

SOCIAL RESEARCH NUMBER:

47/2022

PUBLICATION DATE:

11/10/2022

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

(Includes a summary of stakeholder discussions and research tools)

Mae'r ddogfen yma hefyd ar gael yn Gymraeg.

This document is also available in Welsh.

Title: Review of the Demand, Capacity and Design of Neurodevelopmental Services: Annexes to the Full Report (Includes a summary of stakeholder discussions and research tools)

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Holtom, D and S Lloyd-Jones (2022). *Review of the Demand, Capacity and Design of Neurodevelopmental Services: Annexes to the Full Report*. Cardiff: Welsh Government, GSR report number 47/2022
Available at: <https://gov.wales/review-neurodevelopmental-services>

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
ALN	Additional Learning Needs
AMHS	Adult Mental Health Services
ASD	Autistic Spectrum Disorder (also referred to as Autistic Spectrum Condition and autism)
CAMHS	Child and Adolescent Mental Health Service
CYP	Children and Young People
DLD	Developmental Language Disorder
EHWB	Emotional Health and Well-Being
EP	Educational Psychology
GP	General Practitioner
IAS	Integrated Autism Service
IT	Information Technology
LA	Local Authority/Authorities
LD	Learning Disability
LGBT	Lesbian, Gay, Bisexual, Transgender
LHB	Local Health Board
MH	Mental Health (services)
NAS	National Autistic Society
NAT	National Autism Team

ND	Neurodevelopmental
NDC	Neurodevelopmental Condition
NDWSP	Neurodiversity Wales Shared Platform (previously called the Do-It profiler)
NEST	Nurturing Empowering Safe Trusted
NICE	The National Institute for Health and Care Excellence
OT	Occupational Therapy
PhD	Doctorate of Philosophy
PLASC	Pupil Level Annual School Census
QA	Quality Assurance
RCPsych	Royal College of Psychiatrists
RCSLT	Royal College of Speech and Language Therapists
SEN	Special Educational Needs
SLTs	Speech and Language Therapists
T4CYP	Together for Children and Young People
UK	United Kingdom

1. Introduction

1.1 This review of the demand, capacity and design of Neurodevelopmental (ND) services for children, young people and adults in Wales, was undertaken in order to develop recommendations and evidence-informed options for improvements to services. The review's approach and methodology, findings and recommendations, including proposals for developing ND service models, are outlined in the full report¹.

1.2 This supplementary document contains annexes to the full report, including:

- A summary of key themes in the written comments made by participants in the two stakeholder workshops for children's and adult ND services (section two);
- A summary of the ND Review's Working Group's discussions of options to reduce demand and/or increase capacity in the short term (section three); and
- Examples of the research tools used to gather data for the review (sections, four, five and six).

¹ Both the full report and summary report on the review are available here: [Review of Neurodevelopmental Services](#)

2. Summary of key themes in the written comments made by participants in the two stakeholder workshops for children’s and adult ND services

Children’s ND services workshop 42 participants.	Adult ND services workshop 30 participants.
<p>Demand</p> <ul style="list-style-type: none"> • The PLASC data raises lots of questions about high and increasing numbers of autistic children, which may be suggestive of over-diagnosis (it was noted that ‘the diagnostic rate is now beyond the prevalence rates’); in contrast, much smaller numbers of children with ADHD, which may be suggestive of under-diagnosis and/or children being missed. • Increasing demand should be celebrated and gatekeeping is problematic: we ‘should not restrict access’ although we may need to diffuse demand across the system, rather than concentrating it upon ND services; and we need to decouple diagnosis from access to services. However, this risks just delaying demand for a diagnostic assessment. • Increasing demand for assessment also means increasing demand for pre- and post-diagnostic support. 	<p>Demand</p> <ul style="list-style-type: none"> • Demand for adult diagnosis is rising. This should be welcomed (and ‘not be resisted’). • IAS data on demand is skewed by COVID-19 and is increasing. • Increasing complexity of cases also increases demand. • Diagnosis is driven by the search for answers and sense of identity, but ‘diagnosis is still required to access the benefit system, education, and support in the workplace. Much more awareness still required for people to make adjustments.’ • ‘Demand for ADHD is growing quickly and yet it remains an unmet need in most areas.’

Capacity

- The pressure services are under threatens their sustainability and the model is near breaking: “There needs to be a paradigm shift - not just tweaks”
- Workforce retention and recruitment are key challenges (and mean more funding will not, of itself, solve the capacity problems).
- Waiting time targets are seen as unhelpful: they distort priorities and increase the risk services ‘hit the target but miss the point’.
- There is too much emphasis on a 'diagnosis' not an assessment; need to focus upon the need not the diagnosis; there should be an 'early help', truly needs-led, person-centred approach, with a rethinking of the role / function of diagnostic assessment in the whole system that is ‘informed by a full understanding of the current functions of diagnosis (within education, benefits entitlements, etc etc).’
- There is too much emphasis upon autism, to the detriment of other NDCs.

Capacity

- Demand for diagnosis is rising. Although this should be welcomed, demand is clearly greater than capacity, which threatens the sustainability of services which are ‘fragile’ (given their small size and the risk of staff ‘burn out’). There is also a need to identify who's best placed to diagnose an individual (e.g. AMHS? the IAS? LD services?) but there is limited capacity in some of these services.
- A quality assessment takes time, especially for ‘complex’ cases.
- Pre- and post-diagnostic support is as important as a diagnosis; but need not and should not only be provided by the IAS (the third sector has a key role for both autism and ADHD, and ‘primary care and GP clusters have a role in offering services prior to referral to secondary care MH and LD services and the IAS’).

The design of services

- There is 'no easy answer or solution', 'just throwing money at it won't work on its own' [although more money might help give services a breathing space] and there needs to be 'a long-term ND strategy'.
- There is a need to rethink the role that diagnostic assessment plays and to strengthen the wider system: 'health cannot solve this alone, there is not enough money or staff to ever fix the current system, must be the whole system' (e.g., by 'prioritising early intervention and support through increasing knowledge, skills and capacity within our universal and targeted services (e.g., health visiting, Flying Start, primary teachers, social workers)').
- There is a need for workforce development for both ND services and the wider workforce.
- Co-production is vital: 'we must ensure that the voice of the child and young person is central to whatever we do.'

The design of services

- The 'system is struggling rather than broken'. 'Whatever we decide on ND we must NOT break the IAS teams'; we need to build upon the foundations - the 'IAS isn't perfect, but it's a start'.
- However, the IASs should not be set in stone and 'can be flexible and reshaped'. This could include looking at staffing structures and the allocation of funding to different IASs. It was also felt that the demand-capacity 'gap needs to be closed first then you might find more head space to think about service re-design'.
- Joint work, collaboration, co-location, improving communication etc. are valuable (and may be easier than reconfiguring services) but take time and breaking down silos is difficult in practice (so should not be seen as easy or cost-free solutions).
- There is a need to develop services for adults with ADHD. However, views on a standalone ADHD services vs an adult ADHD service linked to the IAS were divided. It was noted that: 'knowledge and expertise around ADHD and other ND services [are] lacking in IASs.'

	<ul style="list-style-type: none">• Transitions between children to adult services can be challenging. Views on all-age services were divided, although there was scepticism about whether there were true all-age services, and some favoured greater collaboration (e.g., through models like transition workers) to address the issues.• A systems-wide approach is needed to provide (i) pre- and post-diagnostic support (including the role of the third sector and 'peer mentors and networks') and (ii) access to diagnostic assessments (e.g. from AMH, LD and IA services).• User-led involvement essential in any redesign of services.
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3. Summary of the ND Review's Working Group's discussions of options to reduce demand and/or increase capacity in the short term

3.1. As outlined in section two of the main report, participants in the Working Group's first meeting were asked to respond to a series of options intended to reduce demand and/or increase capacity in the short term. Once each option including a description and rationale was presented, members of the Working Group were invited to comment and asked to identify:

- What inputs and activities are required? (in effect, how can this be realised?)
- What differences do you think the change(s) will make? and
- What potential barriers are there?

3.2. Six options were put to the Working Group, but given their responses, and comments, options 3, 4 and 6 have been split into sub options, to better reflect the Working Group's discussions. The Group's comments on each option are outlined in the following tables:

- Option 1: Reduce the number of referrals accepted by services
- Option 2: Suspend waiting time targets for children's ND services until the demand-capacity gap closes.
- Option 3a: Decoupling a diagnosis of autism or ADHD from access to support [by changing practice in education settings]
- Option 3b: Decoupling a diagnosis of autism or ADHD from access to support [by moving to a neurodiverse approach to supporting NDCs]
- Option 4a: Increasing efficiency in diagnostic assessment [through triage and streamlining some assessments]
- Option 4b: Increasing efficiency in diagnostic assessment [processes by addressing bottlenecks and constraints]
- Option 5: Restructure ND staff teams
- Option 6a: Drawing upon capacity beyond ND services: diagnostic assessments
- Option 6b: Drawing upon capacity beyond ND services: support.

Option 1: Reduce the number of referrals accepted by services

Description	Rationale	What inputs and activities are required?	What differences do you think they'll make?	Potential barriers	Other comments
<p>Restricting who can make a referral to an ND service; increasing the amount of information required before a referral is accepted; requiring certain actions to be taken before a referral is accepted (e.g. a graduated response in schools, where settings use their resources and strategies before a referral is accepted); enhancing screening before a referral is accepted; and/or</p>	<p>A diagnostic assessment is costly (so there is a case for rationing access to those who most need it); a diagnosis should not be needed to access support or services; PLASC data suggests that current level of demand for autism diagnosis assessments is higher than it should be; and ND services are 'fragile' (given their small size and the risk of staff 'burn out') and there is a need to reduce the</p>	<p>Rewrite the process - buffer it, slow it down while we gather information, support families during this time; sometime [we] see attachment [disorder], so [we] may filter some out; putting support in - starting the [ALN/SEN] graduated response; gatekeeping in education too – [schools have] got to see [have access to] autism [advisory] services.</p>	<p>There'd be riots; people have waited a lifetime; would just 'shunt' [demand for an assessment] to other services like CAMHS who won't see them.</p> <p>One member [of the Working Group] felt like their service has the right balance - about 70%. Even the 30% who don't get a diagnosis have a need so it wouldn't be right not to assess and give them some kind of formulation.</p>	<p>How would we do it? tape up the letterbox? we're raising awareness [of NDCs] - but not accepting [referrals for diagnostic assessments of NDC]?</p> <p>A referral is made because someone has a concern. We have a responsibility to acknowledge that concern.</p> <p>Some CYP [are] rejected as [they're] not in crisis [which] disadvantages those with supportive</p>	<p>We should take this [option] off the table.</p>

<p>diverting children and young people or adults to other services.</p> <p>The Do It Profiler [the Neurodiversity Wales Shared Platform] - may help 'triage' [referrals]</p>	<p>pressure they are under.</p> <p>[In the discussions it was also observed that it might be possible to] Triage [cases] by impact - based on distress [and some people who were referred to services were] just interested; if no significant impact on their life [do they need an assessment?]</p>		<p>This would delay referrals.</p>	<p>families; ND [services] don't use crisis as a reason for referral.</p>	
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Option 2: Suspend waiting time targets for children's ND services until the demand-capacity gap closes.

Description	Rationale	What inputs and activities are required? What else is required?	What differences do you think they'll make?	Potential barriers	Other comments
<p>Suspend waiting time targets for children's ND services until the demand-capacity gap closes.</p>	<p>Given the mismatch between demand and capacity, the current targets for children's ND services are unachievable and increase the risk that services (try to) 'hit the target but miss the point'. Suspending the target recognises the reality of the current situation; would reduce the pressure upon services which are</p>	<p>Change legislation; waiting times are on LHB risk registers</p> <p>[There are] Other ways to measure performance via our IT system.</p> <p>When there is a co-morbidity of conditions - all the conditions need to be addressed when on the waiting list.</p>	<p>Focus upon what's important to the CYP/adults.</p> <p>[There would be] Little difference because we don't meet them anyway and there are no consequences.</p> <p>Waiting times are meaningless but countable. It would be more beneficial to measure outcomes.</p>	<p>NICE guidelines are 13 weeks!</p> <p>Caution re: suspension given the potentially negative impact upon public confidence; discrepancy in UK, discrepancy with NICE [Guidelines]</p>	<p>[We're] constantly firefighting; so glad IAS haven't had this target.</p> <p>There are other opinions about waiting list targets, but members didn't think this should be a priority.</p> <p>How we respond to this [pressure upon services] is important and [the] negative consequences and impact on staff have</p>

	<p>'fragile'; and is likely to be welcomed by services. Abolishing the target could also give services greater flexibility to develop more person (rather than target) centred services.</p> <p>[Participants also reported that the] HB is obsessed with the waiting times; it's the only thing they count; so demoralising; [the] waiting time target [is] not helpful.</p> <p>There are examples of services that over-focus on waiting lists to the detriment of</p>		<p>Parents would still say how long are we waiting? ...[we have] got to build confidence, [so people] know you'll get a better service and waiting for the first appointment is not the point</p>		<p>to be addressed. There could be alternative performance measures, but these are not short-term actions.</p>
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	<p>focusing on outcomes.</p> <p>[It means we] Focus upon 1st appointment not conclusion.</p>				
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Option 3a: Decoupling a diagnosis of autism or ADHD from access to support [by changing practice in education settings]*

Note: A number of comments focused upon enhancing support in schools and the wider system, which would support this decoupling. Other comments focused upon the co-occurrence of NDC and ‘complex’ cases (as one comment put it there are ‘also other NDCs e.g., DLD’), and are discussed in table 3b.

Description	Rationale	What inputs and activities are required? What else is required?	Potential barriers	Other comments
<p>A strategy, such as a public information campaign and changes in practice where a diagnosis is currently required (e.g., to access some specialist provision, such as special schools and the IAS) would be implemented to ensure that a diagnosis is not required to access support and that this is widely understood.</p>	<p>There is a longstanding aspiration that a diagnosis of autism or ADHD should not be required to access support. However, there are examples where this is the case - as one participant in the stakeholder workshops put it: ‘diagnostic assessment is currently too central / too “relevant” to too many things and there is a widespread perception</p>	<p>Need the right provision and the right support from primary [schools] right through to university. Invest into [the] education offer for children that are already excluded to get back into education - address difference and need.</p> <p>What could we do for the wider systemic response?</p> <p>Increase support for trusted adults in every education provision for every child that</p>	<p>[There are] No local authority ADHD advisors.</p> <p>We should deal with problems not a diagnosis, but some people want a diagnosis; [we have] got to deal with what people want.</p>	<p>Education has the power in this instance with children.</p> <p>[We need]... a holistic approach for ...people Stop the infrastructure of the system being how we respond. Let’s focus on the individual in this instance.</p>

<p>The group's discussion suggests this would also need to be underpinned by changes in practice in education settings (which would require workforce development to increase skills and confidence).</p>	<p>that a diagnosis, and in particular a diagnosis of autism, is a "magic key" that will open doors, which are otherwise shut.' Developing a more needs rather than diagnosis led approach could also help other groups of neurodiverse children and adults (e.g. those who fall short of diagnostic thresholds, but who have real needs).</p> <p>[In the group's discussion, it was also noted that] Historically people have been excluded [e.g. from education, as a result of unmet needs linked to an NDC].</p>	<p>has a difference / need, to proactively address risk of exclusion. Keep children in school and build on strengths.</p> <p>Happy and safe environments that support learning.</p> <p>Increase special provision to address children excluded.</p> <p>Create trusted adults in school for children at risk of exclusion.</p> <p>Consider [the ALN/SEN] graduated response and coherent discussion with education to address earlier help and support.</p> <p>Consider interface with [the] NEST model.</p>		
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		<p>In the short term could we do something about training for individuals within the system to mobilise the workforce. [So] There's a training need [and it] needs to be part of a coherent plan. Upskill the wider community (as the IAS does). Consider targeted training [like the CAMHS] in reach [programme]</p> <p>EHWB [emotional health and well-being] services to provide ND friendly strategies and approaches.</p> <p>Consider [the] role of 3rd sector regarding telephone access to helpline to facilitate support and signposting, [it is] critical to be part of wider coherent plan that can be communicated to the public.</p>		
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		[Foster] confidence that you'll be supported. Prioritise those [with the] greatest need [for a diagnostic assessment].		
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* No comments were directly made on the difference this option would make

Option 3b: Decoupling a diagnosis of autism or ADHD from access to support [by moving to a neurodiverse approach to supporting NDCs]*

Description	Rationale	What inputs and activities are required? What else is required?	Potential barriers	Other comments
<p>Moving to a neurodiverse approach to the way NDCs are supported; an approach which is needs- rather than diagnosis-led. This should mean that support is not specific to diagnosis but recognise[s] neurodivergence and associated needs and co-morbidities.</p>	<p>There is a longstanding aspiration that a diagnosis of autism or ADHD should not be required to access support. However, there are examples where this is the case (see table 3a) Developing a more needs rather than diagnosis led approach could also help other groups of neurodiverse children and adults (e.g., those who fall short of diagnostic thresholds, but who have real needs).</p> <p>[In the group’s discussion, it was also noted that:] Historically people have been excluded [e.g. from education,</p>	<p>We need to see the whole child/young person in the context of their family and follow the graduated response to ensure every ND condition is considered in the identification of difference and need - not just ASD 1% but equally ADHD 5% and equally DLD 7.5% and equally LD and dyslexia, dyscalculia, Tourette’s. Then build a profile, within the family context of what’s important for them and what’s important to them. This is a whole system / multiagency problem so let’s tackle it that way.</p> <p>Consider targeted ND specific support and training to be</p>	<p>Uncoupling takes time - not a short-term solution.</p>	<p>Acceptance of difference, so ND is considered like LGBT [people] are now.</p>

	<p>as a result of unmet needs linked to an NDC]</p> <p>The IAS works well but only addresses autism.</p> <p>[There is an] Over emphasis upon autism. [Support for other NDCs is less developed, even though the numbers of children and young people with these conditions is greater]: ASD 1%...ADHD 5%DLD 7.5% and ... LD and dyslexia, dyscalculia, Tourette's.</p>	<p>addressed as part of a national coherent policy. Option to address co-morbidities that impact on CYP and adults e.g. anxiety, self-harm, disruptive behaviours affecting access to education and employment.</p> <p>Consider targeted training to [the CAMHS] in reach [programme]</p> <p>EHWB [emotional health and well-being] services to provide ND friendly strategies and approaches.</p> <p>Consider [ALN/SEN] graduated response and coherent discussion with education to address earlier help and support.</p> <p>Consider interface with [the] NEST model.</p>		
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		<p>Consider [the] role of [the] 3rd sector regarding telephone access to helpline[s] to facilitate support and signposting, [it is] critical to be part of wider coherent plan that can be communicated to the public.</p> <p>The IAS works well but only addresses autism. We either need to expand the IAS ...or expand the children's ND service to support interventions.</p>		
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Option 4a: Increasing efficiency in diagnostic assessment [through triage and streamlining some assessments]*

Note: two ways to increase efficiency were discussed: (1) using triage to identify (i) less complex cases (which could be done more swiftly) and (ii) those most in need who could be expedited; and (2) increasing the efficiency of existing diagnostic assessment processes which is discussed below in table 4b

Description	Rationale	What inputs and activities are required? What else is required?	Potential barriers
<p>The Demand and Capacity review identified that consideration could also be given to offering formulations rather than full ND diagnostic assessments and/or streamlining assessments where a diagnosis is clearer / more clear cut.</p>	<p>A 'full' diagnostic assessment is lengthy and time consuming and may not be required in every case (e.g. as one participant put it: 'in clearer cut cases', where there is good information and the soc[ial] com[munication] checklist [has been completed] but we're not allowed [to expedite these cases on this basis, so they stay on the waiting list]. Streamlining assessments in these cases would increase capacity, without requiring an increase in resources.</p>	<p>[We] expedite if greater need e.g. co-occurring cases - could we stream?</p>	<p>There aren't that many [cases] that are clear cut. [You can] cut corners but [this] causes problems later. Separate autism / ADHD pathways [means you] don't know about co-morbidities until you do the assessment. All got an equal need.</p>

* No comments were directly made on the difference this option would make

Option 4b: Increasing efficiency in diagnostic assessment [processes by addressing bottlenecks and constraints]*

Description	Rationale	What inputs and activities are required? What else is required?	Other comments
<p>The Demand and Capacity review identified a number of issues, bottlenecks and constraints and gaps in ND services. These include: a shortage of administrative support (which means that clinical staff have to undertake administrative tasks); problems with accommodation (which can, for example make scheduling assessments difficult); problems with IT (which can hamper moves to work online); problems getting the information required for an assessment in a timely way; and/or bottlenecks, when the time of one or more clinicians</p>	<p>In part the demand-capacity gap is caused by issues, constraints, and gaps in diagnostic assessment processes. Addressing these should increase efficiency and therefore increase capacity, without requiring an increase in resources.</p>	<p>Other services [have a role in] gathering evidence - sending over EP [Educational Psychology] advisory reports; advice clinics for schools, if [they] don't know what to do, but sheer volume is a challenge.</p> <p>The benefit of efficient gathering of information as part of the ND assessment was discussed. This will be addressed by the new digital platform the NDWSP [Neurodiversity Wales Shared Platform] ... but [the] timescale for national rollout [is still] several years [off].</p>	<p>The group decided to take this [option] off the table because if there were more efficiencies to be made, they would have been made.</p> <p>It feels like work is happening on this.</p>

<p>who must be part of the process are limited.</p>		<p>Managing capacity, targeted training, in-house structures to allow progression- attractive jobs to retain staff as a separate point - admin support to provide a human point of contact to address recurrent themes regarding queries and enquiries - this could be supplemented by virtual technology.</p>	
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Option 5: Restructure ND staff teams*

Description	Rationale	What inputs and activities are required? What else is required?	Barriers	Other comments
<p>NICE guidelines require multidisciplinary teams including, for example, psychiatrists, psychologists and speech and language therapists. However, the salaries and prospects for recruiting different professionals differ, and in restructuring teams there is scope to reduce the commitment of some (expensive) professionals' time to ND services and expanding others' roles.</p>	<p>ND services' structures should not be 'set in stone'. Restructuring staff could help increase capacity without increasing staffing costs where, for example, health care workers take on tasks from specialist nurses and specialist nurses take on tasks from medics. It could also ease problems with the recruitment and retention of staff; make teams more diverse and multi-disciplinary (and therefore potentially</p>	<p>Great opportunities to increase breadth of staff available to ND service, consider as part of a wider approach with training and peer review to maintain standards.</p> <p>Work collaboratively with others to do it together; overhaul governance arrangements. ND should be more like IAS; recognise specialists.</p> <p>The NDWSP offers a guardian login so different people can contribute to</p>	<p>Risk is dilution and loss of expertise.</p> <p>SL [speech and language] needs a consultant mentor, health is health; nonclinical members of [an ND] team can be difficult to manage - but IAS is [an] integrated service, it can work.</p> <p>Corporate governance in the [L]HB. I've got to QA [quality assure] our services, [we've] got a medical and clinical director that limits what we can do.</p>	<p>No waiting time for SLT [Speech and Language Therapy] in Cardiff - but there is for a PEAD [paediatrician]</p> <p>Do we need medics? consultants? No! draw upon expertise where it is needed.</p>

	<p>more confident working with neurodiversity), and address bottlenecks in services (e.g., by bringing in non-medical prescribers to free up psychiatrists' time (where prescribing ADHD medication causes bottlenecks).</p>	<p>assessment[,] but it is overseen - could we develop capacity to provide oversight, governance, training from a core ND team and upskill, empower [the] wider workforce [? This would help reduce risks linked to 'dilution and loss of expertise'].</p>		
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* No comments were directly made on the difference this option would make

Option 6a: Drawing upon capacity beyond ND services: diagnostic assessments*

Note: two different models were discussed: drawing upon capacity to augment diagnostic assessment teams and drawing upon capacity in the wider system, and in particular the third sector, to augment post-diagnostic support, which is discussed below in 6b.

Description	Rationale	What inputs and activities are required? What else is required?	Barriers	Other comments
Aspects of a diagnostic assessment can be undertaken by appropriately skilled professionals, such as educational psychologists, who are not part of ND services, while waiting list initiatives in which, for example, private providers undertake assessments, are a well-established model.	Drawing upon expertise in the wider system, including professionals who may know more about the child, can add breadth to the multi-disciplinary assessment which should increase the quality of a diagnostic assessment. More broadly, demand for ND services outstrips capacity and solutions to increase capacity are	Look at resource in other services - take demand away from core services in the community e.g. bring SLT, OT [occupational therapy] - draw down resources, work they're doing anyway, move that resource into ND; supervision for SLTs, but it is inefficient do it twice.	SLT can do it – but NICE guidelines [mean they] need to be trained; means inexperienced staff do it – see Julie’s PhD [²] Limitations on available educational psychologists. Health Boards would want QA around those, and they’d look to us (again) for this which we	Controversially maybe, but I would say outsourcing for both diagnosis and support can and does work. Wider systemic response makes sense but as part of a wider coherent approach.

² Mullis, J.A. (2021) ‘How Do Speech and Language Therapists Develop Competence to Work with Children with Autism Spectrum Disorders?’ Professional Doctorate Doctor of Health Studies.

	<p>only likely to do so in the medium to long term.</p>	<p>Commission any outsources to include ... follow on care and support? Otherwise who case holds?</p> <p>[Enhancing capacity to provide post-diagnostic support].</p> <p>Our local NAS is doing parent workshops for parents over four weeks with recorded information from multiagency partners. This means they get the information, just not from us, which is probably much better for parents.</p>	<p>don't want to do at all because it's a minefield.</p> <p>The'demand from non-NHS Ax [assessments] is already unmanageable and hugely time consuming.</p> <p>Non-clinical ND assessments; are risks e.g. differential diagnosis - is there capacity to move away from the medical model?</p>	
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* No comments were directly made on the difference this option would make

Option 6b: Drawing upon capacity beyond ND services: support

Description	Rationale	What inputs and activities are required? What else is required?	What differences do you think they'll make?	Potential barriers
<p>Build on existing and enhanced role of 3rd sector (not including diagnosis). Broadening connected support - education and 3rd sector AND broadening ND Team</p> <p>Split this between different third sector services, for example NAS (have residential services that they could offer).</p>	<p>If third sector resources weren't so limited, [they] could hold onto a family for a year so that they're able to look after themselves.</p> <p>Families always comment on how short-term local authority interventions are but the children's needs and impact on the family are long term and not 'resolved' in a few weeks.</p> <p>Not just to plug gaps; third sector do a lot of work far better than we do in health and local</p>	<p>Identify the pinch points on an individual's journey and focus the resources at specific areas in people's lives.</p> <p>Autistic Minds ... get people into work. So, if you want more people in employment, then give them funding.</p> <p>Accommodation - you'd fund NAS.</p> <p>Identify the needs in the area and for the family, then work out who can deliver the best intervention.</p>	<p>Let's offer the right thing from the right people in the right way for them. Children led not system led</p> <p>Increase [the] confidence and resilience of families and individuals.</p>	<p>What are we increasing capacity for? The third sector is there ... but the resources aren't there to have the capacity to deliver a specific service.</p>

	authority and they can offer families better outcomes than we can too.	Create a list of specific service[s] provided by different voluntary sector [organisations] within a locality. Have a single point of entry.		
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4. Questions used in an online questionnaire for members of the Royal College of Psychiatrists

1. Which local health board or boards do you work in?

Aneurin Bevan University Health Board

Betsi Cadwaladr University Health Board

Cardiff & Vale University Health Board

Cwm Taf Morgannwg University Health Board

Hywel Dda University Health Board

Powys Teaching Health Board

Swansea Bay University Health Board

2. What best describes the type of mental health service do you work in? please select all that apply

Primary mental health service

Children's neurodevelopmental service

Child and Adolescent Mental Health Service (CAMHS)

Community Mental Health Team (CMHT)

Learning Disability Service

Specialist service (e.g. eating disorder)

Mental health unit at a hospital

Substance misuse service

Other (please specify):

3. Do you undertake or contribute to diagnostic assessments for ASD?

Yes

No

4. In your view, how important are the following constraints on your capacity to undertake diagnostic assessments for ASD in the health board(s) you work in?

Very important Quite important Not important Don't know

Lack of time to undertake a diagnostic assessment

Lack of training to undertake a diagnostic assessment

Lack of experience or confidence to undertake a diagnostic assessment

Delays or problems accessing reports or information required to complete a diagnostic assessment

Very important Quite important Not important Don't know

Delays or problems
securing the
involvement of
other professionals
in the diagnostic
assessment

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

Other (please
specify below)

5. Please read the following statements and select the response that best describes how you feel:

Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Don't know / not sure
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There is sufficient
capacity to meet
the demand for
diagnostic
assessments for
ASD for children in
the health board I
work in.

Strongly agree Agree Neither agree nor disagree Disagree Strongly disagree Don't know / not sure

There is sufficient capacity to meet the demand for post diagnostic support for autistic children in the health board I work in.

There is sufficient capacity to meet the demand for diagnostic assessments for ASD for adults in the health board I work in.

There is sufficient capacity to meet the demand for post diagnostic support for autistic adults in the health board I work in.

There is sufficient capacity to meet the demand for post diagnostic support for the parents and carers of autistic children (or adults) in the

Strongly agree Agree Neither agree nor disagree Disagree Strongly disagree Don't know / not sure

health board I work in.

Transitions between children's and adult services for young people with ASD, are well managed in the health board I work in.

6. Do you undertake or contribute to diagnostic assessments for ADHD?

Yes

No

7. In your view, how important are the following constraints on your capacity to undertake diagnostic assessments for ADHD in the health board(s) you work in?

Very important Quite important Not important Don't know

Lack of time to undertake a diagnostic assessment

Lack of training to undertake a diagnostic assessment

Very important Quite important Not important Don't know

Lack of experience
or confidence to
undertake a
diagnostic
assessment

Delays or problems
accessing reports
or information
required to
complete a
diagnostic
assessment

Delays or problems
securing the
involvement of
other professionals
in the diagnostic
assessment

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

Other (please
specify below)

Other (please specify)

8. Please read the following statements and select the response that best describes how you feel:

Strongly agree Agree Neither agree nor disagree Disagree Strongly disagree Don't know / not sure

There is sufficient capacity to meet the demand for diagnostic assessments for ADHD for children in the health board I work in.

There is sufficient capacity to meet the demand for post diagnostic support for children with ADHD in the health board I work in.

There is sufficient capacity to meet the demand for diagnostic assessments for ADHD for adults in the health board I work in.

There is sufficient capacity to meet the demand for post diagnostic support for adults with ADHD in the

Strongly agree Agree Neither agree nor disagree Disagree Strongly disagree Don't know / not sure

health board I work in.

There is sufficient capacity to meet the demand for post diagnostic support for the parents and carers of children (or adults) with ADHD in the health board I work in.

Transitions between children's and adult services for young people with ADHD, are well managed in the health board I work in.

9. What improvements would you like to see in neurodevelopment services for children and/or adults with autism and/or ADHD in the local health board you work in? Why?

10. Looking beyond neurodevelopment services (for example, in education, social care, employment services etc.) what improvements would you like to see in provision for children and/or adults with autism and/or ADHD in the local health board you work in? Why?

11. Do you have any other comments?

5. Copy of the ND Demand and Capacity Review topic guide for ND Services

Introduction

1. Can you please briefly describe your role within the service.
2. Can you please describe a child OR adult's journey to and through the service; for example:
 - *How do children and young people or adults access the service?*
 - *How are children and young people or adults assessed?*
 - *which types of NDC do you consider as part of an assessment?*
 - *do you know how other types of NDC are assessed?*
 - *What happens after the assessment? What pre- and post-assessment support do you offer?*
3. [Referring to the system map] who are the key partners? Can you please describe how your service fits within the wider system?.
 - *Who else (people, services) is involved? Explore e.g. the role of children's and adult mental health services*
 - *What other services are involved in the assessment of NDCs? (e.g., community paediatrics, CAMHS, Adult MH and LD services)*
 - *What other services provide support for NDCs? (e.g. schools, social services and children or adult disability teams, the voluntary sector)*

Demand for the ND Service

4. Can you please describe what work you have done to date to assess demand for your service?
 - *how well do you understand demand for assessment and diagnosis and how it has changed over the last three years? What information can you*

share with this review? [consider numbers of people and time each assessment takes – average and range]

- *how well do you understand demand for support for your services from children OR adults and/or parents or carers and how this has changed over the last three years? What information can you share with this review? [consider numbers of people and time support is provided for average and range]*
- *how well do you understand demand for support for your services from professionals/other services and how this has changed over the last three years? What information can you share with this review?*
- *What impact has COVID-19 had upon this? [e.g. is pre-pandemic modelling of demand and capacity now out of date?]*
- *What did you or your service learn from your work with the NHS Delivery Unit OR the National Autism Team to assess demand for the service?*
- *What work was undertaken? (e.g. collecting data on demand and/or backlogs)*
- *Did you look at referral processes? Did you consider their efficacy (e.g. numbers of people being referred inappropriately?)*

5. How is demand for the service managed?

- *Are referral processes clear and accessible?*
- *Roughly what proportion of those assessed do not meet diagnostic criteria?*
- *Are the criteria for accepting or rejecting referrals effective at screening out those for whom an assessment would not be appropriate?*
- *What pre-assessment support is offered?*

6. What happens to those referred to your service, who are not eligible for assessment or support?

- *Is there 'no wrong door' in practice?*
- *What support is offered to those who don't meet diagnostic criteria? By whom?*

7. In your view, why do people seek an assessment and/or support from your service? What difference do they hope an assessment and/or support will make to them and their lives or their families' lives?

In your experience, do people believe it will help them:

- *Better understand themselves?*
- *Access education or support in education?*
- *Access employment or support to find employment?*
- *Access welfare benefits?*
- *Access social care?*

How important have changes in public awareness of NDC been?

How important have changes in diagnostic criteria been?

8. [following on from Q5] Have these factors changed at all in the last three to five years? Why? (what's driven the changes?) and do you expect them to change in the next three years? Why? [consider a visual tool like an impact tree or way of conceptualising linkages and/or timeline of key events]

- *What impact has COVID 19 had upon demand?*
- *What impact, if any, have policy changes in areas like education or social care had upon demand? What impact has practice in the education sector had? (consider e.g. whether a diagnosis is required to access support in school, college and/or university)*
- *What impact, if any, does the voluntary/third sector have upon demand for ND assessments and/or support from ND services?*
- *what's the role of the voluntary/3rd sector in meeting demand?*
- *Have you started working with new partners (e.g. youth/criminal justice)? Has this affected demand?*

9. What could be done, if anything, to help reduce demand for assessment and/or support from your service?

- *In your view, what changes in education policy and practice would reduce the need for an ND assessment and/or demand for pre- and post-assessment support from your service? Why?*
- *what changes in employment or employment support policy and practice would reduce the need for an ND assessment and/or demand for pre- and post-assessment support from your service? Why?*
- *what changes in welfare and benefits policy and practice would reduce the need for an ND assessment and/or demand for pre- and post-assessment support from your service? Why?*
- *what changes in social care policy and practice would reduce the need for a ND assessment and/or demand for pre- and post-assessment support from your service? Why?*

Capacity to undertake ND assessments and provide support pre- and post-assessment

10. Can you please describe what work you have done to date to assess the capacity and activity of your service?

- *how well do you understand your service's capacity to undertake, and levels of activity in relation to, assessment and diagnosis and how it has changed over the last three years? What information can you share with this review? [consider numbers and type of staff involved and time each assessment takes – average and range]*
- *how well do you understand your service's capacity to provide, and levels of activity in relation to, support for children, adults and/or parents or carers and how this has changed over the last three years? What information can you share with this review? [consider numbers and types of staff involved and time support is provided for - average and range]*
- *how well do you understand your service's capacity to provide, and levels of activity in relation to, support for professionals and other services and how*

this has changed over the last three years? What information can you share with this review?

- *What impact has COVID-19 had upon this? [e.g. is pre-pandemic modelling of demand and capacity now out of date?]*
- *[if not already covered] What did you/your service learn from your work with the NHS Delivery Unit or the National Autism Team to assess your capacity?*
- *What work was undertaken? (e.g. process mapping; collecting data on capacity and/or activity)*
- *How are decisions on how clinical time is used made? (e.g. how they divide their time between e.g. assessment and support)*

11. What's working well? What are your service's strengths?

- *Are there any examples of good practice you would like to highlight?*

12. What are the key issues that are impacting on your ability to deliver timely and high-quality ND assessments and support children and young people OR adults AND families AND professionals?

- *Is there a tension between timeliness and quality? How is this managed?*
- *What are the bottlenecks and constraints?*
- *Are there any gaps in your provision/your service?*
- *What impact does the way the service is organised or structured have? For example, does the team have the right mix of skills? Are roles and responsibilities clear?*

13. [Following on from response to Q10] Have these factors changed at all in the last three to five years? Why (what's driven the changes)? Do you expect them to change in the next three years? Why?

- *What impact has COVID 19 had upon capacity?*
- *Has your staffing changed? What difference has this made?*
- *Has the way you work changed? What difference has this made?*

14. In your view what changes would increase your capacity?

- *What can you do yourself (as a service) within existing resources?*
- *What do you need additional resources, support etc. to do?*

Cross cutting questions

15. What impact, if any, do you think the Autism Code of Practice will have upon demand for your service and your capacity to undertake ND assessments and provide support?

16. [Children's ND services only] what impact do you think the Do-It profiler pilot³ will have upon demand for your service and your capacity?

Transitions between services

17. How is the transition between children's and adults' services managed within your service?

- *What works well? Why?*
- *What doesn't work well? Why?*

18. How could young people's, families' and services' experiences of transitions between children's and adults' services be improved across all services?

- *What are the barriers to change/improvement?*
- *What resource or support or change in policy would be required?*

Service design and fitness for purpose

³ [Do-It Profiler](#)

19. How well do you think neurodevelopmental services meet the needs and expectations of different groups of people?

- *Are some groups under- or over-represented in terms of demand (or referrals) / assessment/ pre- and post-assessment support? And if so, why?*
- *How well does your service comply with the Equality Act? For example, do you think that any groups are treated worse by your service because of who they are [direct discrimination] or by treating groups equally, disadvantage some groups [indirect discrimination]? [explore e.g. discrimination on the grounds of gender, age, race sexual orientation, or disability]*
- *Do you ask about the language of choice?*
- *Do you have the capacity to offer Welsh language assessment and support?*
- *To what extent do you do this in practice? What are the challenges?*
- *Is the Welsh language as visible as the English language? [i.e. is there an 'active offer' with services provided in Welsh without people having to ask for them]*

For reference: the protected characteristics are:

[age](#); [disability](#); [gender reassignment](#); [marriage and civil partnership](#); [pregnancy and maternity](#); [race](#); [religion or belief](#); [sex](#) and [sexual orientation](#)

20. How effective do you think the current service structure is, which if I can simplify a little, has an integrated ND Service for children and an Integrated Autism Service for adults, alongside adult mental health and learning disability services?

- *In your view, what are the key strengths of this service structure? Which groups' needs are well served by this structure?*
- *How well do you think the service structure meets the needs of people with different types of NDC? e.g. adults with ADHD? Children who fall short of diagnostic thresholds?*
- *Who does the current service structure work well for? Who doesn't it work so well for? Why?*
- *In your view, what are the key weaknesses of this service structure?*

- *Should the structure of services for children and adults and for different types of NDC change? [If yes], how and why?*
- *Do you think that the IAS should work with people with other NDCs, such as ADHD? If yes, just ADHD? Why?*
- *Are there any lessons from the way services are organised in the other UK nations or other European countries?*

21. What alternative models do you think the review should consider? (e.g. an all-age ND model; adults' ND service)

- *In your view what are the potential advantages and disadvantages of a holistic all-age, pan-NDC model?*

22. What other changes are required to the wider system?

[Refer back to the system map]

- *Should the role of the voluntary sector change? [If yes], how and why?*

Close

23. Is there anything else that we have not talked about that you think is important?

Do you have any questions?

Thank you very much for your time. We are due to submit a working paper to the Welsh Government in the summer, and if the second phase of the work goes ahead, to facilitate a working group to identify feasible and sustainable options for improvement to children's and adults' ND services, taking into account all the evidence generated as part of the review and also to develop a workforce strategy to support this.

6. Copy of the ND Demand and Capacity Review topic guide for service users

Profile of the interviewee

Interviewee's sex:	
Interviewee's approximate age:	
Interviewee's current situation (e.g. currently employed?)	
Rough date when ND assessment done	

Introduction

My name is...[insert name]. I work for a charity called People and Work. People and Work have been commissioned by the Welsh Government to review services for children, young people and adults in Wales who are autistic, or have another neurodevelopmental condition like ADHD, in order to identify options for improvements to services.

I would really like to ask you some questions about your experiences of getting an assessment and diagnosis and any support you have had. It will probably take somewhere between twenty minutes and an hour. It's up to you if you want to talk to me or not, and it will not cause you or your family any problems if you choose not to talk to me.

You can choose not to answer any questions I ask. You can also decide to stop the interview when you have had enough. Even after this interview you can change your mind and decide you don't want to take part, and it will not cause you or your family any problems.

If you are happy to talk to me I will take notes of our discussions and, with your permission, also audio record the discussion. People and Work will use the notes and the audio recording, along with notes from lots of other interviews, to help write a

report for the Welsh Government. I cannot promise that all your views will be used in the report, but they will help. The report will be published on the Welsh Government website. This means anyone who wants to can read the report.

We will not use your name in the report, and we will do everything we can to make sure you cannot be identified by other people. If there is anything that you don't want us to write about in the report, because for example you don't want other people to read about it, please tell me you don't want me to write about it in the report.

Do you have any questions you would like to ask me?

Can I please check, now that I've explained what I would like to do, would you like to talk to me about your experiences? Are you happy for me to record the discussion?

Thank you

[Provide information sheet and privacy notice if not already provided]

[Ensure that they understand that participation is voluntary, that they can ask questions and they have agreed to take part]

Structured questions

1. Can you please tell me about the effect autism / ADHD has upon your day-to-day life?

How has this changed over time? (explore e.g. transition from education to employment, independent living etc). What, if anything, is more difficult because of your autism/ADHD?

2. Can you please tell me when you first suspected/were first told you might have autism / ADHD?

How old were you? Who spotted it (you, parent, teacher, partner etc.)? Who did you/they go to for advice? What advice and support did you/they get at that time? How were you referred for the assessment? (e.g.

doctor/teacher/self-referral/other)

Why did you (OR your parents, school etc..) decide to get a diagnostic assessment?

What difference did you expect that having a diagnosis would make?

3. Can you please tell me about how you got your diagnosis of autism / ADHD?

When did you get your diagnosis? Roughly how long did it take from when you were referred for an assessment to getting a diagnosis? Where did you go for your assessment? Did you get enough information about the assessment and diagnosis process? What difference, if any, has having a diagnosis made to you?

4. [If a Welsh language interview] when you contacted the [insert name of the service] were you offered the choice of talking or writing in Welsh or English?

Did you choose to talk to or write to [insert name of the service] in Welsh or English? Why? Did you continue to use Welsh or English during your assessment? Were you supported by someone who spoke Welsh? What difference did this make to you? Would it have been/was it more difficult for you if/because you were not assessed it supported by someone who spoke Welsh?

5. Can you please tell me what support you were given after you got your diagnosis of autism/ADHD?

What did you hope would happen after you got your diagnosis? Did you want information? Did you want help and/or support (what kind)? Was it easy to get this? Who did you get information from/help from/ support from? Did the

support meet your needs? Was there any help or support you wanted, that you could not get?

6. Can you please tell me what support you have had from [insert name of Service]?

How were you referred to the service?

How has the support from [insert name of Service] helped you? Is there anything you wanted the support from [insert name of Service] to help you with, which the service could not do? How long have you been supported by the service for?

7. Who else has supported or helped you? This could include people and also services like...[insert examples]
8. [if relevant] can you please tell me how you felt when you started getting support from adult services?

Were you or your family supported by children's – or social services? [If applicable – i.e... they have accessed children services] What was different about the support you have had from adult services, compared to the support you have had from children's services?

How different was the support you have had from adult services, compared to the support you have had from children's services [was there a big or small difference]?

Did you feel that the transitions from children's to adults' services was well planned or well managed? Why?

9. Given your experiences, how do you think [insert name of service] could be improved?

What would you like them to do differently?

What else, if anything, would you like them to offer people like you?

Is there anything you would like them to stop doing?

10. [If appropriate] At the moment, most children with a neurodevelopmental condition like ADHD or autism are diagnosed by children's neurodevelopmental services. In contrast, some adults with autism are diagnosed by the Integrated Autism Service while adults with other neurodevelopmental conditions like ADHD are diagnosed by adult mental health services. Several options for developing services are being considered, including an adult neurodevelopmental service that would assess and support adults with autism and adults with neurodevelopmental conditions like ADHD, or an all-age neurodevelopmental service that would work with children and adults with autism and ADHD.

Do you think an adult neurodevelopmental service would be better at supporting people like you? Do you think it might be worse at supporting people like you? Why?

Do you think that an all-age neurodevelopmental service would be better at supporting people like you? Do you think it might be worse at supporting people like you? Why?

Close

Is there anything else that we have not talked about that you think is important?

Do you have any questions?

Thank you very much for your time. We are due to submit a working paper to the Welsh Government in the summer, and if the second phase of the work goes ahead, to facilitate a working group to identify feasible and sustainable options for improvement to children's and adults' ND services, taking into account all the evidence generated as part of the review.

Thank you

.....

Alternative narrative questions

I would really like you to tell me, in your own words, about your life before you had a diagnosis, why you wanted to have a diagnosis and your experiences of getting an assessment and diagnosis of [autism, ADHD etc]. It's your story and you can choose where to start.

Prompts to aid the telling of their story and to help clarify their story

- Did you enjoy school?
- What happened after school?
- Where and when?
- What happened then?
- What else was happening in your life then/at that time of your life? [explore e.g. family, relationships. work, health etc]

Prompts to encourage reflection upon the story and their journey.

- Why did you do this?
- Did your family or friends help you to do this?
- Did you enjoy it? How confident did you feel?
- What was good about it? What was bad about it?
- What, if anything, made it difficult or held you back?
- What difference did it make to you? What did you gain? Was it worth it? Why? What do you think would have happened or been different if you had not done...[x]?

Recommendations

Given your experiences, how do you think services could be improved?

Close

Is there anything else that we have not talked about that you think is important?

Do you have any questions?

Thank you very much for your time. We are due to submit a working paper to the Welsh Government in the summer, and if the second phase of the work goes ahead, to facilitate a working group to identify feasible and sustainable options for improvement to children's and adults' ND services, taking into account all the evidence generated as part of the review.

Thank you