultural change required will take time and in many ways, the ALNET Act reinforces changes in culture and practice, adding greater emphasis to, and extending, legal rights of redress, rather than marking a radical change of direction (WG, 2019a, p.122).

4.30. Two stakeholders from children’s and adults’ services respectively, raised concerns or cautioned about the potential risks of, for example, offering interventions such as parenting courses before a full

²⁰ For example: “Estyn reports that the emerging impact of Person Centred Planning (PCP), which is expected to play a key role in improving schools’ and colleges’ understanding of learners’ needs, and also in improving relationships with family members and carers, has been encouraging” (Estyn, 2018). This is in line with evidence from the ALN pilots (Holtom and Lloyd-Jones, 2014) and contributes to the Welsh Government’s confidence that the ALN Transformation Programme will improve experiences and outcomes for learners with autism and also their parents and carers” (WG, 2019a, p.122).

assessment of need was undertaken. Whilst there are elements of parenting programmes that parents or carers of autistic children may find helpful, it may delay other more effective interventions focused specifically upon autism, such as social interventions like “peer-mediated instruction and intervention”²¹. Any delay in effective intervention to support the child can fuel families’ frustration. Their frustration can be exacerbated when they also feel they are being ‘blamed’ for their child’s difficulties and labelled as ‘poor parents’ (by being referred to a parenting course). One of the parents interviewed for the study explained that this had happened to them.

- 4.31. It was also observed by an interviewee from a health service that “evidence-based interventions”²² require a diagnosis to guide the use of appropriate interventions. While some interviewees felt they could be a somewhat blunt instrument, particularly where they held a more dimensional, rather than categorical, view of ND disorders, the emphasis upon evidence-based interventions is firmly rooted (Ibrahim & Sukhodolsky, 2018). It is, for example, reflected in the Welsh Government guides: Support for Children and Young People with Autistic Spectrum Disorder (ASD) in educational settings (WG, 2019b) and Support for Children and Young People with Attention Deficit Hyperactivity Disorder (ADHD) in educational settings (WG, 2019c).

Gatekeeping and diversion

- 4.32. Services have adopted a number of different gatekeeping strategies, to determine who can access the service and ensure that referrals are “appropriate”. Services look for evidence of impact upon “functioning”

²¹ This involves “Children and young people without ASD interact with and/or help children and young people with ASD to acquire new behaviours, communication skills and social skills, by increasing social and learning opportunities within natural environments” (p9, WG, 2019b)

²² I.e. interventions that have been robustly evaluated and whose efficacy has been demonstrated.

(ability to do things), as referrals are based upon concerns about children's or young people's development or behaviour and what steps have already been taken to meet needs (in line with, for example, the graduated response to meeting SEN). This helps services rule out other possible explanations of the delays in development or behavioural problems that are observed in the child or young person, before a ND assessment is undertaken. To enable this, all services use some form of screening or triage to ensure that there is sufficient information to make a decision on whether to assess or not. Six ND services use information from screening questionnaires or forms in order to decide whether to accept a referral or not and in the other three services, an initial assessment is undertaken by a paediatrician²³. However:

- there are differences in the referral forms or tools used and how much evidence of pervasive signs and symptoms that are impacting on functioning is required before a referral will be accepted; and
- there are differences in how referrals can be made. In the most open pathways, referrals can be made by anyone, including parents. However, in most cases only health professionals and/or schools can make a referral and, in a small number of cases, only paediatricians can make referrals.

4.33. Services described having to strike the “balance between open access, but not so open that anyone can come in” and “being accessible, but also getting quality information”. Concerns about the quality of information were a key reason why most services would not, or did not in practice, accept referrals solely from parents. Services reported that the quality of referrals had improved because of work with referrers like

²³ The three ND services in North Wales are treated as separate services

schools and GPs. The forthcoming review commissioned by PHW on Neurodevelopmental teams in Wales and compliance with the national standards is expected to make recommendations on improving referral processes.

- 4.34. The consequent differences in how open the referral pathway, or “door”, to the service is, leads to differences in both the total number of referrals made, and also the proportion of referrals being accepted (ranging from 60 per cent to 80 per cent). However, while a narrower door may reduce the number of referrals (and therefore demand for the service) and can improve the quality of referrals, it can also cause great frustration for families who feel they cannot access ND services. It can also discourage referrals, increasing the risk that needs are not identified, and it can lead to people being “bounced back” to other services, and in some cases, returning to the ND service later, so that it only defers the problem.
- 4.35. Moreover, it was observed that even when diagnostic criteria were not met, this did not mean that a thorough assessment of needs was not warranted or useful; as one interviewee observed “very few [children they assessed] have no needs”. In a similar vein, one of the ND services in Betsi Cadwaladr had initially established screening by ND clinicians and paediatricians but abandoned this, as they found approximately 95 per cent of young people they screened were put forward for a full assessment. It was reported though that this was sometimes in response to parental requests for a full assessment, rather than a clinical judgment that a full assessment was warranted.
- 4.36. Services can also try to manage demand by diversion - referring to another service - but there is limited scope to do this. The ND service is intended to be a single referral point for assessment when there is evidence of pervasive signs and symptoms that are impacting on

functioning. Consequently, while referrals may be rejected on the grounds of insufficient information, they are rarely diverted to another service. The main exception to this is where paediatricians still continue to undertake assessments, or where there are separate pathways for ADHD (seen by paediatricians) and autism (seen by the ND team), as is the case in Hywel Dda and in one of the three ND services operating in Betsi Cadwaladr. There are also referrals onto other services after the assessment (e.g. to speech and language therapy or occupational therapy).

Mitigation

- 4.37. Strategies to mitigate the impact of long waiting lists upon families include:
- support while waiting, including access to workshops for parents and young people focused on issues like sleep or anxiety, and also advice from the service, as the Betsi Cadwaladr ND service offers, as waiting for support was identified as a key cause of parental stress;
 - expediting urgent cases as, for example, the Hywel Dda and Betsi Cadwaladr ND services do; and
 - providing information about waiting times, which all services offer.
- 4.38. None of these strategies reduces the overall waiting lists, unless families choose not to continue to wait.

Focusing upon what is measured

- 4.39. Services are required to start assessments within 26 weeks (six months), and services report they face considerable pressure from LHBs to meet this target. Some of the gatekeeping strategies

discussed above can effect services' ability to meet the waiting time targets. Where, for example, referrals are rejected because they do not have sufficient information, this can delay the start of the waiting time 'clock'. However, it is important to note that services reported doing this to ensure that they had adequate information to start an assessment, and to help improve the quality of referrals.

4.40. Services' practice appears to be inconsistent. Some services accept referrals, and start the waiting time 'clock' even when there is not sufficient information, whilst others wait until they have collected sufficient information to judge whether it is appropriate to accept the referral or not. It was also reported that in one area there could be lengthy delays before a child was formally referred to a service, as referrals needed to be supported by a professional such as an educational psychologist. It was reported that this meant that a family could, in some cases, wait six months before they could see an educational psychologist, and have their referral to the ND service and the waiting time 'clock' starting. It was reported that these pre-referral delays were falling as the quality of referrals improved.

4.41. There is also considerable variation across services in how long assessments take to complete once they are commenced. This can range from a few weeks to up to four months or even a year or more in a small number of cases. Some of this reflects the complexity of some assessments, periods of "watchful waiting", and constraints upon capacity, discussed below, which can delay assessments. However, given waiting time targets, there is also a strong incentive for services to start an assessment within 26 weeks, even if they cannot complete the assessment in a timely way. The focus of ND services' attention has, therefore, in part been upon changing systems and processes so they can start assessments within or close to the 26 week (six month) target, rather than looking at the length of the whole assessment

process. This helps reduce the political and organisational pressure to meet targets. However, it does not address families' frustration at how long they have to wait.

Capacity to assess

- 4.42. As table 1 illustrates, each of the seven ND services' pathways includes broadly the same elements. However, there are choices about how each element is undertaken. This contributes to a large degree of variation in how assessments are conducted across services, and also variation within services depending on the nature and complexity of need, with more abbreviated assessments for ADHD common, and more extended assessments for more complex cases.
- 4.43. Table 1 provides an indication of the typical time taken by services for a diagnostic assessment of autism. The total time is 10-15 hours, which is in line with practice in England (Galliver et al., 2017); in comparison:
- an assessment of ADHD might be as little as a few hours, if based solely upon history collected via questionnaire and a single clinical interview;
 - an assessment by the Aneurin Bevan tertiary ND service is estimated to be around 17.5 hours; and
 - the exemplar pathways in the NICE guidelines have professional times ranging from 16 to 49 hours (Galliver et al., 2017).

Table 1. Capacity: assessment and diagnosis for a non-complex case of ASD

Stages	Mins	Time or cost can be reduced by
History	60-90	Collecting this information by questionnaires, rather than interview
Observation	90-120	Only one clinician undertaking the observation (rather than two), a health care support worker (rather than clinician) undertaking the observation; the observation being done in the service's premises, rather than, for example, in school. In one area, the scope for the school to undertake observations is being explored
Clinical interview	60-90	Only one clinician undertaking the interview (rather than two); the grade of post ²⁴ ; and the choice of tools used (as some are faster)
Decision	90	Only one clinician making the decision, rather than two or more (e.g. a multidisciplinary panel)
Report	90	The use of templates; the length of reports (which range from six to sixty pages in different areas) maximising the use of administrative support in organising and sending out reports.
Post-diagnostic support	30-60 +	Minimising the support offered.

²⁴ Cost depends on grade of post. For example, consultants' hourly rate is generally twice that of other members (Galliver, et al, 2017). It was suggested by services that the focus ought to be upon the competency of staff rather than their grade and that there could be scope to develop "extended practice, when a registered health professional undertakes clinical tasks or roles usually associated with another profession" (CHRE. 2010) for some health professionals involved in the process.

4.44. All the services have worked to streamline the process. By making some of the choices outlined above, such as reducing the number of staff involved, changing the way interviews and observations are conducted, using new tools and approaches to shorten the process and adopting more efficient arrangements, such as single contact assessments, important marginal gains have been made; for example, in one part of Betsi Cadwaladr, the total clinical time needed for assessment has been reduced from around fourteen to ten hours. However, as we discuss below, quality is in part linked to time, and as one interviewee put it: “you get to the point where...if you drop too much, streamline too much, the potential for misdiagnosis goes up and the understanding of the child’s needs and strengths is not great”.

Constraints and blockages

4.45. The scope to further streamline the assessment process has been limited by five factors:

- staffing, including the size of staff teams, their skills and confidence, which can be limited by difficulties with recruitment, or absence (e.g. due to maternity leave or sickness);
- differing views on quality, compliance with NICE guidelines and, consequently, what is robust enough and how far the process can be streamlined;
- difficulties securing adequate accommodation for services, which can make it difficult to schedule assessments (extending the time needed to complete the assessment), or, for example, offer single contact assessments and which can lead to clinicians travelling between sites (which takes time);
- the size and rurality of some health boards which means clinicians and/or families have to travel long distances, and compounds

difficulties in finding suitable clinical space and accessing IT systems (when working remotely); and

- limitations in IT and administrative support, which can mean clinicians taking on administrative tasks and which can make booking, managing and monitoring the process more difficult and create difficulties in accessing clinical records, which can delay assessments.

4.46. Given the demands they face, services are under considerable pressure to streamline the process as much as possible. There is a feeling that practice has been pushed right up to the limit of what is safe and robust and, possibly at times, has been pushed over the line. Some services raised concerns that narrow (and swift) ADHD specific assessments meant that some children did not receive a complete ND assessment that fully identified their strengths and also needs. It also increased the risk of diagnostic overshadowing or misdiagnosis, as other alternative or additional diagnoses were not considered, or over diagnosis, where a diagnosis of ADHD was not warranted. There were also concerns about the impact of the volume of assessments on the quality of each individual assessment. As one interviewee reported: “if you are doing 15 reports in one go, after a time they all look the same “and you “lose the nuances” about individual children.

4.47. The pressure upon staff as a result of the mismatch between demand and capacity is considerable. This is most acute where, as in areas like Abertawe Bro Morgannwg and Betsi Cadwaladr, the number of referrals exceed their capacity to assess, so that it is inevitable that waiting lists and waiting times will continue to lengthen (unless something changes), or where, as is the case in Powys and Hywel Dda, the ND service inherited a large backlog of referrals. This pressure can leave staff feeling “overwhelmed”, and may undermine their clinical interest and skills (as few staff want to undertake only

diagnostic assessments). It cannot be considered sustainable. As another interviewee from a health service observed, “if we do nothing” the impact on the workforce in terms of morale, sickness and stress will be “significant” and “if we lose the workforce we cannot easily replenish it”.

Post-diagnostic support

4.48. The high levels of demand for assessment and diagnosis mean most ND services offer very little post-diagnostic support. Access to support therefore depends on:

- whether a diagnosis of autism is made or not as parents and carers of diagnosed autistic children are able to access support from the IAS, where it is fully operational (there is no equivalent service for parents or carers of children with ADHD, or for children with ND needs which fall short of criteria for different diagnoses); and
- choices made by other services, most notably education²⁵, but also children’s health and social services, about what support to offer, and the thresholds for accessing that support, and the availability of voluntary sector provision.

4.49. There was also frustration among some children and young people’s ND services that the IAS could not work directly with children, as initial announcements about the IAS as an “all age” service had raised hopes that it would, with the expectation that it could increase post-diagnosis capacity.

²⁵ As the evaluation of the IAS and refreshed ASD SAP identified, while schools play an important role in supporting children, there is evidence of parental frustration with mainstream education provision, and concerns about a lack of support in the home, particularly in areas where the IAS was not yet operational (WG, 2019a).

4.50. As a consequence of this, differences in this (non ND) service provision in each area means post-diagnostic support varies from area to area. As we outline in section 8, while it is not possible to systematically assess, anecdotal evidence consistently reports that post-diagnostic support for children with ADHD and their parents and carers is less developed than provision for autistic children and their parents.

5. Waiting times for assessment and diagnosis: the Integrated Autism Service

5.1. As outlined in the introduction, the assessment of waiting times for the IAS focuses upon the length of time from referral to initial assessment. Unlike children and young people's ND services, there is currently no waiting list target for the IAS, although a six month (26 week) waiting time target has been proposed. Like children and young people's ND services, waiting times for assessment and diagnosis have increased²⁶; for example, in late 2018:

- in Cwm Taf there was a four to six month wait for an initial assessment;
- in Cardiff and Vale, there was a six to eight month wait for an initial assessment;
- in Powys there was an 12 month wait for an initial assessment on average; and
- in Gwent there was a 12 month wait for an initial assessment, but there were fears that it could rise to 18 or even 24 months, if there were to be no change in demand or capacity (WG, 2019a).

5.2. The four IASs provided updated data in June 2019:

- in Cwm Taf, average waiting times from referral to initial assessment had crept up a little to seven months;
- in Cardiff and Vale, waiting times had increased to eight to ten months and there were fears that they could rise to twelve months, unless demand fell, and/or the capacity of the service could be increased through additional funding;

²⁶ As with ND services, the available data lack precision, as for example waiting times can increase at some time of the year and fall at others, but provide an indication of the range of average waiting times in each area.

- in Powys, waiting times remained stable at around twelve months, although this was expected to increase, as one of their clinicians had recently left the team; and
- in Gwent waiting times had stabilised at twelve months and there were hopes that if additional funding could be secured (outlined below in the discussion of services' capacity), it could be reduced to around six months.

Demand

- 5.3. Like children and young people's ND services, all five operational IASs²⁷ report high, and in the case of Gwent, continually increasing demand for diagnostic assessment. The three remaining IASs (North Wales, Western Bay and West Wales) anticipate that demand will be high.
- 5.4. Levels of demand were higher than anticipated, but it is difficult to assess long-term trends, as, like the context for children and young people's ND services, assessment and diagnosis takes place across a range of clinical specialties, and robust data on the number of assessments and diagnoses undertaken in each year is not available.
- 5.5. There are five key drivers of demand :
- increasing awareness amongst adults and professionals;
 - changes in thresholds for referral and diagnostic criteria;
 - the legacy of past services;
 - the continuing need for a diagnosis to access some types of support and the demand for diagnosis as an explanation; and
 - population distribution and change.

²⁷ At the time the research was conducted in late 2018 and early 2019 these were Cwm Taf, Cardiff and Vale, Gwent, Powys and North Wales.

Increasing awareness and changes in diagnostic criteria

- 5.6. As outlined above (in the context of children and young people's services) increasing awareness amongst families and professionals is widely reported, although difficult to quantify. This means adults who might previously have been considered "different" are now more likely to be recognised as being on the autistic spectrum. As discussed above (in the discussion of children and young people's ND services), there has also been a widening of thresholds and diagnostic criteria, which also applies to adults.

The legacy of past services

- 5.7. Before the IAS was established, with the support of the all-Wales ASD Diagnostic and Pre/post Counselling Network for Adults, new services were established in some areas like Hywel Dda/West Wales and existing services in other areas were strengthened. However, the adults' network was only funded to deliver 125 assessments a year, the increase in diagnostic capacity was patchy, and much depended upon individual clinicians with an interest and expertise in ASD (WG, 2016c). This meant that hoped for increases in diagnostic capacity in MH and LD services were more limited than anticipated.
- 5.8. The small size (and consequently limited capacity) of the pre-existing services in areas like Cwm Taf, Gwent and West Wales means demand for assessment and diagnosis by the IAS in these areas is high. The long waiting lists held by pre-existing services in Cwm Taf and Hywel Dda are an indication of previously unmet demand. The IASs in these areas inherited all or part of these waiting lists, creating a backlog. The lack of clarity around pathways in some areas, particularly before the All Wales Adults' Clinical Network was

established in 2010, may also have meant referrals were not made (creating latent demand). More positively, the impact of this should lessen over time, meaning demand levels off or reduces. Moreover, the legacy of the Adults' Network also means that in areas like Cardiff and Vale, Gwent and West Wales, the capacity of IAS has been increased by integrating or linking to elements of existing services.

- 5.9. The legacy of historic weaknesses in children and young people's ND services is also important. It means that, in some areas, more adults are seeking a diagnosis because they were not diagnosed as children. Long waiting lists for children and young people's ND services can also mean that young people nearing the age of 18 are placed upon IASs waiting lists. Over time, improvements in children and young people's ND services should reduce the number of undiagnosed adults (and therefore demand upon services).

The value of diagnosis

- 5.10. Although there are potential downsides²⁸, a diagnosis of autism has considerable value to many adults. A diagnosis is still needed to access some types of support, including for example support from the IAS. A diagnosis may, also for example, be needed to provide proof of eligibility for Disabled Students Allowance and other support from universities and may make it easier to claim disability related benefits and to claim rights under the Equality Act (2010)²⁹. However, the importance of a diagnosis in accessing services is generally less pronounced for adults than it is for children, in part because there are fewer services available to adults.

²⁸ For example, a diagnosis of autism may block entry to the army; alternatively, some people dislike the label and the risk of categorisation.

²⁹ Access to benefits and support should be based upon need, rather than diagnosis, but it is widely reported that a formal diagnosis makes it easier to demonstrate need to assessors.

- 5.11. As the evaluation of the IAS illustrates, a diagnosis can also be very valuable to adults and also their partners and families and friends, in better understanding and explaining their difficulties (WG, 2019a). Several IASs also reported that demand for diagnostic assessment was greater than demand for post-diagnostic support, because for many people, the value was the understanding provided by the diagnosis rather than the potentially greater access to support and services that (as illustrated above) could come with a diagnosis.

Population change and distribution

- 5.12. The size of the adult population differs markedly across regions, from approximately 70,000 people aged 16-64 in Powys, to over 400,000 in North Wales (Stats Wales, 2018). This means demand for each IAS is likely to differ. The uneven distribution of individuals with autism, as a result of random distribution and social factors, such as the flow of young people into and out of university cities, may also create localised clusters where demand is higher. However, population growth is unlikely to be an important factor at a national level (given the slow annual growth of between 10,000-30,000 people a year).

Managing demand

- 5.13. The approach taken by IASs to manage demand is similar to that taken by children and young people's ND services, although there is more emphasis upon gatekeeping and diversion and less emphasis upon prevention as a potential solution. The absence of waiting time targets for IASs means incentives to focus attention on how fast assessments can be started, rather than how fast they can be completed, do not apply to the same extent as they do to children and young people's ND services.

Gatekeeping and diversion

- 5.14. Gatekeeping and diversion have been key strategies for managing demand as, unlike the children and young people's ND services, the IAS is only intended to be one of a number of services undertaking assessments³⁰. Establishing boundaries to manage demand and building capacity in other services, most notably MH services, to ensure that the IAS does not become overwhelmed by demand, has been an important part of the IASs' work (WG, 2019a). However, it takes time to set boundaries and pathways and also to build the capacity of other services (where needed), drawing on resources which could be devoted to undertaking assessment and diagnosis. This was, therefore, likened to an "invest to save" approach that would provide longer-term gains.
- 5.15. In contrast to children and young people's ND services, although some steps have been taken, there has been less emphasis upon restricting the pathway to reduce demand. Cwm Taf and, to a lesser degree, Cardiff and Vale IASs, both reported that initially pathways were perhaps too open when the services were first established. In response, action has been taken to ensure that, for example, MH services continue to work with autistic people with moderate to severe mental health difficulties. Cardiff and Vale has also worked to educate referrers, most notably General Practitioners (GPs), about the information required before they will consider an assessment, and also to highlight the clinical time needed to undertake a diagnostic assessment (discussed below) in order to ensure that decisions to refer

³⁰ The IAS is only intended to undertake diagnostic assessments of adults who do not have a moderate to severe mental health or learning disability.

someone for assessment are only made where there are reasonable grounds to suspect that a person may be autistic.³¹

- 5.16. Other strategies that have been taken to manage waiting lists: include not actively publicising the pathway, as Cwm Taf initially did, and sending out opt-in letters, explaining to people how long the wait will be, coupled with waiting lists sweeps, to ensure that those on waiting lists still want to wait, as Powys has done. These were seen as important measures to ensure that people both understood how long they would have to wait, and that they were prepared to wait, to help reduce the number of appointments that were missed because people did not attend.
- 5.17. Cardiff and Vale IAS, which has a relatively high non-diagnosis rate of 50 per cent of all referrals, has piloted more intensive screening, but concluded that it is no more efficient or quick than not screening. Cwm Taf, which has a similar non-diagnosis rate, has also been looking at strengthening screening by MH services, from which many of its referrals come³².
- 5.18. Beyond these steps though, as one service observed, having a more open pathway had proved more efficient overall, as they found some people just needed information. There were also concerns that reducing access could simply delay referrals.
- 5.19. IASs have also been able to divert some demand or mitigate the impact of long waiting times by offering support and signposting before an assessment is undertaken. Gwent IAS, which has the longest

³¹ For example, the NICE Guidelines: Autism spectrum disorder in adults: diagnosis and management, outline when an assessment of autism should be considered (NICE, 2016).

³² It was reported that services currently use AQ10 screening tool but that this is not felt to be good enough, and it seems that some referrals are made where MH services have exhausted interventions and suspect the problem might be autism.

waiting list, has the most developed strategy. This includes providing advice on how to access services and support for day to day life without needing a diagnosis; making it clear that adults can still access other services while waiting; making it clear that access to MH services and social care is not dependent upon diagnosis, but upon need, and offering drop in sessions to help people “off load”. This has helped ease pressure upon the service, and because much is provided by community support workers, helps minimise the impact upon clinical staff time that could be used for assessment and diagnosis.

Prevention

- 5.20. Some stakeholders expressed hopes that the SSWB Act should reduce pressure to get a diagnosis, but as the evaluation of the IAS (WG, 2019a) illustrates, the impact to date appears to have been limited. Moreover, as outlined above, for many adults the understanding offered by a diagnosis is as, if not more, important than the impact upon access to support and services.

Capacity to assess

- 5.21. As table 2 illustrates, the pathways of each of the four IASs, which were fully operational when the research was undertaken (in late 2018) - Cwm Taf, Cardiff and Vale, Gwent and Powys - include broadly the same elements. There is greater consistency than in children and young people’s ND services (discussed in section 4). This reflects a number of factors including:
- the national IAS model and guidelines and the more limited flexibility offered by the NICE guidelines for autism services (the NICE guidelines for ASD are more stringent than those for ADHD); and

- the difference in ethos between the IAS and ND services, with a greater focus upon diagnosis rather than broader ND assessments to identify an individual's strengths and needs, in which a diagnosis may be of secondary importance.
- 5.22. Nevertheless, there are choices and also constraints about how each element is undertaken in each region, contributing to some variation in how assessments are conducted across services. Tables 2 and 3 outline the timings provided by Cardiff and Vale and Gwent IAS and table 4 outlines some of the choices services can make to help streamline assessments.
- 5.23. A Level 3 assessment, for a very complex case, would add another seven hours for cognitive assessments, which brings the total to around 29 hours.
- 5.24. Data were also provided by Powys IAS, which indicated that the assessments, using for example The Autism Diagnostic Observation Schedule (ADOS) and Diagnostic Interview for Social and Communication Disorders (DISCO) diagnostic tools, would involve two professionals, a total of 2 days of clinicians' time. Drafting a report would take approximately half a day and feedback and a post diagnostic session including, summary letter, would take a further half day, to give a total of 22.5 hours. Given the differences in the way the timings are calculated and reported, direct comparisons between the three services are not appropriate.

Table 2. Estimates of the time necessary for different elements of a diagnostic assessment in Cardiff and Vale for a “Level 1” assessment, which would be the majority of people assessed and a more complex “Level 2” assessment.

Stages	Level 1 standard assessment		Level 2, more complex assessment	
	# staff involved	Minutes (total)	# staff involved	Minutes (total)
Preparation, pre-reading , gathering history	2	60	2	60
1 st assessment appointment, covering consent, risk and assessment	2	180-240	2	180-240
Observation (ADOS)	2	60	2	60
Pre reading	1	30	2	60
2 nd Assessment appointment (clinical interview to cover all relevant areas); feedback in same interview, if possible	1	90-120	2	180-240
Feedback appointment or 3 rd assessment (level 2 only)	N/A	N/A	2	60-90
Writing the report	2	240-360	2	300-480
Total (minutes)	N/A	660-880	N/A	960-1320
Total (hours)	N/A	11-14.5	N/A	16-22

Table 3. Estimates of the time necessary for different elements of a typical and complex diagnostic assessment in Gwent

Stages	Standard assessment		Complex assessment	
	# staff involved	Minutes (total)	# staff involved	Minutes (total)
Gathering history and background	2	120	3	360
Observation,	1	90	2	240
Assessment / Clinical interview	1	180	-	-
DISCO	-	-	2	480
ADOS	-	-	2	240
Specialist consultation	-	-	2	300
Discussion and decision	2	120	4	240
Writing the report	2	300	2	300
Post diagnostic meeting	1	90	2	180
Total (minutes)	N/A	900	N/A	2340
Total (hours)	N/A	15	N/a	39

Table 4. Choices at different elements of a diagnostic assessment

Stages	Time or cost can potentially be reduced by
Gathering history and background	Effective screening and administration to ensure all the necessary material is available in a timely way; initial appointment to assess risks and decide the minimum number of clinicians needed at each stage and assessments needed; working with the patient to gather history (e.g. self-reporting by structured questionnaire).
Observation,	Choices about tools e.g.; ADOS is reported to help speed the process.
Assessment / Clinical interview	Choices about tools e.g. The abbreviated DISCO is faster than a 'full' DISCO; new interview tools, such as King's College 3DI diagnostic interview, which is being piloted, may also be faster. Focusing upon the competency, rather than just the grade of staff, to enable a range of health care professionals to undertake this; the organisation of assessments and standardisation of the process.
Decision	Minimising the number of people involved in making a multi-disciplinary decision.
Writing the report	Having a clear plan or template for the report, administrative support and/or dictating software; using computer software to generate elements of the report from responses to the structured interview.

Constraints and blockages

- 5.25. Skill, experience and confidence, coupled with the complexity of the presentation, were described as the key factors that influenced how fast assessments could be safely undertaken. Timings provided by very

experienced clinicians were therefore somewhat shorter than those provided in table 3. Whilst, as outlined above, timings for complex presentations could be up to 30 hours in a small number of cases.

- 5.26. The complexity of cases was a key challenge for services. The IAS was not designed to work with complex cases, in part because those with moderate to severe co-existing conditions such as MH or LD needs were not expected to be assessed by the IAS. Nevertheless, examples were given of: adults who did not easily fit into existing service models or “boxes”; who had had negative experiences of MH services and would not willingly access them again for assessment and diagnosis; or where MH services were reluctant or felt unable to support their mental health difficulties, given their autism. There were also a small number of people who were felt to have been misdiagnosed. These cases took more time to assess and also demanded more work with other services.
- 5.27. Given the higher than anticipated level of demand for assessment and diagnosis, IASs are under considerable pressure to streamline the process as much as possible. As with children and young people’s ND services, there is a feeling that practice has been pushed toward the limit of what is safe and robust. However, there is perhaps more confidence than in children and young people’s ND services that they have not yet been pushed over the line.³³

³³The concern for IASs is the same concern for children and young people’s ND services, that the pressure to streamline the process, and spend less time on diagnostic assessment, increases the risk of misdiagnosis and/or over diagnosis.

5.28. Like children and young people's ND services, scope to further streamline the assessment process in IASs has been limited by five factors:

- staffing, including the size of IAS teams, differences in the professionals involved, and their skills and confidence, and difficulties with staff recruitment, sickness or absence;
- differing views on quality and compliance with NICE guidelines and consequently how the process can be streamlined;
- inadequate accommodation, such as shortage of clinical space, which can make it difficult to schedule assessments;
- rurality, which can mean clinicians and clients need to travel long distances; and
- limitations in IT and administrative support, which can make booking, managing, monitoring the process of undertaking assessments and diagnosis more difficult.

5.29. The key concern, beyond the impact of lengthy waits upon clients, is that the demand for assessment and diagnosis will push IASs to draw resources away from post-diagnostic support, as has happened to other adult autism services, such as in Sheffield and the children and young people's ND services in Wales. This reduces the value of diagnosis. It may also threaten the sustainability of services, as it can make it harder to retain clinicians, given the pressure they face, and the more limited opportunities it would provide to work with and support clients after diagnosis, and maintain their clinical skills and interest.

6. Action to address waiting times

- 6.1. Action to address waiting times can focus upon reducing demand and/or increasing capacity. There is no evidence that greater alignment of children and young people's ND services and IASs would either reduce demand or increase overall capacity. Indeed, as we outline in section 8, in the short to medium term the potential disruption of services could reduce capacity, and further increase waiting lists.

Reducing demand

- 6.2. As outlined in sections 4 and 5, children and young people's ND services and IASs have taken steps to reduce demand through, for example, gatekeeping, but their scope to further reduce demand in the short to medium term is limited. Legislation such as the ALNET and SSWB Acts may reduce demand by reducing the need for a diagnosis in order to access services and support, but are only likely to do so in the medium to long term given the cultural changes needed, and there is no guarantee that they will. Moreover, they would not reduce the explanatory value of a diagnosis to families, adults and also services (for example, in helping guide the use of evidence-based interventions).
- 6.3. Societal changes, such as making schools and workplaces more autism friendly and increasing awareness and understanding of autism may also, over the longer term, reduce the need for diagnosis. However, this may only defer the demand to a time when people move from an autism friendly and aware environment to one that is less congenial.
- 6.4. Therefore, reducing demand for assessment and/or diagnosis, by reducing the need for it, whilst a desirable goal, cannot be considered a viable short or even medium term strategy to reducing the pressure children and young

people's ND services and the IASs face, and the long waiting lists many children and adults experience.

Increasing capacity

- 6.5. Action to increase capacity can focus upon making better use of the available resources through efficiencies and increasing the total size of resources, either by diverting other resources, as children and young people's ND services have done by reducing post-diagnostic support. Capacity can also be increased by accessing additional funding, as some children and young people's ND and IAS services, such as Hywel Dda, have been able to do, by using slippage monies from the IAS or by accessing ICF monies. However, these are not sustainable funding sources. They can help ease a short-term capacity gap, but cannot sustain increased capacity over the long term.

Streamlining the process

- 6.6. As outlined in sections 4 and 5, in order to increase capacity, children and young people's ND services and IASs have sought to streamline their processes to maximise efficiency by, for example, standardising processes, using new and faster tools, reducing the number of clinicians involved and improving administration and management of the process. Given the range of practice, there is likely to be some scope for benchmarking across services, which may enable some further marginal gains in efficiency to be identified and realised by individual services. Work commissioned by PHW to review ND services in Wales, and the IAS Community of Practice are likely to be helpful here. There may, for example, be scope for the T4CYP National Steering Group to agree an all Wales ND referral form and/or guidance on what information is needed to make decisions about whether to assess or not.

- 6.7. However, this does not mean that uniform processes should be enforced across all services. Differences in the size and staffing of services, the contexts in which they operate and differences in the constraints each service faces, means that a “one size fits all” approach would not be appropriate, and would probably be strongly resisted by services and clinicians.
- 6.8. As outlined in sections 4 and 5, developing different pathways depending on the complexity of cases, can also help increase efficiency. There are already different pathways for ADHD and autism in many ND services, and standard and more extended assessments involving greater multidisciplinary input and also more assessments, in both ND services and IASs, depending on the complexity of presentations.
- 6.9. However, there are potential risks of over-diagnosis or misdiagnosis, if an individual is placed on the wrong pathway. Unpicking the factors that account for a presentation can be complex and time consuming. Linked to this, there has been discussion of the scope for a “bald” assessment of autism³⁴ (which would be swifter) but also concerns and resistance to this; for example, one interviewee described it as overly medicalised and an “autistic handshake” that did not adequately assess people’s needs.
- 6.10. There was a strong and consistent view amongst clinicians from children and young people’s ND services and IASs that there had to be, as one put it, an “honest discussion about capacity” and that “a quality assessment takes time”. Therefore, while there has been scope for making marginal efficiencies that speed up the process and make it more efficient, there is a limit to how fast IASs can undertake a multidisciplinary diagnostic assessment, and how fast children and young people’s ND services can

³⁴ This would only focus on whether diagnostic criteria were met or not and would not, for example, identify the person’s care and support needs as part of the assessment.

undertake a thorough multidisciplinary assessment of a child's strengths and needs.

- 6.11. As we outline in section 8, there is also discussion about the extent to which IASs should consider other ND disorders, like ADHD. This would increase the length of the assessment process, and would not therefore generate efficiencies for the IAS, although it could help relieve pressure upon services such as CMHTs, who undertake assessments of ADHD in many areas. There are examples where ADHD and ASD assessments are done at the same time, but this is limited to clinicians with an interest and expertise in this area, who have dual roles in MH services and the IAS.

Increasing the resource allocated to diagnostic assessment

- 6.12. A number of children and young people's ND services and IASs have implemented waiting list initiatives. This has been done using staff from their services or LHB, such as Aneurin Bevan's, Cwm Taf's and Powys' ND services' "evening and weekends initiatives", or Cardiff and Vale IAS's "intensive assessment and diagnosis weeks". Services such as Hywel Dda ND and Powys and Cwm Taf IASs have also commissioned assessment and diagnosis, from, for example, the University of South Wales' Dyscovery Centre, using slippage monies. In June 2019, Gwent IAS was currently awaiting the outcome of additional bids under Mental Health Improvement Fund monies and Waiting List Initiative monies and Cardiff and Vale had put forward a business plan for additional funding to reduce their increasing waiting times.
- 6.13. Given additional resources, the size of teams could potentially be increased, but this would only be a medium term solution, and is likely to face challenges linked to the small size of the workforce (hampering recruitment) and the challenges linked to accommodation. Extending

teams could also provide scope to increase the roles played by less costly staff, such as health care support workers, or less experienced staff, who might be easier to recruit and who could be supervised by more senior staff while they developed their expertise in services. Investing in administrative support and IT systems and equipment could help some ND services and IASs by improving management of the process, and freeing up clinicians' time.

- 6.14. Table 5 summarises the main options and their strengths and weaknesses. With the exception of the first option (do nothing) none of the options are mutually exclusive so, for example, action to reduce demand could be combined with mitigation strategies and capacity building.

Table 5. Options for reducing waiting times

Options	Potential advantages (positives)	Potential disadvantages (negatives)
Do nothing (status quo)	No financial cost	Waiting times continue to stay high and in some cases, increase.
Strategies to reduce demand/need for assessment and diagnosis (e.g. ALNET, SSWBA)	This should improve experiences for children, adults and families, and would reduce pressure upon ND services and the IAS.	Largely beyond ND services or IASs' control. Also unproven and likely, at best, to be a medium to long-term solution.
Diversions and gatekeeping (e.g. restricting access to services to those with the clearest need)	Short-term solution to reduce pressure upon services; limited financial costs; effective gatekeeping and diversion should mean those who need an assessment can access it more swiftly; 'educating' referrers can improve the quality of referrals, even if not necessarily the number of referrals.	May simply defer problems and may deny access to children and adults who would benefit or need an assessment; can be frustrating for adults, families and other services (e.g. schools) who may need an assessment/diagnosis to unlock resources and/or identify effective interventions.
Mitigation (e.g. access to information and support while waiting)	Short-term solution to improve the experience of children, adults and families, whilst waiting; can mean support is accessed more swiftly.	Little evidence that it reduces waiting times and if it draws in resources, which would otherwise be spent on

		assessment, may increase waiting times.
Benchmarking across services to identify opportunities to streamline processes	Short to medium term solution that could increase efficiency and capacity, without large additional costs, and may increase consistency in practice across services	Services have already focused upon streamlining processes, so the scope for further marginal gains is likely to be constrained.
Increase capacity (e.g. recruitment, waiting list initiatives and/or investment in administrative support and/or accommodation)	Medium term solution that could improve the experiences of children, adults and families and reduce the pressure upon services. Investing in administrative support is likely to be more cost effective than relying upon clinicians to undertake administrative tasks. Developing clinicians and health care support workers' roles (to reflect their competency) as "extended practice" ³⁵ , may also be cost effective.	Costly, likely to take time (e.g. to recruit additional staff) and may be constrained by, for example, limited accommodation (so this might also need additional funding) and the small size of the workforce.

³⁵ I.e. when "a registered health professional undertakes clinical tasks or roles usually associated with another profession" (CHRE, 2010).

7. Neurodevelopmental services in the UK and other OECD countries

7.1. The increase in demand for assessment for ND disorders means that services in the UK and other countries have been under considerable strain to meet demands. Much of the literature reviewed for this study focuses upon this pressure upon services in the UK and 35 other countries who are members of the Organisation for Economic Co-operation and Development (OECD)³⁶ and the search in these countries for cost-effective responses that do not compromise on service quality, and that do not further add to waiting times.

Service models

- 7.2. The service delivery models for ND disorders can be categorised into three broad types:
- no formal pathway or designated service for assessment and diagnosis;
 - a formal pathway with multiple secondary services, such as CAMHS or CMHTs, designated to undertake assessment and diagnosis of some or all ND disorders. Provision for adults with ADHD in parts of Wales is an example of this; and
 - a formal pathway with a specialist multidisciplinary service or services, established either within existing services (e.g. CAMHS or CMHTs) or as a separate service, designated to undertake assessment and diagnosis of some or all ND disorders. As well as the children and young people's ND services and IAS in Wales, other examples of this (outlined in the appendix) include: Avon and Wiltshire's Autism Spectrum Health Care

³⁶ The OECD is a membership organisation of primarily "advanced" industrialised economies such as the UK. The current members are: Australia, Austria, Belgium, Canada, Chile, Czech Republic, Denmark, Estonia, Finland, France, Germany, Greece, Hungary, Iceland, Ireland, Israel, Italy, Japan, Korea, Luxembourg, Mexico, the Netherlands, New Zealand, Norway, Poland, Portugal, Slovak Republic, Slovenia, Spain, Sweden, Switzerland, Turkey, the United Kingdom, and the United States. The OECD was chosen to enable practice in other comparable industrialised economies/societies to be explored.

Pathway for children; Manchester’s Social Communication Assessment and Intervention Teams, which sit in CMHTs and undertake assessment of ASD; Bristol’s ASD and ADHD services for adults, and the Toronto adults’ ND service. There were also examples of services that described themselves as “all age” ND services, but in practice, pathways and provision for children and adults are separate/different.

- 7.3. For the purpose of this review we focus upon the second and third models, which are at least potentially compliant with NICE guidelines on the diagnosis and management of ASD and ADHD, which (as outlined in section 3) recommend multidisciplinary specialist services or teams and require a full clinical and psychological assessment, developmental and psychiatric history and observation (NICE, 2018; 2019). Further details on the literature (and models) reviewed are outlined in the appendix.
- 7.4. There are a number of variations on these three basic models; these include:
- different pathways and services for people of differing ages; for example, the Norfolk NHS Trust operates three different pathways with three different designed services for children (0-10), young people (11-17) and adults (18+). As outlined in section 5, some ND services in Wales continue to operate separate pathways for children under the age of five, and those aged five and over;
 - different pathways depending on the complexity of presentations; for example, Rutherford et al. (2018) developed a service in Scotland that operates “abbreviated” and “specialist” ND assessments and, as illustrated in section 5, in Wales both Aneurin Bevan and Cardiff and Vale have specialist (tertiary) ND services;
 - differing levels of pre-assessment screening; for example, both Peterborough ND services and the Isle of Wight ND services, and Cheshire and Wirral Partnership (CWP) Autism Spectrum Disorder Adult Service Pathway services undertake extensive screening; and

- differing types and levels of post-diagnostic support. This ranges from no post-diagnostic support, a single session or appointment including feedback and a diagnostic report together with referral or signposting to alternative support services (as is the case with many children and young people's ND services in Wales), to more intense support with up to 8-10 sessions of support, or more (as is the case with the IAS).

7.5. The review was constrained by the information available on the pathways and on evaluation of their cost effectiveness. The limited evaluative material identified supports the NICE model of specialist multidisciplinary teams as being more costly but also more effective. It also highlights a number of common challenges:

- parental concerns about a lack of information on diagnosis and support and lengthy waiting lists (see e.g. Mansell and Morris's (2004) evaluation of a district diagnostic service for children with suspected ASD in London);
- concerns about the lack of post-diagnostic support offered by many services (see e.g. Huttunen-Lenz, 2015);
- workforce issues, including staff training and expertise (see e.g. Au-Yeung et al., 2018); and
- the difficulties in making a multidisciplinary team work effectively³⁷.

³⁷ For example, in their evaluation of the Colchester East Hants Attention-Deficit/Hyperactivity Disorder Clinic in Canada, McGonnell et al. (2009) report that: "teams of professionals described as multi- or interdisciplinary are often not that in practice. In terms of client contact, they work in parallel, not as a team." Similarly, in their review of autism interventions, Dillenburger et al. (2014) highlight the dangers of "multidisciplinarity and eclecticism", rather than true multidisciplinary working.

The challenges associated with integration

- 7.6. Despite the support for integration, it is striking that the evidence of the impact of integration and joint working upon improved outcomes for users, remains patchy (Cameron et al., 2015; Hillary, 2011). Some literature suggests the evidence in terms of improved outcomes for organisations (as distinct from users, such as patients) is better (Ham et al., 2013)
- 7.7. There is no single model of integration, with some report authors:
- distinguishing between “hard” or “real” (such as merging organisations) and “soft” or “virtual” integration (such as forming networks and alliances) (Ham & Walsh, 2013), or
 - describing a continuum from co-operation between entirely separate organisations through the coordination of services in multidisciplinary networks (e.g. managed clinical networks) to fully integrated services with pooled funding, joint planning and management, and multidisciplinary teams (Kodner & Spreeuwenberg, 2002).
- 7.8. Ham and Walsh (2013), conclude that: “there is no evidence that any one form of integration is superior to others”. They go on to argue that:
- The main benefits of integrated care occur when barriers between services and clinicians are broken down, not when organisations are merged. A fundamental building block is the creation of integrated or multidisciplinary teams comprising all the professionals and clinicians involved with the service or user group around which care is being integrated (Ham and Walsh, 2013, p.4).
- 7.9. The evidence, including that from the establishment of the children and young people’s ND service and IAS, also suggests that integration is likely to be costly, time consuming and challenging (Ham & Walsh, 2013), given the difficulties of integrating different systems of management, staffing, funding, information sharing, quality assurance and accountability (Goodwin et al., 2012).

8. The alignment and development of autism and neurodevelopmental services

The alignment of children and young people's ND services and the IAS

8.1. As outlined in the introduction, before the ND services and IAS were established, there was a gap in assessment and diagnosis and post-diagnostic support in many, but not all, areas for autistic children and adults, children and adults with ADHD and their families. The two new services helped fill this gap, particularly in relation to autism. Although the two services were developed in parallel, the gap was large enough and their roles different enough, that the two services did not overlap. Moreover, as one interviewee observed, despite the differences at a strategic level, people on the ground “talked to each other” and good working relationships have been established between children and young people's ND services, the IAS and LAs in the three regions where the IAS was first established (Cardiff and Vale, Gwent and Powys). Consequently, there is little duplication between the two services and, to date, the two main points of interface between the two services have been well managed; these are around:

- post-diagnostic support for parents or carers of autistic children, where good working relationships have been established between children and young people's ND services, the IAS and LAs in Cardiff and Vale, Gwent and Powys, albeit not without challenges given, for example, differences in the post-diagnostic support offered by the five LAs in Gwent (WG, 2019a); and
- to a lesser degree, assessment and diagnosis for young people approaching adulthood, where an assessment by the IAS may be more appropriate; for example, it was observed that there can be issues with young adults aged 16 and over, as the way a 16 year old is assessed is very different to the way a six year old is assessed. Given differences in the approach to assessment taken by the two services (outlined in sections

4 and 5), some people raised concerns that the outcome of an assessment could differ, depending on whether a young person was assessed by an ND service or by the IAS.

- 8.2. Over time, it was also observed that there may be a further interface as children assessed by ND services begin to access the IAS as adults. Crucially though, the limited post-diagnostic support offered by children and young people's ND services (outlined in section 5) means children and young people do not automatically make a transition from support from ND services to the IAS, considerably simplifying the potential challenges linked to the alignment of these two services.
- 8.3. Moreover, in many ways the alignment of children and young people's ND services and the IAS with other services, such as education (particularly for ND services), children's and adults' MH services and social care, is as, if not more, important than the alignment of ND services and IASs, because there are many more points of contact (or interfaces) with these other services.

The development of services

- 8.4. The development of services is more complicated than any alignment of ND services and the IAS, as even once the IAS is fully operational, there are still likely to be gaps in services:
- for the parents and carers of children with ADHD or other ND difficulties (other than autism), such as Tourette's or dyspraxia);
 - for adults with ADHD or co-occurring ND disorders (which mean they don't easily fit into the IAS) or other ND difficulties (other than autism).
- 8.5. As several interviewees from children and young people's ND and adult MH services observed, the establishment of the IAS has highlighted (or illuminated) potential inequities, in which one outcome of an assessment, a

diagnosis of autism, “unlocks resources”, while others, such as a diagnosis of ADHD or an assessment that identifies ND difficulties that do not meet diagnostic thresholds, does not. For parents and carers and adults, this can feel grossly unjust, even if, as may sometimes be the case, the differing diagnoses are associated with differing levels of need. It should be noted that this review did not extend to an in-depth exploration of the clinical and educational need for services for people with ADHD.

- 8.6. This is not a criticism of the IAS, nor is it solely attributable to the IAS. The IAS and other actions under the refreshed ASD SAP, such as the local ASD infrastructure, programmes such as Learning with Autism, Working with Autism and the ASDinfoWales websites, are much needed (WG, 2019a), but there is no equivalent for ADHD or other ND disorders, where needs may be comparable to autism. The voluntary sector infrastructure of both national organisations like NAS Cymru and Autism Spectrum Connections Cymru (ASCC) and local support groups is much weaker for ADHD, and largely limited to ADHD Connections in South Wales. Moreover, it was reported by both the voluntary sector and some professionals that social services and schools offer little or no support when children or adults present with a diagnosis of ADHD rather than autism. As a consequence, as one interviewee put it, “parents are desperate”, and provision for children and adults with ADHD was reported by several interviewees from both services and the voluntary sector, to be “twenty years behind” that for autism.

ADHD provision

- 8.7. As outlined in section 5, the establishment of the children and young people’s ND service has helped strengthen arrangements for the assessment and diagnosis of ADHD and other ND disorders. However, as outlined in section 4, there are lengthy waiting lists in several areas, and very limited post-diagnostic support from ND services. It was reported that little was offered beyond medication, and consequently children and their families are

dependent upon the responses of education, children's services, paediatricians or CAMHS and the limited voluntary sector support. It should be noted that this review did not extend to a full assessment of need or in depth review of services for people with ND disorders. Nevertheless, it is reasonable to infer that this reliance upon other services creates some notable inconsistencies in access to support depending on where people live.

- 8.8. For adults, it was widely reported that "no one "owns" ADHD". There is no dedicated service in most areas, so responsibility rests with community MH services such as CMHTs. It was also reported that, because there are no specific targets for ADHD, it is not a priority of LHBs and, with the partial exception of Cardiff and Vale, it does not feature prominently in most Population Needs Assessments.
- 8.9. There are reported by adult MH services to be increases in the numbers of adults coming forward for an assessment for ADHD. This, coupled with the nature of the disorder, which requires ongoing medical input (so patients are not discharged) increases demand upon already stretched adult MH services.
- 8.10. Referral pathways for adults suspected to have ADHD are not always clear and there is reported to be an overall lack of expertise in ADHD in MH teams. There are individual clinicians with an interest and expertise in ADHD and other ND disorders. However, many of those involved in assessment and diagnosis of ADHD reported being told that they had to take on ADHD as it was within their existing job roles. Although they were committed, they described themselves as self-taught, and were frustrated that they were expected to be experts without any formal training, with limited access to multidisciplinary decision making or advice. Moreover, in one area (Aneurin Bevan / Gwent) there is reported to be no assessment and diagnosis service

for adults with ADHD, although proposals for a service have been put forward.³⁸

- 8.11. There is widely reported to be a lack of support and intervention beyond medication. Although the NICE guidelines for post-diagnostic support for ADHD are less stringent than those for autism, adult MH services generally reported they could not meet these standards. Medication and clinical observations were offered, but psycho-social support, such as cognitive behavioural therapy (CBT), or (with a few exceptions, such as the small ADHD and autism support service in Abertawe Bro Morgannwg/Western Bay) support with social issues like debt, employment, help with benefits or daily living could not be provided. Moreover, in contrast to autism, there are reported to be very few post-diagnostic resources and very few ADHD support groups.
- 8.12. There was also reported to be a high occurrence of ADHD coupled with drug and alcohol misuse, mental health difficulties such as anxiety and depression, and a disproportionate number of adults in the secure estate (prison) were reported to have ADHD. Consequently, as one interviewee put it, adults with ADHD who are not effectively supported are “high [and costly] service users”. It was also reported in several areas that MH services struggled to engage and/or follow up clients who were not engaging. Young men, including those making a transition from CAMHS to adult MH services³⁹, and those leaving prison, were identified as high risk groups. Health professionals reported that the danger here is that without continuing medication, adults’ ability to fully participate in society could deteriorate and they might only re-engage with services when they hit crisis point.

³⁸ The health board does not commission any specific services in relation to the assessment, diagnosis or interventions for adults with ADHD and instead relies upon third sector support services offering, for example, counselling, advocacy and training (ABUHB, 2018).

³⁹ For example, Swift et al. (2013), explore the difficulties young people with ADHD experienced making the transition from CAMHS to adult MH services, particularly where they had milder or less complex problems, so might not reach thresholds for adult services.

8.13. Overall, it appears that ADHD provision for adults and parents and carers is similar in terms of the inconsistency and fragility of service provision, to that before the Adults' Clinical Network was established and community support posts were launched in 2010, and later, the IAS was launched in 2016. Although the evidence was consistent, it is not comprehensive (e.g. in terms of the areas covered) and has only involved a handful of adults with ADHD or parents or carers. Further work to scope and map the needs and aspirations of people with ADHD is needed before decisions about service development could and should be made.

Co-occurrence

8.14. Research suggests that rates of co-occurrence of autism and ADHD are relatively high. Co-occurrence of autism and ADHD with other conditions, such as learning disabilities and mental health needs, is also high. There is some evidence that a diagnosis of ADHD may delay a diagnosis of autism (diagnostic overshadowing) (Miodovnik et al., 2015 cited in Spicer-White and Howells, 2018).

8.15. The views of staff from ND services and IASs on the degree of overlap and co-occurrence of autism and ADHD, differed. Staff within ND services were more likely to talk, for example, about a "cluster" or "galaxy" of ND disorders, including what has been described as a "dimensional" view (Ibrahim & Sukhodolsky, 2018). One interviewee also described how his views on this had changed markedly since they started working for an ND service. In contrast, some staff within IASs saw autism and ADHD as quite distinct and different conditions. In two cases, clinicians from the IAS questioned how robust a diagnosis of ADHD could be (in contrast to a diagnosis of autism). Those who saw autism and ADHD as more distinct conditions, often highlighted co-occurrence of autism with other mental health conditions, as more significant. However, this was not uniform and some staff within IASs reported high levels of co-occurrence of autism and ADHD. Their concern was

that they lacked the expertise to assess and diagnose for ADHD and that there was no service for people with a diagnosis of ADHD to go to.

- 8.16. Co-occurrence of conditions can challenge services, as it can mean people do not fit easily into existing service structures, which are often condition specific. The greater breadth of the children and young people's ND service, compared to the IAS, can therefore be considered a strength, but it does not resolve the problem, it simply makes the "silo" bigger, and as noted above, co-occurrence of, for example, ND and MH issues, can still challenge services around the interface between different specialist services. There are also concerns that creating specialist services can lead to deskilling in more mainstream services.

The scope for the IAS to develop into an adult ND service

- 8.17. Most ND services supported the idea of developing the IAS into an adults' ND service (or "all age" ND service, which we discuss below). There is an expectation amongst some (but not all) stakeholders in some areas, like Cwm Taf and Gwent, that the IAS will become an ND service to help fill gaps in service provision. It is argued that the co-occurrence of ADHD and autism means it is logical to bring assessments of the two conditions together. As one interviewee put it, it is: "madness if they are only partially assessed in this service" and the risk of misdiagnosis was higher if all possible conditions were not considered at the same time. It was also observed that there are people who do not meet criteria for ADHD or autism, but who have a range of ND issues. Some services, such as Betsi Cadwaladr, Hywel Dda and Cardiff and Vale ND services, also saw opportunities to increase alignment of the children and young people's ND service with adult services and, for example, to share training and expertise.

8.18. However, with the exception of Gwent IAS that was open to the idea in principle, but had very serious concerns about the practicalities, staff in IASs were generally opposed, and often strongly opposed, to the idea of developing an adults' ND service or all age ND service. They highlighted a range of practical challenges and objections to this, including:

- clinicians' interest and expertise, as several staff from IASs reported they were autism specialists – not ADHD / ND specialists;
- the potential impact upon existing services, and the risk that it could lead to deskilling in MH services (if clinicians no longer dealt with ADHD);
- differences in the support and interventions needed by adults with ADHD and autism, including the need for medication, and therefore the need to involve psychiatrists in teams (to prescribe and oversee medication);
- resourcing given the increased demand it would place upon IASs (or a new adults' ND service) and concerns that without adequate additional resourcing, it would add further pressure upon already stretched services and disadvantage autistic adults; and
- concerns about the impact of restructuring upon services that were only just starting, which it was feared could cause a crisis in terms of demand and also staff morale.

8.19. As outlined above, there were very differing views on how similar or dissimilar autism and ADHD were as conditions (with staff in IASs generally seeing them as quite distinct), and a feeling that the needs of adults with ADHD were often quite different to the needs of autistic adults. The logic of bringing the two conditions together into a single service was therefore questioned. This is consistent with evidence from many children and young people's ND services in Wales and also the service models from other parts of the UK and OECD reviewed for this study (see section 7), which identified very few adults' ND services, and a tendency for adults' ND services to operate separate pathways for ADHD and autism.

The scope for the IAS to develop into an all age ND service

8.20. Like proposals for adults' ND services, views on the desirability and viability of establishing an all age ND service were broadly, although not uniformly, split, with staff from children and young people's ND services much more in favour of the idea, while staff in IASs opposed it. In addition to the practical and philosophical challenges outlined, it was observed that differences in the development, ethos and roles of ND services and the IAS would mean, as one interviewee put it, that integration of ND services and the IAS would be a "huge task"; the differences include:

- ND services focus upon identifying an individual child's strengths and needs, and the IASs focus is on assessment and diagnosis;
- differences in staffing, location and hosting (e.g. many ND services sit in CAMHS or Community Paediatrics), while the IAS is an integrated, joint LA/LHB service, that usually sits in adult MH services. It was also noted that a larger service might face even more acute problems finding adequate accommodation; and
- differences in the demands of services working with children and adults; for example, staff from IASs observed that they were generally not "a paediatrically skilled team" and that there were also practical and safeguarding issues associated with having both children and adults accessing the same service.

8.21. Moreover, it may be significant that although the literature review identified services that described themselves as "all age" ND services, in practice, these services operated different pathways and services for children and adults.

Alternative service models

- 8.22. A “softer” model of integration of services (discussed further in section 7) for people with ND disorders, such as an agreed national pathway and clinical networks to share expertise and encourage joint working, may be easier than a “hard” integration of services. Collaborative working, much as the IAS works with MH services where there are co-occurring mental health issues, may be more prudent and proportionate than hard integration of services. The examples of practice where IAS staff with expertise undertake both ADHD and autism assessments could also potentially be developed, to make the IAS, as one interviewee put it, “more of an ND type service”, without formally changing the structure of the service. However, as the experience of the All Wales Autistic Spectrum Disorder Diagnostic and Pre/Post Counselling Network (the predecessor to the IAS) illustrates, there are also risks associated with this type of approach (see e.g. Holtom & Lloyd-Jones, 2016). For example, it gives local areas/services greater autonomy, and is more reliant upon individual clinicians taking initiative (e.g. in developing their expertise, practice and joint working), which can lead to inconsistencies in provision.

9. Conclusions and options for the alignment and development of neurodevelopmental and autism services in Wales

Waiting times

- 9.1. The reason for long waiting times for diagnostic assessments for children and adults is a mismatch between demand and capacity. Demand for assessment by both ND services and also the IAS has been higher than forecast and the scope to increase capacity has been limited. Differences in the size of the mismatch between demand and capacity account for differences in waiting times across services, and areas where the gap between demand and capacity is largest, have the longest waiting times.
- 9.2. Long waiting times can delay early intervention for children, and are a source of huge frustration for families and adults. Even when waiting time targets are met, it can take over a year after concerns are first raised (e.g. by school), before a diagnosis is made, and families feel they get the answers and support they feel they need at a critical time in their child's life. Long waiting times may also mean that some individuals who would benefit from a diagnosis either choose not to be assessed, or are not put forward for assessment by their families, or feel compelled to pay for a private assessment.

Demand for assessment

- 9.3. It is not possible to measure long-term trends in demand, due to the lack of data, but the data that are available, including education data and anecdotal data from services, are consistent and suggest a sustained increase in demand. This reflects social and environmental factors, such as increasing awareness of ND disorders and also of the new services, the perceived need for a diagnosis to access support and services, and the legacy left by historic

weaknesses in assessment and diagnostic services for both children and adults.

- 9.4. The level of demand individual services experience is different, given differences in the size and socio-economic characteristics of the population they serve and also the legacy left by the assessment and diagnostic services that preceded the ND service and IAS.

The capacity of services

- 9.5. The capacity of individual services is also different. This reflects differences in:
- national funding, with the IAS (£3m p.a.) benefiting from markedly higher levels of funding than ND services (£2m p.a.);
 - local funding with, for example, Cardiff and Vale IAS benefiting from additional resources, and the Hywel Dda ND service benefiting from slippage monies, to help fund a waiting list initiative;
 - their workforces with, for example, more experienced clinicians generally swifter than less experienced clinicians and the impact of sickness and absence upon individual services; and
 - the way assessments are conducted.
- 9.6. The capacity of IASs to meet a proposed six month (26 week) waiting time therefore also varies. Services such as Cardiff and Vale and Gwent expect to be able to meet this target if given additional resources, but without additional funding they expect to struggle. Adding targets which could not be met in the short to medium term would simply add to the pressure already stretched services face, and would increase the likelihood that resources were diverted from post-diagnostic support to assessment and diagnosis.

Actions to reduce waiting times

- 9.7. There are no simple solutions to reduce waiting times. There appears little scope to further reduce demand, at least in the short to medium term through, for example, prevention or by diverting children and adults to other services. Therefore, a reduction in waiting times will require an increase in capacity. Services have sought to streamline assessments to increase efficiency (and therefore capacity), but given the variation in practice, there is likely to be some scope for benchmarking to help identify further marginal gains for services. In some cases, it may be appropriate to develop an agreed standard approach for Wales to maximise efficiency and promote consistency, without compromising quality. However, imposing a “one size fits all” approach to assessment and diagnosis is unlikely to be appropriate.
- 9.8. The scope to generate efficiencies by changing practice is likely to be constrained, as in large part the quality of an assessment depends upon the time invested in it. If assessments are conducted too swiftly and /or too narrowly and/or by a single professional, the risk of over- or misdiagnosis increases.
- 9.9. Increasing funding to increase the size of clinical teams is therefore likely to be necessary to increase capacity. However, even if additional resources were made available, the impact upon capacity could still be constrained by difficulties in recruiting staff and in finding suitable accommodation. Moreover, any increase in funding nor the service is likely to have a knock on effect upon funding for other services.
- 9.10. There is no evidence that greater alignment would either reduce demand or increase capacity, unless it was underpinned by additional resources to expand capacity. Nevertheless, as we outline below, there may be a case for further developing services to better fill gaps.

The current service configuration

- 9.11. As outlined in section 1, children and young people's ND services and the IAS were developed largely in parallel. However, on the ground, where the IAS is fully operational, working relationships between the services have developed. This means that the key interface between the two services around post-diagnostic support for parents and carers of autistic children is well managed. Further alignment to enable, for example, joint working with autistic young people or the sharing of expertise would be valuable, but does not require hard integration or more formal alignment of children and young people's ND services and the IAS.
- 9.12. The establishment of children and young people's ND services and the IAS has markedly increased the quality of assessment and diagnosis although, as outlined above, services have struggled to cope with demand, leading to lengthy waiting times in some areas. Where fully operational, the IAS is valued by both autistic adults and the families of autistic children. The IAS offers access to a specialist service that is generally felt to understand their needs, and which helps fill gaps in post-diagnostic support (WG, 2019a).
- 9.13. Although a comprehensive assessment of needs and provision was not possible, the available evidence indicates that the current service configuration (of children and young people's ND services and the IAS) leaves gaps, particularly for individuals with ADHD or ND disorders other than autism, and their families. There is obviously asymmetry in establishing a children and young people's ND service, without an equivalent service for adults and therefore a plausible, but currently unproven (*prima facie*) case for developing services to help fill this gap.
- 9.14. However, there is no clear consensus amongst children and young people's ND services or IASs on a preferred service model, such as an adult ADHD service or ND service or all age ND service. The evidence, including that from

the establishment of children and young people's ND services and the IAS, suggests that further restructuring and/or integration of existing services would be likely to be costly, time consuming and difficult. It would also potentially disrupt existing services, which are already fragile given high levels of demand and, particularly in the case of the IAS, still establishing themselves. Some service models, such as developing the IAS into an ND service, would also potentially benefit some groups, such as adults with ADHD, at the expense of other groups (e.g. autistic adults), unless the increased demand for services this would create was matched by increased resources.

- 9.15. The purpose of further alignment and/or development of services needs to be crystal clear, given the potential costs, difficulties and disruption it would entail; for example, greater alignment of children and young people's ND services and the IAS would be complicated by differences in their ethos and approach: many children and young people's ND services work across a range of ND disorders, and focus upon an assessment of an individual child's strengths and needs rather than a diagnosis *per se*. In contrast, IASs are more focused upon diagnostic assessment for autism, but also provide much greater post-diagnostic support than ND services can.
- 9.16. Moreover, given the co-occurrence of neuro-developmental disorders with other conditions such as mental health problems and substance misuse, alignment of children and young people's ND services and the IAS with other services may be as important as their alignment with each other, and it may be more appropriate to focus time and attention upon strengthening their alignment and interface with other services.

Alternative service models

- 9.17. The review of alternative models discussed in section 7 (and the appendix) finds that the evidence base is limited. The available evidence (including that considered by NICE) supports the development of specialist multidisciplinary teams/services (like the IAS and children and young people's ND services).

However, it also recommends these services provide post-diagnostic support and also that they support other services, as the IAS does, but which the children and young people's ND service struggles to do, given the demand it faces for assessments. There are also interesting examples from across the UK and OECD countries. These are worth exploring in more depth, particularly if the option of developing either an adult ADHD or an adult ND service is considered. However, the available evidence does not suggest any particular model is inherently superior or more cost-effective. It should be noted that the experience of children and young people's ND services in Wales and autism and ADHD or ND services in other parts of the UK, often end up developing different pathways and services for people with autism and ADHD. Variants on the models, including "softer" models of integration, such as the way the IAS currently works with adult MH services or clinical networks, which may prove to be more prudent and proportionate, should also be considered. Evidence from the evaluation of the IAS (WG, 2019a) suggests that autistic adults and their families value having a specialist service. It is reasonable to infer that adults with ADHD and their families would value a specialist adult ADHD or adult ND service.

Options appraisal

- 9.18. Given the uncertainty about the purpose of further alignment and/or development of services, and the gaps in services, it would be premature to recommend a particular option. Subject to these important caveats, table 6 outlines the key options considered by the study and their relative strengths and weaknesses.

Table 6. Options appraisal for service alignment and development

Options	Potential advantages (positives)	Potential disadvantages (negatives)
Do nothing (status quo)	Simple, no financial cost; alignment is developing.	Gaps remain, particularly in relation to post-diagnostic support for adults with ADHD; parents / carers of children with ADHD; and also in relation to access to assessment and diagnosis for adults with ADHD and those with other ND disorders.
Increase alignment of ND and IAS e.g. through networks, collaboration and sharing of practice (soft integration)	Simpler, less costly than developing new services / integrating existing services (e.g. to create an adult ND service), builds upon existing links and models (e.g. the IAS's joint work with mental health services) to ensure the interfaces between the services are well managed.	Gaps are likely to remain, particularly in relation to post-diagnostic support for adults with ADHD; parents / carers of children with ADHD; and also in relation to access to assessment and diagnosis for adults with ADHD and those with other ND disorders.

<p>Invest to increase the post-diagnostic capacity of ND services</p>	<p>Likely to improve the post-diagnostic experiences of children and families; would help fulfil the original vision of the children and young people's ND service.</p>	<p>Costly; increases need for alignment with the IAS (e.g. if young people made a transition from the ND service to IAS and other services like schools; gaps remain, particularly in relation to assessment and diagnosis and post diagnostic support for adults with ADHD and those with other ND disorders.</p>
<p>Invest to increase post-diagnostic capacity of other services (e.g. schools, children's disability services)</p>	<p>Likely to improve the post-diagnostic experiences of children and families.</p>	<p>Costly; alignment of the ND service with the IAS and other services becomes more important (e.g. to ensure a smooth transition from the ND service to post-diagnostic support from other services) and potentially challenging; gaps remain, particularly in relation to assessment and diagnosis and post -diagnostic support for adults with ADHD and those with other ND disorders.</p>

<p>Develop a 'virtual' adults ADHD service within existing services. This could be supported by a clinical network of ADHD clinicians (e.g. to support training and access to specialist expertise) and/or an agreed national pathway for ADHD</p>	<p>Likely to improve the experiences of adults with ADHD; building expertise and capacity within existing services is likely to be simpler and faster than developing a new specialist service; could be an intermediate stage or 'stepping stone' before a new service was established; avoids creating another 'silo'.</p>	<p>Costly; alignment with the IAS and also for example, MH and LD services would need to be carefully managed (e.g. where there was co-morbidity); pressure upon existing services like CMHT could make it difficult to protect/ring-fence the capacity of the new service. Likely to still leave gaps for adults with ND disorders other than ADHD or autism.</p>
<p>Develop an adults' ADHD service and national pathway for ADHD</p>	<p>Likely to improve the experiences of adults with ADHD; adults with ADHD may prefer a dedicated specialist service.</p>	<p>Costly; likely to be challenging and time consuming to establish; alignment with the IAS and also, for example, mental health and learning disability services would need to be carefully managed (e.g. where there was co-morbidity). Likely to still leave gaps for adults with ND disorders other than ADHD or autism.</p>

Develop an adults' ND service by extending the role and capacity of the IAS, so that it became a 'full' ND service, working with all ND disorders.

Consistent with Welsh Government policy which favours greater integration of services; favoured by some stakeholders; likely to improve the experiences of adults with ADHD and also those with autism and ADHD (and/or other ND disorders) and the parents and carers of children with ADHD (and/or other ND disorders), if, like the IAS, the service supported parents and carers; could generate economies of scale between ND services and the IAS and opportunities to share and build expertise.

Costly; likely to be challenging and time consuming to establish; potential to disrupt existing services (most notably IASs) and strongly opposed by many IASs; alignment with other services such as mental health and learning disability services would need to be carefully managed (e.g. where there was co-morbidity). Could potentially disadvantage autistic adults and/or parents or carers unless demand for the service from adults with ADHD and parent or carers was adequately resourced. Not clear if the workforce with ND skills is available and could risk cannibalising staff from existing children and young people's ND services.

Develop an all age ND service by integrating the existing children and young people's service and IAS. This could operate as separate services and pathways for ADHD and autism or as a fully integrated ND service.

Consistent with Welsh Government policy which favours greater integration of services; supported by some stakeholders; should ease transitions from children's to adults' services; likely to improve the experiences of adults with ADHD and also those with autism and ADHD and parents and carers; could be better suited than the children's ND service for young people (e.g. those aged 15-17); could generate economies of scale with the IAS and children and young people's ND services and opportunities to share and build expertise.

Costly; the most complex and ambitious model, which could maximise benefits, but also potentially be the most disruptive, risky and time consuming to develop; strongly opposed by many IASs; may be difficult to recruit a workforce with both paediatric and adult skills; may in practice develop in separate children's and adult services (as many existing all age ND services currently operate); unless adequately resourced, risks disadvantaging adults (as resources may be drawn to assessment and support for children). Alignment with other services like education/schools, children, CAMHS and CMHTs and learning disability services would need to be carefully managed.

10. Recommendations

1. The T4CYP National Steering Group, Public Health Wales, the National Autism Team and the IAS Community of Practice should support benchmarking of practice across ND services in order to identify potential efficiencies and improvements to assessment processes.

2. Children and young people's ND services and IASs should provide a strategic plan setting out the number of assessments that they can do in a year, identifying what this means for their waiting lists and making costed proposals on how to increase capacity so it matches demand. LHBs will need to consider the impact of this upon other services.

3. The Welsh Government, Local Health Boards and Local Authorities should review the funding for children and young people's ND services and the IAS to ensure it is commensurate with the demands they face. Consideration will need to be given to the impact of this upon funding for other services.

4. The T4CYP National Steering Group, Public Health Wales and the National Autism Team should continue to support the further alignment of services through, for example, joint meetings and training.

5. Service leaders in children and young people's ND services and IASs should continue to collaborate and ensure that where alignment is needed (e.g. around post-diagnostic support for the families of autistic children) the interface between the two services is well managed, and that opportunities for the services to share practice and expertise, and improve alignment (e.g. through co-location of services) are taken.

6. Regional Partnership Boards, Public Health Wales and the National Autism Team, should monitor how effective the alignment and interface between the two services is. This should focus upon the key points of alignment: post-diagnostic support for parents or carers of autistic children and assessment and diagnosis for young people approaching adulthood, where an assessment by the IAS may be more appropriate. This could include, for example, services reporting on joint working in these areas as part of service monitoring.

7. Further work to inform the development of services for individuals with ADHD, and/or other ND disorders other than autism, and their families should be undertaken. This should focus upon identifying needs and gaps in service provision. This could be taken forward at a national level (for example led by the Welsh Government and/or PHW) and at regional level (for example led by LHBs and/or RPBs).

8. Any proposed development of services should be done co-productively, involving individuals with ND disorders, their families and also existing services, such as children and young people's ND services, IASs and Community Mental Health Teams. This could include, for example, the involvement of "experts by experience" (people with experience of ADHD or autism or of caring for someone with ADHD or autism) and the voluntary sector in national and regional working and steering groups tasked with developing services.

9. ND and IAS service leaders should ensure that any steps to further align ND services and the IAS, do not unduly compromise or undermine steps to align and manage the interface of the children and young people's ND service and IAS with other services, such as education and mental health and social care.

10. Given the weakness of the evidential base for the cost-effectiveness of specialist integrated services like the IAS and children's ND services, further evaluation of their cost-effectiveness is warranted to inform the future development of services. This should be undertaken by services themselves (self-evaluation) and also feature in evaluations commissioned at a national level by the Welsh Government, National Autism Team and/or Public Health Wales and at a regional level, by for example, RPBs and/or LHBs.

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12. Appendix: examples of specialist service models

Introduction

12.1. This section presents examples of the different type of specialist service models identified by the literature review. The services are described and where evidence of cost-effectiveness is available, this also presented. Where available, in almost all cases, this is limited to evidence of effectiveness drawn from qualitative research with service users and professionals, with limited discussion of cost or value for money. Compliance with NICE guidelines (outlined in section three) was also considered. However, the scope to assess this was limited by the evidence presented. In most cases services appeared to be compliant, as they involved specialist multi-disciplinary teams and comprehensive assessments. The scope, to for example verify whether professionals were suitably trained, to examine the range of information considered in assessments, or assess how person-centred services were (which feature in the NICE guidelines), was limited.

Specialist autism services

The Suffolk Autism service

12.2. Suffolk has three age-specific services for ASD diagnosis. The children's ASD service for 0-11 year-olds is part of children's community health services with two separate ASD pathways. Referrals go through paediatricians in Suffolk Community Health (SCH). Norfolk and Suffolk Foundation Trust (NSFT) provide services for 11-17 year-olds and 18+ adults as two separate services. Referrals to NSFT go through the Access and Assessment Team (AAT). Services for 0-11 year-olds and 11-17 year-olds have a comprehensive information gathering system that incorporates a holistic view of all parts of the person's life, with multidisciplinary diagnostic assessment.

12.3. The service was evaluated in 2015. Huttunen-Lenz' (2015) study provided an analysis of service specifications across all age ASD services in Suffolk (excluding Waveney) through interviews with service providers and a focus group for parent/carer feedback.⁴⁰ In their evaluation of the service, Huttunen-Lenz (2015) notes that there have been some minor issues around incorrect referrals. The pathways are age-specific and do not coordinate with each other. Children under 11 have access to a package of assessment and diagnosis, interventions (co-ordinated between home and school) and support, as well as support for parents. However, there is limited service provision for children over 11 and adults, with access only for those with diagnostic needs. There is unequal access to post-diagnostic support in Suffolk. Huttunen-Lenz also found issues relating to the screening process for ASD diagnosis and recommended the development of an agreed protocol of how ASD referrals are processed. Dillenburger et al. (2014) note that multidisciplinary models often refer through GPs and education professionals in the child's school, however they will be unlikely to have received ASD training. Norfolk county council has its own ASD pathway but it is very similar in structure to Suffolk's age-specific services for ASD diagnosis.

The Avon and Wiltshire Autism Spectrum Health Care Pathway (0-18)

12.4. Referral onto the The Avon and Wiltshire Autism Spectrum Health Care Pathway (0-18) is through the relevant service within the Community Children's Health Partnership (CCHP) when symptom criteria are met. Following this, the child will have an initial appointment and a nominated lead professional. In CAMHS this will be with the Choice and Partnership Approach (CAPA) Choice clinician. The CAPA Partnership determines whether the case should be referred to specialist ASD professionals. The outcome of an initial appointment can result in referral to an appropriate service, or discharge if autism is not

⁴⁰ No details are provided of the numbers of interviewees limiting the scope to assess the quality of evidence.

present; a patient may also be asked to wait to see how symptoms develop, or a decision is made to undertake an autism diagnostic assessment.

- 12.5. Where a diagnostic assessment is indicated, this should occur within three months of referral to the autism team. A standard assessment would involve at least two different professionals from more than one setting collating as much information as possible around the case, gathering information from the educational setting and observation. After the assessment there will be a diagnostic meeting and feedback meetings to discuss outcomes and identification of support needs.
- 12.6. If a diagnosis is given, parents will receive basic information about autism and be signposted to local support groups and courses. Following diagnosis, the child and family are offered a six to eight week post-diagnostic appointment. If a diagnosis is made through CAMHS the mental health issues present will be the foundation of the care plan. Follow up will be agreed with families based on their need. Many will not need an appointment to be routine, and much of the signposting, support and intervention will take place in the educational setting or support groups. Interventions from other health services would be personalised to each child's needs. When the young person turns 17 they can consider transition to adult services (Sheahan & Howlett, 2016). No evaluation of the service was identified, so the scope to assess the effectiveness of the service was very limited.

Manchester's Social Communication Assessment and Intervention Teams (SCAITS)

- 12.7. In Manchester, Social Communication Assessment and Intervention Teams (SCAITS) were established within CAMHS, involving child and adolescent psychiatrists, community paediatricians, CAMHS practitioners, specialist speech and language therapists (SALT), and educational psychologists (EP). All are trained in assessing autism. If informed and referred directly from a GP

or paediatrician, the team produces individually tailored plans for each person for diagnosis and care.

- 12.8. The service was evaluated in 2011. Mockett et al.'s (2011) survey with 20 parents⁴¹ found considerable differences in the time taken between referral and diagnosis, with most in the study having taken longer than the recommended time of 17 weeks. Interestingly, the child seen within the shortest timeframe was least happy and those seen over the longer timeframe were happier.
- 12.9. However, recently this approach has been found no longer fit for purpose, predominantly due to a considerable increase in referrals. MPCF's (2018) review noted that their parent carer surveys found issues with access, long waiting times, assessment duplication and inconsistencies in services. Unfortunately, there is little evidence available to judge the robustness of these findings. Consequently, all the services involved (with MPCF) have designed a new pathway, for which NHS Clinical Commissioners are funding a two year pilot which began in October 2018. In the new referral pathway, referrals will be assessed by a core triage team of advanced clinical practitioners and each referral case will be assigned a named key-worker to support them through the assessment process. The main differences will be that assessment will no longer solely take place in CAMHS but in the community, and there will be formalisation of assessment tools so that there is a consistency of service (MPCF, 2018).

⁴¹ 35 parents of children diagnosed with ASD from December 2008 to May 2010 were invited to participate and 20 (57 per cent) completed their survey by returning it in the post or via telephone.

Cheshire and Wirral Partnership

- 12.10. Following referral from GPs and other NHS staff to the service, individuals that meet the criteria for the Cheshire and Wirral Partnership autism service are sent a questionnaire. The questions for assessment are based around the questionnaire responses. The assessment is carried out by an Occupational Therapist and a psychiatrist, after which feedback and a provisional diagnosis may be given. After this, a report will be sent to the person and their GP and later a follow up appointment to confirm a diagnosis. Information about where to access support and strategies for building strengths will also be provided. The individual is discharged from the service once a diagnosis is made and a post-diagnostic review is complete (Cheshire and Wirral Partnership NHS Foundation Trust, no date. a.). No evaluation of the service was identified, so the scope to assess the effectiveness of the service was very limited. Derbyshire Adult Autism Service is a similar example of this type of service (Derbyshire Healthcare Foundation Trust, no date).

Abbreviated and specialist pathways: Community Child Health services in Scotland

- 12.11. In Scotland, Rutherford et al. (2018) developed an evidence-based ASD pathway for children based on evidence of core elements of processes and practice that impact waiting time. As part of this, assessments will have core components of developmental history, contextual assessments and observation, much like the previously described pathways. In cases where autism is more evident, children would follow an “abbreviated pathway” without seeing a specialist team and autism is diagnosed using reports and observation from community staff. For more complex cases, there is flexible but informed use of standardised tools (Rutherford et al., 2018) to identify that multidisciplinary autism triage with staff from CAMHS, Community Child Health (CCH), and Speech and Language Therapy (SLT) allows allocation of cases to abbreviated or complex pathways from the beginning. Having a single pathway

and way of recording referrals means that less time is wasted through duplication and consequently, waiting times are shorter.

12.12. The service was evaluated in 2017, reporting on cases referred in a 12 month period once practice had been established (in the second year of pathway implementation). The study collected baseline information through staff interviews and case note analysis and set up a clinical database to measure user involvement in the pathway. As a result of the baseline and local scoping exercise the new pathway was developed which included use of a single and abbreviated pathway. Key findings from the study showed that demand for autism assessment was underestimated without a systematic procedure for data collection. Rutherford et al. (2018) note that this has implications for meeting service demand, and that clinicians would benefit from data management specialists to help gather data so that services could be budgeted more effectively. This is consistent with the difficulties some ND services and IASs have experienced forecasting demand and demonstrating the gap between demand and capacity.

The Leeds Autism Diagnostic Service (LADS)

12.13. The Leeds Autism Diagnostic Service (LADS) incorporates a team of MH and LD professionals with specialist autism knowledge. Once a referral is accepted the person is invited for an initial assessment appointment to bring together background information and complete an Autism Diagnostic Interview (ADI). Preferences in the ADI form will influence how each individual goes down the pathway, so consequently not all users will go down the same pathway. After the appointment, if autism is diagnosed then a follow up appointment would be arranged where further information about the diagnosis and signposting to appropriate support services would be provided. If it is not yet determined this would be arranged for a later date. It is also possible in complex cases that further assessments and review would need to take place at a clinical decision meeting. Consultancy support is also available on request for those who need

it (Leeds and York Partnership NHS Foundation Trust, no date). No evaluation of the service was identified, so the scope to assess the effectiveness of the service was very limited.

Specialist ADHD services

The Colchester East Hants ADHD Clinic in Canada

- 12.14. The Colchester East Hants ADHD Clinic in Canada is based upon a multidisciplinary team, including clinical psychologists, educational psychologists, and paediatricians, in addition to other professionals as required.

- 12.15. The service was evaluated in 2008. McGonnel et al.'s (2009) evaluation of the perceived effectiveness of and satisfaction with the service found that GPs in particular noted issues with lengths of waiting times and lack of post-diagnostic services, however additional clinic days were added to address this. Interviews with 31 service providers (working for the health or school board) and survey invites for 204 service users (approx. 90 responses (44%)), followed by quantitative and qualitative analysis found that the clinic was effective in diagnosis and there were plans to expand the service. They concluded that a multidisciplinary model is, and should be, widely endorsed, the authors noted that previous research indicates that professionals working alone can be diagnostically ineffective, and the multidisciplinary model has wider implications for clinical practice beyond this specific setting for ADHD assessment.

ADHD clinical services in Dundee and Angus

- 12.16. Specific ADHD clinical services in Dundee and Angus are managed by the CAMHS service for NHS Tayside. They have developed an evidence-based clinical ADHD pathway over the last two decades. Due to limited resources the service takes advantage of the available staff so that most work is carried out by nurses who are not qualified to prescribe ADHD medication. However, a multidisciplinary team of experienced clinicians train and supervise those less experienced on ADHD assessment and management.
- 12.17. There are four key stages to the pathway. In stage 1 following referral, the child may take part in a pre-assessment screening before an assessment. In stage 2a, nursing staff will gather assessment information on developmental and family history and undertake a structured ADHD evaluation, a physical examination, cognitive and intelligence testing and production of an initial assessment report. In stage 2b, a senior doctor discusses the diagnosis and treatment planning with the patient and family. Where there is a confirmed diagnosis, the service provides psycho-education⁴² and post-diagnostic support. If ADHD is not diagnosed, discharge arrangements are made unless there are other mental health issues, in which case follow up arrangements are made. In stage 3, treatment is initiated. Non-pharmacological treatment usually involves a programme of behavioural parenting work. This is in addition to initial dose titration (the process of adjusting the dosage of a drug like Ritalin to determine the level required), which is closely monitored. The final stage is continued care and monitoring of treatment; patients are seen every 6-12 months as required and other problems may also be identified.
- 12.18. The service was evaluated in 2015. Key features of the pathway include standardised protocols for assessment, dose titration, and monitoring of clinical care. Tools used are reported to be accessible (use of Likert scale for

⁴² Psychoeducation is a therapeutic intervention that teaches patients (and their family in this instance) about their condition.

each criteria to collect information about symptoms to create a score and space for medication information), cost effective and clinically relevant (can be adapted according to setting needs). Another key feature is that clinical care is delivered in a non-academic clinical setting with close links to the University of Dundee. These links have been central to the development and evidence base of the pathway (Coghill & Seth, 2015). The pathway relies on well-trained staff and is time-intensive, however it is reported to be cost effective to use existing staff skills and time through a structured core pathway (Coghill & Seth, 2015).

- 12.19. Healthcare Improvement Scotland (2012) was somewhat more equivocal about the service. They found that high caseloads and varying approaches by partner agencies limited the integration of the pathway and made it difficult to provide non-pharmacological interventions. They also noted a lack of protocols and variation in the treatment and management of adults with ADHD.

The Bristol ADHD Clinic

- 12.20. The Bristol ADHD clinic consists of a specialist team of doctors, psychologists, an OT and nurses working solely with adults with ADHD. Following referral from a GP or health professional, the service user is placed on a waiting list and later sent questionnaires to complete prior to assessment. The assessment itself involves gathering information about the person's background and a diagnostic assessment. After this they, along with their GP, are sent a report. Should a diagnosis be made, treatment and support are offered in the form of appropriate medication for ADHD, psycho-social interventions, and peer support and skills group (Avon and Wiltshire Mental Health Partnership NHS Trust, no date). No evaluation of the service was identified, so the scope to assess the effectiveness of the service was very limited.

12.21. Other examples of specialist adult ADHD services include the Wirral adult ADHD service⁴³, Northumberland, Tyne and Wear⁴⁴ and Norfolk and Suffolk⁴⁵.

Specialist ADHD and autism / neurodevelopmental services

The Toronto neurodevelopmental service

12.22. The Toronto Neurodevelopmental Service is structured to offer an outpatient programme and a Brief Intervention Inpatient Unit (BIU) that is aligned and operates in the Centre for Addiction and Mental Health (CAMH) teaching hospital in Toronto. Referral is through a single access point for the hospital. Following initial processing there is a referral to the adult ND outpatient programme where intake assessments are conducted. Information from this is used to refer the service user to one of five pathways:

- 1) psychiatric consultation clinic;
- 2) medication consultation clinic;
- 3) high-functioning autism pathway;
- 4) inter-professional assessment and treatment pathway; or
- 5) intensive intervention pathway.

12.23. The BIU is accessible through any of the pathways, the emergency department or another inpatient unit. Follow up services are offered from outpatient clinics following discharge from BIU.

⁴³ See: [Wirral Adult ADHD Service](#)

⁴⁴ See: [Northumberland Tyne and Wear Adult ADHD Service](#)

⁴⁵ See: [Norfolk and Suffolk Adult ADHD Service](#)

12.24. The service was reviewed in 2016. The review draws upon findings from an earlier review, which was not discussed in the paper, and also a survey of staff⁴⁶ and case studies of individual patients. The review identified that people with ND and mental health issues may require provision from multiple agencies. Consequently, it was important for the service to support “inter-professional collaborative care”. The service restructured itself to improve inter-professional collaboration by having it led by point of care teams for inpatient and outpatient pathways that are in charge of everyday clinical operations. The team includes a manager, psychiatrist and advanced practice clinician. There is also an executive leadership team, which oversees strategy and planning. Both teams make decisions together, although it is the point of care team that communicates with staff (Summers et al., 2016).

The Peterborough Neurodevelopmental Service

12.25. The Peterborough Neurodevelopmental Service builds on the structure of the National Autism Plan for Children patient pathway (NAS, 2003) to offer a wider neurodevelopmental model. Following referral to the service, information is reviewed and passed to the Primary Mental Health Worker who collates more information about the child’s developmental history. If a ND disorder seems possible and the child has not met with a paediatrician in the last year then they will undertake a general developmental assessment. If a ND disorder seems probable, the child is referred to one of three integrated multiagency teams (ADHD, ASD, and LD) for a multiagency assessment. The teams will work with other agencies to implement relevant interventions. Should there be uncertainty over cases they can be brought to the ND forum, which is attended by all team members in the service who discuss and refer to others if necessary and a second opinion can be

⁴⁶ This was part of wider staff survey, which included questions on staff confidence in relation to their inter-professional knowledge and skills (Summers, et al, 2016). No further details on the survey or responses rates were provided.

provided by the ND team for those with more complex issues. The ND team also arranges short courses and tailored child and parents training, as required. Very complex cases can also be referred regionally or nationally.

- 12.26. De Vries et al.'s (2007) description of the service and discussion of findings from an evaluation on the services' progress (within the service and by service users, commissioners and referrers) after one year found positive responses from service users and commissioners. New posts were created for primary mental health workers to bridge the gap between clinicians, schools, specialist services and between teams, and an admin worker. Local Education Authority (LEA) funding also supported the appointment of specialist roles within teams. An ND executive committee was also created to manage and monitor progress of the service. However, the service faced challenges in terms of waiting lists and access to knowledge and skills in integrated multiagency teams. Staff also felt that teams were working in isolation with uncertainty about roles. It was also felt that the ND forum was underused and consequently it was placed more centrally within the service. Further details and evidence around the evaluation is unclear, however the paper concluded that although multiagency working is important, it needs time and commitment to form teams and should be tailored to local needs-

The Hampshire Autism and ADHD Service

- 12.27. After referral to the Hampshire Autism and ADHD Service, service users will be sent a number of self-completion tests including a short sensory profile and two information gathering tools. These are used during an appointment with the practitioner to make an initial assessment and produce a diagnostic report. If an autism diagnosis is made, then there would be a referral to the service partner Autism Hampshire, which would arrange a follow up appointment to consider support options. A diagnostic report with possible strategies and referrals will also be sent to the GP should this appointment

not be taken up. As the service specialises in autism and ADHD, a multidisciplinary team is only involved if the diagnosis is unclear or complex. Autism Hampshire offers non-clinical pre- and post-diagnostic support in the form of one to one support, a post -diagnostic follow up meeting, and drop in sessions. The ADHD Service follows a similar pathway. Once an ADHD diagnosis is confirmed, treatment options are discussed. If this is a treatment such as CBT, a referral to a relevant service would be made, and if the treatment is medication there would be regular follow up meetings to monitor progress before being discharged (Surrey and Borders Partnership, no date). No evaluation of the service was identified, so the scope to assess the effectiveness of the service was very limited.

Other examples of ND services for adults

- 12.28. Other examples of ND services for adults include: Barberry Neuropsychiatry services, which are managed by Birmingham and Solihull Mental Health NHS Foundation Trust, which offers assessment, diagnosis and treatment for a broad range of neuropsychiatric disorders. Other examples of similar adult autism and ADHD or neurodevelopmental services include the Devon Partnership⁴⁷, South London and Maudsley⁴⁸, Sheffield Adult Autism and Neurodevelopmental Service (SAANS)⁴⁹, Dudley, Derbyshire and Walsall Mental Health Partnership⁵⁰, and the Coventry and Warwickshire Partnership⁵¹ service.

⁴⁷ See: [Devon Partnership Adult Autism and ADHD Service](#)

⁴⁸ See: [South London and Maudsley ADHD and ASD Services](#)

⁴⁹ See: [Sheffield Adult Autism and Neurodevelopmental Service](#)

⁵⁰ See: [Dudley and Walsall Mental Health Partnership Adult Neurodevelopmental Service](#)

⁵¹ See: [Coventry and Warwickshire Partnership Adult Neurodevelopmental Service](#)

13. Methodology for the desk-based literature review

Introduction

13.1. A desk-based literature review of autism and ND services, both within the UK and internationally, was undertaken. This included a systematic search of peer-reviewed academic material, and other material published on the internet, such as evaluations of services to (subject to the study's resource and time constraints) comprehensively:

- map and describe the different models of autism and ND services (e.g. in terms of the age range covered, services offered, the structure of services, and, where available, the costs of services); and
- identify evidence on the cost-effectiveness of services (where available), including what works well and challenges and areas where the service could encounter problems.

Evaluating the evidence of the cost-effectiveness of services

13.2. The most commonly used approach to evaluate the quality of evidence is to focus upon the design and methods used, with “experimental” designs such as randomised controlled trials (RCTs) generally considered the “gold standard”, providing the most robust evidence of impact. However, this approach risks excluding high quality evidence generated by other methods (Breckon, 2016). Because large scale, well conducted RCTs are rare, it also risks severely constraining the volume of evidence that can be considered. Therefore, as we outline below, the methods used, and evidence presented, were assessed on a case by case basis, to determine whether claims about the effectiveness of the service were supported by good quality evidence. As outlined in section 12, in most cases, there was a reliance upon qualitative evidence of effectiveness, drawn from small samples of service users and professionals, limiting the external validity of findings.

Inclusion criteria for the review

13.3. In order to determine which items (such as a journal article or evaluation report) identified by the search would be included in interview, inclusion criteria were developed. The criteria used focused upon:

- relevance: the item (such as journal article or report identified through the search) must either describe and/or evaluate an autism or ND service that offers assessment and diagnosis to children and/or adults, that is based in an OECD country⁵² and is either currently operational, or has operated in the last 10 years, and that is in countries like the UK, with a government funded health service (like the NHS), part of the government funded health service, rather than a private provider;
- timeliness: only literature published in the last fifteen years (2003-2018) will be included;
- utility: the item must include sufficient information to enable a service to either be described and/or its effectiveness to be considered for it to be included; and
- languages: the item must be published in the English language.

Search strategy

13.4. The sources searched were:

- PubMed, JSTOR and Google scholar and to identify academic literature;
- Google, to identify other relevant material, such as evaluations of ND or autism services; and

⁵² I.e. Australia, Austria, Belgium, Canada, Chile, Czech Republic, Denmark, Estonia, Finland, France, Germany, Greece, Hungary, Iceland, Ireland, Israel, Italy, Japan, Korea, Luxembourg, Mexico, the Netherlands, New Zealand, Norway, Poland, Portugal, Slovak Republic, Slovenia, Spain, Sweden, Switzerland, Turkey, the United Kingdom, and the United States. For more information: [OECD Member Countries](#)

- The Evidence for Policy and Practice Information (EPPI) Centre, The National Institute of Clinical Evidence (NICE); Social Care Institute for Excellence (SCIE) and the Campbell Collaboration Library, to identify any previous meta reviews in this area.

13.5. The search terms were based upon two strings of search terms:

- autism OR ASD AND service AND diagnosis*
- Neurodevelop* ^[53] OR neurodisabili*^[54] OR ADHD AND service AND diagnosis

Sift and review strategy

13.6. A two stage sift was undertaken in early 2019 (January-February, with some further additional follow up work in March-April). The title and executive summary of items identified through the search were reviewed, and those that were clearly irrelevant (e.g. because they did not relate to a ND or autism service) were discarded. Given the choice to use deliberately broad search terms, increasing sensitivity, at the expense of specificity, the sift of Google and Google Scholar searches were limited to the first 1,500 hits. The full text of items included after the first sift was then reviewed and those that did not meet the inclusion criteria were discarded.

13.7. Those items included after the two stage sift which were purely descriptive (which address the objective to “map and describe the different models of autism and ND services”), were included. Those items which included evaluative material, such as an evaluation of a service, were reviewed to establish if the evaluative material met the quality thresholds for the study (outlined below) so that they could be included.

⁵³ Or “neurodevelopmental” where “*” wildcard is not used in search.

⁵⁴ Or “neurodisability” where “*” wildcard is not used in search.

Quality thresholds: assessing the strength of evidence of cost effectiveness

13.8. Given uncertainty about the likely strength of the evidence base, no overly restrictive quality criteria, such as the use of experimental designs, were imposed. This reduced the risk that useful evidence was discarded purely because it does not meet the very highest standards. Instead, for items that evaluate the effectiveness of assessment and diagnosis and/or support for autistic people or those with another ND disorder, there must be:

- sufficient description of the service, such as the context in which it works and the way in which the assessment and diagnosis is undertaken and/or support is provided, to enable the service to be understood and described and where possible, its compliance with NICE guidelines considered; and
- adequate description of the evaluation methodology, to enable assessment of any claims about the effectiveness of the service and to make a judgment about its strengths and limitations. This would include information on:
 - the rationale for the study design and methods used (to enable a judgment on the appropriateness of the study design/approach and methods to be made);
 - the sample(s) and sample selection (to enable consideration of how representative findings drawn from the sample are likely to be);
 - how data were collected (including consideration of the type of outcomes measured, such as service use satisfaction and waiting times) and for example, how outcomes were measured; and
 - how conclusions were reached (to enable a judgment to be made about the credibility of findings, e.g. is there a clear link between the data, interpretation and conclusion?⁵⁵)

⁵⁵ See e.g. Nutley et al., 2013. [What counts as good evidence?](#) and Spencer et al., 2003. [Quality in Qualitative Evaluation: A framework for assessing research evidence](#)

13.9. This approach meant that items (such as journal article or evaluation reports) that only described a service (and were therefore relevant), without evaluating the service, could be included. It also meant that items that described a service, but which also included poor quality evaluative material (e.g. due to weakness in study design), could be included, with the description included, but poor quality evaluative material excluded.

13.10. Table 7 presents the results of searches.

Table 7. Results of searches

Search terms	autism OR ASD AND service AND diagnosis*			Neurodevelop* OR neurodisabili* OR ADHD AND service AND diagnosis		
Sources	Sift 1	Sift 2 (After timeliness)	Reviewed/ Included	Sift 1	Sift 2 (After timeliness)	Reviewed/ included
Google	207	159	44	82	30	12
Google scholar	990	983	98	984	970	24
PubMed	631	544	29	1107	945	15
JSTOR	202	198	5	107	90	0
EPPI	0	0	0	0	0	0
NICE	78	62	12	0	0	0
Campbell Collaboration	0	0	0	0	0	0