




Autism diagnosis in Wales: The case of governance-driven medicalisation in care pathways

Michael Arribas-Ayllon 

Cardiff School of Social Sciences, Cardiff University, Glamorgan Building, King Edward VII Ave, Cardiff, CF10 3NN, United Kingdom

ARTICLE INFO

Handling Editor: Medical Sociology Office

Keywords:

Medicalisation
Care pathways
Autism
Diagnosis
Standardization
Governance

ABSTRACT

The medicalisation of autism has traditionally been framed as a process driven by professional expansion or parental advocacy. However, in state-managed healthcare systems, medicalisation is increasingly structured through governance and policy mechanisms. This paper examines governance-driven medicalisation in Wales, where neurodevelopmental (ND) care pathways regulate autism diagnosis through standardisation, eligibility criteria and administrative oversight. Drawing on a qualitative case study of a socioeconomically deprived health board in South Wales, I explore how ND pathways function both as engines of medicalisation and as institutional gatekeeping mechanisms. Findings demonstrate that standardised assessment tools, referral thresholds and multidisciplinary panels reshape professional discretion and mediate parental access to diagnosis, reinforcing administrative rather than purely clinical decision-making. By engaging with theories of medicalisation, expertise and clinical governance, I show how the redistribution of diagnostic authority among healthcare professionals, educators and policymakers contributes to the administration of autism services. Comparisons with the U.S. context further illustrate how governance structures shape medicalisation in distinct but functionally similar ways. This study extends medicalisation theory by showing that in state-run systems, policy frameworks – not just medical professionals – play a central role in structuring diagnosis, access and service provision.

1. Introduction

The increasing global prevalence of autism diagnoses raises questions about the medicalisation of neurodevelopmental conditions. While classical theories emphasise the expansion of medical authority over social life (Zola, 1972), contemporary research highlights the role of policy institutions, advocacy groups and multiple ecologies of expertise in shaping diagnostic expansion (Eyal et al., 2010; Chiri et al., 2022; Bergey, 2024). Rather than a straightforward process of professional dominance, recent studies suggest that state-managed healthcare systems regulate medicalisation through standardisation, eligibility criteria and administrative oversight (Decoteau and Daniel, 2020; Timmermans and Berg, 2003a, 2003b). In Wales, neurodevelopmental (ND) pathways exemplify this shift, transforming autism diagnosis into a process mediated largely by administrative controls rather than professional discretion.

This paper examines how ND pathways in Wales function as both engines of medicalisation and regulatory technologies that determine who receives an autism diagnosis and under what conditions. Rather

than simply streamlining services, pathways are formal tools that actively shape clinical decision-making, redefine professional roles and mediate parental access to support. Situating the Welsh case within broader trends in the policy-driven regulation of neurodevelopmental conditions (Bergey, 2024; Conrad and Bergey, 2014), this study demonstrates how medicalisation is managed through administrative mechanisms rather than unchecked professional expansion. Drawing on a qualitative case study in a socioeconomically deprived region of South Wales, it explores how governance-driven medicalisation shapes autism as a medical category.

1.1. Medicalisation and governance

Classical theories of medicalisation emphasise the expansion of medical jurisdiction over domains once seen as educational or social (Zola, 1972). Autism exemplifies this broader historical shift in which behaviours once categorised as educational or psychological problems have been redefined as medical conditions requiring clinical intervention – a process that Conrad and Schneider (1980) describe as the

E-mail address: arribas-ayllonm@Cardiff.ac.uk.

<https://doi.org/10.1016/j.socscimed.2025.118333>

Received 16 December 2024; Received in revised form 8 May 2025; Accepted 19 June 2025

Available online 23 June 2025

0277-9536/© 2025 The Author. Published by Elsevier Ltd. This is an open access article under the CC BY license (<http://creativecommons.org/licenses/by/4.0/>).

transformation of deviance “from badness to sickness”. Traits such as atypical communication, restricted interests and repetitive behaviours are now framed within a neurodevelopmental model, reinforcing biomedical approaches to assessment and care. This shift partly reflects what [Clarke et al. \(2003\)](#) term “biomedicalisation”, capturing the complex, multi-sited and multidirectional transformations in contemporary medicine.

This biomedical reframing of autism was reinforced by expanding diagnostic boundaries in the *Diagnostic and Statistical Manual of Mental Disorders* (DSM). The DSM-5 redefined autism as a broad spectrum, encompassing a wide range of presentations from severe impairment to milder social-communicative difficulties ([APA, 2013](#)). This broadening of criteria contributed to a rise in autism diagnoses, intensifying demand for assessments and services in the UK ([Russell, 2021](#)). However, diagnostic expansion has become entangled with policy mechanisms that regulate access to services, transforming diagnosis into institutional gatekeeping rather than a neutral clinical classification.

Recent scholarship highlights a shift toward policy-driven medicalisation embedded in governance frameworks ([Chiri et al., 2022](#); [Decoteau and Daniel, 2020](#)). [Bergey \(2024\)](#) illustrates how global medicalisation is shaped by transnational policy diffusion, diagnostic standards such as the DSM and international advocacy networks. In Wales, the publicly funded National Health Service (NHS) exemplifies a distinctively administrative mode of medicalisation, where clinical governance frameworks seek to enhance performance by standardising assessments and regulating professional work. [Timmermans and Berg \(2003a\)](#) argue that clinical governance employs standardisation to rationalise medical decision-making, reduce variability and enhance professional accountability – a shift from earlier models of professional autonomy ([Freidson, 1970](#)). Standardised tools such as DSM-5 diagnostic criteria, the Autism Diagnostic Observation Schedule (ADOS-2) and formal care protocols are not neutral instruments; they actively modify clinical judgment, requiring professionals to justify diagnoses through structured protocols and aligning clinical practice with evidence-based norms. As [Timmermans and Berg \(2003b\)](#) contend, employing these apparently neutral technical tools constitutes more than a technical refinement but a political act that reconfigures medical authority, regulates diagnostic eligibility and systematically structures access within healthcare systems.

Autism diagnosis is increasingly tied to service provision, reinforcing what [Hacking \(1996\)](#) describes as “looping effects”, where medical classifications shape institutional responses, social expectations and self-identification. The deinstitutionalisation of mental retardation in the 1960s, for example, created a void that was filled by alliances between parents, behavioural psychologists and advocacy groups, forging new institutional pathways for autism diagnosis ([Eyal et al., 2010](#)). This shift reflects a broader transformation in medicalisation, where expertise in autism is no longer monopolised by child psychiatrists but distributed across an alternative “network of expertise” ([Eyal, 2013](#)) that includes educators, therapists and parents. Autism diagnosis has become a regulatory tool that determines access to education, disability benefits and therapeutic interventions rather than merely a clinical classification. Parent networks and advocacy groups have played a crucial role in amplifying demand for neurodevelopmental assessments, particularly in educational settings, where diagnosis is increasingly linked to legally mandated accommodations and additional learning support ([Silverman, 2012](#)). This aligns with [Furedi’s \(2006\)](#) notion of “medicalisation from below”, where individuals and families actively seek medical recognition to legitimise their struggles and secure resources. However, the growing demand for autism assessment has outpaced service capacity, resulting in long delays for diagnosis and follow-up support ([Crane et al., 2016](#)).

While some argue that diagnosis empowers neurodivergent individuals ([Singer, 1999](#)), others highlight a policy paradox in which individuals are medicalised but not necessarily entitled to care ([Chiri et al., 2022](#)). In Wales, ND pathways exemplify this paradox –

formalising access to diagnosis while also acting as gatekeepers to regulate demand. The drive to standardise autism assessments, intended to improve consistency and reduce inequities, has in practice created rigid eligibility thresholds that exclude some individuals from necessary interventions while reinforcing the legitimacy of medical diagnosis as a prerequisite for support. This outcome corresponds to [Decoteau and Daniel’s \(2020\)](#) concept of “subsumptive orthodoxy”, whereby alternative perspectives, such as social and educational models of disability, are co-opted into the prevailing biomedical framework without challenging its primacy. Thus, ND pathways do not simply expand medicalisation; they structure and regulate it through governmental mechanisms that determine who receives medical recognition and assistance.

1.2. Autism policy and governance in Wales

Wales has played a pioneering role in UK autism policy by launching the 2008 Autistic Spectrum Disorder Strategic Action Plan (ASD SAP), the first national autism strategy in the UK. Initiated by the charity Autism Cymru, the plan was developed by the Welsh Government through extensive consultations with autistic individuals, families and professionals. A broad coalition – including Autism Cymru, the National Autistic Society Cymru, the Cross-Party Autism Group in the Senedd, and parent-led organisations such as Autism Parents Wales – lobbied intensively for its adoption. The strategy aimed to create a unified framework to raise awareness and improve diagnostic services ([Welsh Government, 2008](#)), leading to increased school-aged diagnoses from ~0.2 % in 2003/04 to ~1 % in 2012/13. However, implementation was uneven, producing “islands” of good practice rather than systemic change ([Holtom and Lloyd-Jones, 2016](#)).

In 2016, a refreshed ASD strategy established an Integrated Autism Service (IAS) to address gaps in adult diagnosis and support (Welsh Government, 2016). A major reform soon followed with the creation of an All-Wales Neurodevelopmental Service, intended to standardise autism assessments across each of the seven regional health boards responsible for planning and delivering health services ([NHS, 2015](#)). While the National Institute for Health and Care Excellence (NICE) recommends using either DSM-5 or ICD-11 criteria ([NICE, 2011](#)), Wales has historically relied on ICD-10 for administrative coding, in line with national data standards. However, multidisciplinary teams have increasingly drawn on DSM-5 criteria in clinical assessments due to their behavioural specificity and relevance to commonly used tools such as ADOS-2. This dual-framework approach is now formally recognised in Welsh Government guidance, which advises that diagnostic formulations should be based on either ICD-10 or DSM-5 ([Welsh Government, 2021](#)). NICE guidelines also stipulate the development of “local autism pathways”, requiring multidisciplinary input from health, education, psychology and psychiatry, alongside diagnostic assessments using an “autism specific tool” ([NICE, 2011](#)). The adoption of ADOS-2 in Wales was part of an NHS/government-sponsored initiative to create a more standardised and coordinated autism service.

Framed as measures to improve equity and efficiency, these reforms reflect a broader shift toward governance through standardisation. The adoption of formal care pathways in the UK has been linked to emerging modes of clinical governance, in which protocols and audit rules limit professional discretion ([Allen, 2009](#)). Proponents argue that pathways enhance NHS performance while fostering “responsible autonomy” among clinicians ([Degeling et al., 2004](#)). However, critics argue that pathways are more focused on cost-containment and rational planning than on assessing their generative consequences ([Allen, 2009](#); [Hunter and Segrott, 2007](#); [Pinder et al., 2005](#)).

Schools in Wales play a critical but inconsistent role in the autism referral process. Research by [Hurt et al. \(2019\)](#) found that both educators and parents often experience the system as opaque and confusing. Some schools actively facilitate early identification and referral for assessment, whereas others delay or discourage referrals due to resource

limitations or competing priorities. As Tomlinson (2017) and Hurt et al. (2019) argue, educators occupy a gatekeeping position in this system, navigating institutional constraints while making discretionary decisions that can either facilitate or impede access to diagnostic assessment. Historically, Welsh Special Educational Needs (SEN) policy followed a medical model that required a diagnosis to unlock statutory support. To reduce diagnostic dependency, the Additional Learning Needs (ALN) transformation programme was introduced to shift toward a needs-based framework. However, Knight and Crick (2022) identify contradictions in ALN policy, where inclusion rhetoric coexists with deficit-based frameworks that continue to prioritise formal diagnoses. Despite policy commitments to individualised, person-centred approaches, in practice support for children still largely hinges on obtaining a medical label. A recent government review of ND services found that regional inequalities in ALN support mirror broader socioeconomic disparities, effectively creating a “postcode lottery” for autism services (Holtom and Lloyd-Jones, 2022).

The influence of neurodiversity discourse on Welsh services has been relatively recent and gradual. The first statutory reference to neurodiversity appeared only briefly in the Code of Practice on the Delivery of Autism Services (Welsh Government, 2021), which advocated for more inclusive, needs-led services. Subsequent initiatives – such as the Neurodivergence Improvement Programme (Welsh Government, 2022) and the Children’s Commissioner’s “No Wrong Door” approach to neurodiversity (Children’s Commissioner for Wales, 2023) – have aimed to provide support for individuals who fall below traditional diagnostic thresholds. Nonetheless, families continue to report fragmented services, institutional gatekeeping and inconsistent implementation of these principles (Holtom and Lloyd-Jones, 2022). Demand for assessment has grown dramatically: in 2023, over 16,800 children and young people were waiting for ND assessments in Wales, with more than two-thirds waiting longer than the 26-week target (Senedd Commission, 2024). This backlog highlights how rising demand has overwhelmed available resources and capacity.

In summary, Wales demonstrates how rising demand for autism diagnosis is reshaping policies that historically tied diagnosis to support. Recent policy shifts reflect a rhetorical move toward psychosocial models of support, social models of disability and neurodiversity-informed perspectives, signalling efforts to make services more inclusive. However, as Decoteau and Daniel (2020) observed in the U.S. context, such perspectives are often integrated into policy discourse without fundamentally altering the biomedical paradigm. Rather than

reducing reliance on diagnosis, neurodiversity principles have been absorbed into existing administrative frameworks, limiting their impact on alleviating diagnostic dependency.

2. Method

This study is part of a broader investigation into health and social services within a South Wales health board, serving three county boroughs – pseudonymised as “Cwm”, “Afon” and “Duffryn”. These areas, with a combined population of approximately 500,000, include some of the UK’s most deprived communities, where poor health outcomes are often linked to the post-industrial decline of coal mining in the South Wales Valleys. At the time of research, two separate neurodevelopmental (ND) pathways operated within the health board, with Duffryn in the process of merging its pathway with those of Cwm and Afon. This study examines gaps in service provision, capacity constraints and the role of education within these ND pathways.

A single-site qualitative case study approach was employed to explore how autism services were structured and delivered in the region. Data collection spanned five months and involved semi-structured interviews and focus groups with 33 participants from health services, education, third-sector charities and local authorities (see Table 1). Interviews were conducted online and transcribed verbatim by the author or a professional service. While participant observation was initially planned for all three boroughs, time constraints necessitated remote access in Afon and Duffryn. In Cwm, observations were conducted at two sites – an autism support group and an early intervention service for families – offering insight into how families and service users navigate the diagnostic process. This paper focuses on findings from interviews with professionals. Ethical approval was granted by the University Health Board’s R&D Department (Ref. XXX/2071/24).

Data analysis proceeded iteratively, involving cycles of deductive and inductive reasoning. Initially, analysis drew on established medicalisation concepts to systematically analyse interview transcripts and policy documents. Two main frameworks guided the analysis: ‘medicalisation from above’, associated with policy-led professional expansion (Zola, 1972; Freidson, 1970), and ‘medicalisation from below’ driven by grassroots advocacy (Furedi, 2006). The explanatory adequacy of these models was critically assessed. Empirical insights revealed that medicalisation in Wales did not align neatly with these unidirectional models. Instead, findings resonated with more recent scholarship portraying medicalisation as a dynamic, heterogeneous

Table 1
Participant overview.

Sector	Role	Gender	Location	Data Collection
Health	Community Paediatric Consultant (Clinical Lead)	M	Cwm	Interview
	Community Paediatric Consultant	F	Duffryn	Interview
	Community Paediatric Consultant	F	Duffryn	Interview
	Community Paediatric Consultant	M	Duffryn	Interview
	Consultant Psychiatrist	F	Cwm	Interview
	Speech & Language Therapist (Clinical Lead)	F	Other	Interview
	Clinical Nurse Specialist	F	Duffryn	Interview
	Operational Support Manager	F	Cwm	Interview
	Education Clinical Lead Officer	F	All-Wales	Interview
Education	Principal Educational Psychologist	M	Cwm	Interview
	Educational Psychologist	F	Afon	Interview
	Educational Psychologist	F	Duffryn	Interview
	Specialist Teacher (ASD)	M	Duffryn	Interview
	Learner Support Manager	F	Duffryn	Interview
	Psycho-ed Group	M	Cwm	Interview
Third Sector	Early Intervention Group	3F	Cwm	Observation/Focus Group
	Behaviour Management Group	2F	Cwm	Interviews
	Behaviour Management Group	3F, 1M	Cwm	Observation/Focus Group
	Home-Help Group	2F	Cwm & Afon	Focus Group
	Parent Support Group	F	Other	Interview
	Welfare and Resilience Service	F	Cwm	Interview
Local Authority	Commissioning Service	3F, 1M	Duffryn	Focus Group
	Chief Officer, Social Services	F	Afon	Interview

process shaped by intersecting forms of expertise, resistance and stakeholder hybridity (Conrad and Bergey, 2014; Bergey, 2024).

Through iterative coding cycles involving repeated comparisons between empirical data and existing theoretical frameworks, the central theoretical proposition of ‘governance-driven medicalisation’ was refined. Governance structures, policy frameworks and administrative standardisation emerged as critical mediators shaping diagnostic practices. Standardised tools such as ADOS and referral proformas did not merely support clinical decision-making but actively structured it, determining how autism was recognised, managed and contested. Clinicians expressed ambivalence toward diagnostic dependency, acknowledging its necessity for accessing support services while critiquing excessive reliance on medical labels. Consequently, ND pathways functioned as regulatory technologies, structuring access according to institutional and policy-driven criteria rather than clinical judgment alone. This finding aligns closely with Decoteau and Daniel’s (2020) argument that governance can absorb medicalisation pressures into policy frameworks without necessarily expanding service capacity.

In reconceptualising medicalisation as a structured, policy-driven process, this approach resonates with Allison and Zelikow’s (1999) demonstration of how robust theoretical generalisations can emerge through careful, comparative analysis of competing explanatory frameworks within a single-case study. Consistent with Bergey’s (2024) global analysis, this study emphasises “mediating factors”, such as policies, assessment tools and treatment guidelines, as central elements shaping diagnostic practices. Engagement with Chiri et al. (2022) further clarifies how governance mechanisms regulate service access not simply by restricting or expanding medicalisation but by redirecting families toward non-diagnostic interventions. The concept of ‘governance-driven medicalisation’ thus offers analytic leverage in understanding the structured, policy-mediated processes determining autism diagnosis and management in Wales and similar contexts.

The analysis that follows is structured in two sections. The first traces the historical development of ND pathways, examining how referral processes and standardised tools regulate diagnostic access. The second explores what happens after referral acceptance, focusing on multidisciplinary assessment, diagnostic standardisation and post-diagnostic outcomes. Together, these sections demonstrate how policy-driven infrastructures actively mediate the medicalisation of autism in Wales, embedding diagnosis within governance structures. The analysis is guided by the question: How do ND care pathways in Wales structure autism diagnosis, and what are the implications for professional authority, parental access to services and the broader understanding of autism?

3. Findings

3.1. Getting on the pathway

The introduction of ND pathways in Wales exemplifies how governance-driven medicalisation restructures diagnostic access by embedding it within standardised regulatory technologies that operate through protocols, performance metrics and diffusion of expertise. Historically, autism referrals were fragmented across Child and Adolescent Mental Health Services (CAMHS) and community paediatrics, creating a system where referrals often “bounced” between services. The DSM-5’s consolidation of these conditions under ‘neurodevelopmental disorders’ (APA, 2013) provided a biomedical rationale for integrating assessments within a single pathway.

In Wales, ND pathways were aligned within the Prudent Healthcare initiative (Aylward, Phillips & Howson, 2013), positioning diagnostic standardisation as a tool of governance aimed at balancing cost-effectiveness with service provision (Hunter and Segrott, 2007). However, by formalising diagnostic access through structured assessment protocols, the pathway not only managed demand but also inadvertently expanded it – a phenomenon described by Eyal et al. (2010) as

the diffusion of expertise beyond traditional clinical authority. The observed surge in autism diagnoses exemplifies how the “looping” (Hacking, 1996) of diagnostic categories generates self-reinforcing cycles of increased identification and demand for services. The clinical lead of the ND service in Cwm offered a stark account of the rise of autism referrals across the region:

In 1989, there was one child on the register for autism. One. In the early nineties, we had one clinic in the whole of Wales for autism. Now, we have a waiting list of 104 weeks today, just in our health board.

This backlog reveals a central paradox: while ND pathways were designed to streamline services, they have reinforced reliance on diagnosis as a prerequisite for support. Rather than reducing diagnostic dependency, the Welsh government’s reorganisation created an administrative system that regulates access to diagnosis through standardised protocols.

The reallocation of funding from existing children’s services to create ND pathways was framed as a policy intervention to improve efficiency, yet professionals expressed concerns that this restructuring depleted rather than improved service capacity. One clinical lead in a neighbouring health board criticised the fragmented policy landscape governing autism services:

The Welsh government use ND to mean autism, then comes the autism code which is statutory. Then we have the ALN code of practice and legislation, and then the whole school approach to mental health and wellbeing, which is also statutory [...] Autism doesn’t need a label. What you need is for people to see you as a whole person [...] Yes, there is a huge demand/capacity deficit, but you don’t need to have an assessment [...] The paradox is that there’s a massive integrated workforce that is alive and well, they were there all along. But now all those services say, ‘Oh, you need ND’. ‘No you don’t. You’re not waiting for a diagnosis’.

This statement reflects the contradictions of governance-driven medicalisation: while ALN policies advocate a needs-based model, diagnostic classification remains the de facto gateway to services. New statutory autism guidelines created an institutional architecture making diagnosis an administrative necessity rather than a clinical imperative. As Decoteau and Daniel (2020) suggest, alternative frameworks (social or educational models of disability) are often absorbed within biomedical governance without challenging medical authority. Fragmentation between CAMHS and the ND service introduced new inefficiencies rather than resolving them. The clinical lead’s critique echoes Furedi’s (2006) notion of bottom-up medicalisation: parental demand for recognition fuels diagnostic expansion, yet state intervention reorganises that demand within a rigidly medicalised system. Thus, ND pathways continue to prioritise formal diagnosis for resource allocation, reinforcing the institutional constraints of medicalised service access.

3.1.1. Gatekeeping and standardisation

The ND pathway in Wales formalised autism referrals by embedding medicalisation within governance structures. Under the previous ad hoc system, referrals were largely discretionary. Professionals across multiple sectors (paediatricians, educational psychologists, speech therapists, CAMHS specialists) could directly request assessments, often resulting in chaotic, duplicated referrals. The introduction of a new standardised proforma and the delegation of referral responsibility to schools, reconfigured access through administrative control rather than clinical discretion (Timmermans and Berg, 2003a).

In 2017, pre-diagnostic thresholds were introduced to ensure only “robust” cases progressed to assessment. Previously, a “simple letter” from a clinician could initiate an autism evaluation even if, for example, teachers disagreed with the referral. In contrast, the new proforma requires detailed evidence of functional impairment, aligning with DSM-5 criteria that emphasise “pervasiveness” across multiple settings. A

speech and language therapist involved in its design described it as “*turning the diagnostic criteria inside out to create the referral form*”, effectively embedding it in a medical checklist.

Although intended to improve referral quality, the pathway operates as a gatekeeping mechanism that filters access via standardised procedures. A public-facing map of the pathway (Fig. 1) depicts a single-entry point and decision loops. While ostensibly neutral, it obscures how referrals often loop back to referrers, revealing tensions between parents, schools and clinicians. As Pinder et al. (2005) observe, care pathways simplify complexity by abstracting the patient and reifying the condition. In practice, referrals become “abstractions” (Maynard and Turowetz, 2019) of children waiting to access the pathway, only becoming visible as patients once they meet pre-diagnostic thresholds. In this way, ND pathways govern medicalisation pressures by structuring and containing demand rather than directly facilitating care (Chiri et al., 2022).

Shifting referral decision-making to schools has redistributed medical authority across a broader “network of expertise” (Eyal et al., 2010). Non-medical professionals now play a pivotal role in legitimising diagnostic requests. Schools have become both facilitators and barriers to diagnosis: tasked with ensuring referrals meet clinical thresholds while also managing the volume of requests. As the operational manager in Cwm explained, the ideal referral now comes from “the person who knows the child best in a school setting”, indicating that schools are on the frontline of regulating access to the pathway.

However, extending diagnostic authority into schools has introduced new tensions over legitimacy as different actors compete for diagnostic authority. An educational psychologist in Duffryn noted that schools were “overwhelmed” by ND referrals coming from multiple sources (CAMHS, GPs, speech therapists, education welfare officers). While more medical professionals were pushing children toward assessment, schools were expected to “hold” referrals and decide which warranted progression. This redistribution of responsibility reveals how medicalisation pressures are absorbed into administrative structures without necessarily increasing service capacity (Decoteau and Daniel, 2020).

Importantly, the overhaul of referrals was partly a reactive response to growing parental demand for autism diagnoses. As Furedi (2006) argues, medicalisation is often driven “from below” by parents and advocacy groups seeking medical validation and support. Indeed, professionals in Wales observed that many professional-led referrals were ultimately based on parental reporting. Rather than diminishing parental advocacy, professional authority is co-opted to validate parental concerns, reinforcing Hacking’s (1996) “looping effects”. GPs, education officers and CAMHS specialists increasingly rely on parental narratives to justify referrals, blurring the boundaries between medical expertise and lay advocacy. In effect, bottom-up pressures are not eliminated but channelled into the governance framework: professionals become gatekeepers who translate parental concerns into the formal criteria of the pathway.

3.1.2. Diagnosis rates

At the time of the study, the health board operated two parallel ND teams with differing approaches. Duffryn’s consultant-led model was considered “medical heavy” and not fully aligned with prudent healthcare principles, whereas Cwm’s model delegated diagnostic decisions to allied health professionals, making it more flexible and accessible. This contrast shows that ND pathways are not only concerned about diagnosing conditions but also with redistributing professional authority (Eyal, 2013). Duffryn’s stringent criteria preserved tight clinical oversight but inadvertently restricted access, fuelling parental frustration and diverting some families into non-diagnostic programmes. In Cwm, by shifting diagnostic responsibility to non-medical clinicians, the process became more administratively controlled yet somewhat more accessible.

According to the clinical lead in Cwm, the pathway’s diagnosis rate – the percentage of accepted referrals that result in an autism diagnosis –

is a key indicator of effectiveness:

We know from NICE guidelines, once you have a 95 % diagnosis rate, it means many parents are being blocked from at least getting a resolution [...] I think we are round about 70–75 %, which is good. More than 90 % means you’re being too stringent in accepting parents.

The operational manager echoed this concern, noting that Duffryn’s higher diagnosis rate was problematic: “*we wouldn’t want a 100 % diagnosis rate because you’re clearly missing children*”. In other words, if nearly every referral leads to a diagnosis, some children in need are being overlooked. These operational insights indicate that ND pathways are engineered not just to broaden access but to carefully regulate its flow, ensuring medicalisation does not exceed administratively defined thresholds. While NICE guidelines portray diagnosis as a purely clinical process, practitioners in Cwm viewed it as a governance challenge: maintaining an “optimal” diagnosis rate (~70–80 %) balances accessibility with administrative control.

Duffryn’s stricter referral criteria left many parents and schools frustrated. A charity manager in Duffryn described how families were often redirected to other services before they could even enter the ND pathway:

The majority of families will say that they’re fighting for years to have the school listen, that there’s something else there. A lot of families we work with feel that it’s their parenting that is questioned because their child is having outbursts, struggling with emotional regulation or not quite fitting into that school setting [...] but a lot of parents will listen to school and go down a parenting route. So they get referred to universal parenting services, they do those programmes. We deliver disability-specific programmes because a lot of the strategies in the generic ones make situations worse. So by the time parents get to us, they’re exhausted trying to get help for their child.

For parents, this governance-driven approach to medicalisation creates new barriers to accessing services. Making school-based observations the primary gatekeeper of eligibility often marginalises parental concerns, despite policy rhetoric about person-centred, multi-agency approach (Knight and Crick, 2022). In practice, schools filter demand through “graduated responses” that prioritise educational and behavioural interventions over immediate referral. Redirecting families to generic parenting courses exemplifies how governance channels medicalisation pressures into non-diagnostic interventions, containing demand within administratively manageable thresholds instead of expanding diagnostic capacity. This reflects a broader trend in policy-driven medicalisation, which not only determines who qualifies for a diagnosis but also manages how much demand is permitted to reach clinical services (Chiri et al., 2022). In short, ND pathways do not simply facilitate access to diagnosis – they actively structure and constrain it via bureaucratic mechanisms that regulate institutional responses to parental demand.

3.2. On the pathway

After acceptance onto the pathway, families often face a lengthy waiting list – a frustrating limbo during which families receive little to no support. A community paediatrician remarked that some families might be “lucky” to receive interim behaviour support from the local authority or specific charities; otherwise “nothing is happening until that child is seen”. These waiting periods, intended to manage demand, create a liminal phase of diagnostic uncertainty that reinforces institutional gatekeeping.

3.2.1. The standardisation paradox

The ND pathway introduced the ADOS-2 as the gold-standard assessment, aiming to prioritise consistency and efficiency in autism

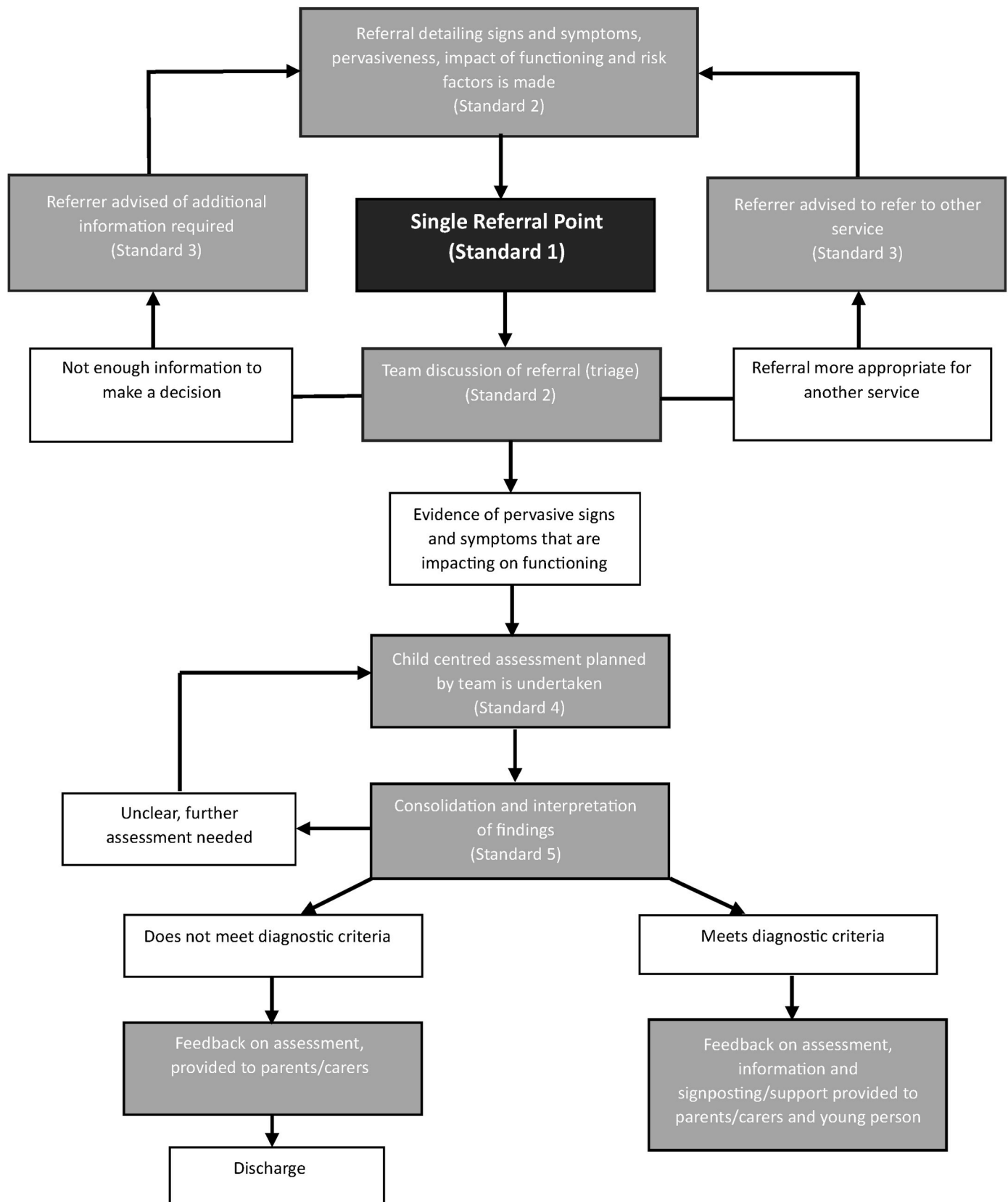


Fig. 1. Neurodevelopmental Diagnostic Assessment Pathway (adapted).

diagnosis. However, a consultant paediatrician in Duffryn cautioned that without sufficient staffing, requiring an ADOS for every case would bottleneck the service. Indeed, the waiting list for an ADOS soon became longer than the entire assessment process combined:

I said, 'I told you so. I told you we'd never keep up with the ADOSes'. And I was thinking this is ridiculous, because some of these I'd seen myself as a community paediatrician, and they were obviously autistic. You don't need an ADOS to tell you that. You need somebody with a lot of experience in autism who has spent time with that child and who has taken the history off the parents.

This scenario illustrates a key paradox of standardisation: while structured tools can sharpen diagnostic precision, their rigid application in a resource-limited system can produce new inefficiencies, undermining the very principles of efficiency that care pathways are supposed to uphold. The consultant's frustration shows how governance-driven medicalisation – implemented through strict protocols – lacked proper coordination without clinical intuition. Faced with the risk of system failure, clinicians developed a pragmatic workaround by relaxing the ADOS requirement in cases where direct observations and corroborating evidence (e.g. from educational psychologists or speech therapists) clearly indicated autism.

Despite critiques of excessive reliance on the ADOS, a community paediatrician in Duffryn noted that ADOS training did provide a valuable framework for clinical observation:

If you'd been ADOS trained, when you're seeing that child, you can put on your ADOS eyes [...] once you start to look through the sieve of an ADOS, you can break that behaviour down and you can say 'His eye contact was appalling, he had a tic, he was doing a repetitive movement'.

This account shows how standardised training can shape clinical expertise. The ADOS functions as a "grid of perception" (Foucault, 1973) that transforms ambiguous behaviours into legible clinical symptoms, sharpening diagnostic precision through what Maynard and Turowetz (2019) call "abstraction by concreteness". This structured observational method reconfigures professional intuition, enabling clinicians to articulate diagnostic features in ways that align with institutional expectations.

In sum, while the ND pathway's reliance on ADOS had structured the diagnostic process to improve quality and reliability, successful implementation still required balancing protocols with professional discretion. As the Duffryn team's experience demonstrates – and as Timmermans and Berg (2003a) argue – standardisation does not eliminate clinical judgment but transforms it. Welsh practitioners learned to navigate between adhering to formal tools and maintaining enough flexibility to keep the service functioning.

3.2.2. Multidisciplinary assessment

In Duffryn, a multidisciplinary "panel" approach was used to ensure rigorous, shared decision-making in diagnosis. Each panel included the lead speech and language therapist, the principal educational psychologist and a consultant paediatrician: *"so we're a triangle and we do not give a diagnosis unless all three is present"*. The consultant paediatrician described how the team arrived at a diagnosis:

We have the original referral which we've talked through [...] the speech and language therapist would say, 'I scored up all the questionnaires, this one's highly suggestive of autism, this one is equivocal' [...] The difficulty is that diagnosing can be a very imprecise science. You have to feel fairly certain, so the more worrying factors, the more you've really got to convince somebody [...] To steer it towards a decision would be a clear history which has, if you look at the NICE guidelines and DSM-5 [...] very good examples from home and school, plus observational evidence from more than one professional source.

This account illustrates that while standardised tools and criteria guide clinical judgment, they do not remove the need for interpretation. Even with formal guidelines (e.g. DSM-5, NICE criteria), cases with mixed or conflicting evidence require deliberation and additional corroboration. Clinicians seek confirmation from multiple sources, reflecting the burden of proof in a contested diagnostic landscape – aware that their decisions may be challenged, especially through parental appeals in education tribunals.

The educational psychologist on the panel explained how they handle diagnostic uncertainty by systematically matching evidence to each criterion:

Sometimes we can give a diagnosis in a couple of minutes. Sometimes we can ponder over an hour on a case [...] We'll be saying, I don't think we've triangulated enough. I don't think we've got enough differential features. If we're not sure, let's call up DSM-5 and we'll look for evidence in each of the boxes so that we are really confident that if we were challenged, we could produce evidence in all of them.

Here, diagnosis is not simply a clinical determination but a bureaucratically accountable act: uncertainty must be translated into standardised evidence (Timmermans and Epstein, 2010). "Calling up DSM-5 to look for evidence in each of the boxes" shows how institutional requirements structure clinicians' reasoning, ensuring clinical impressions align with codified criteria. This triangulation – drawing on checklists, observations and formal definitions – is not only about finding the "right" clinical answer, but constructing a defensible decision within a system of heightened accountability.

The burden of proof applies equally when the team decides not to diagnose. The consultant paediatrician described the challenges of delivering a non-diagnosis, especially when schools report few problems:

In terms of not making a diagnosis, it would be more likely that the school are not seeing anything, that doesn't mean that that child's not autistic, but if we've got very little in the way of signs, and there's lots of other things going on [...] frequent changes of address and school, all things which are likely to have an impact upon a child's behaviour and mental health. And we say, well, it's very difficult to take these out of the picture [...] But when you say, we have not found sufficient information to make a diagnosis, that goes down like a lead balloon [...] You can't say, 'We haven't found enough information' without expecting it to be challenged.

A recurring theme is the significant influence of the school's assessment on the diagnostic outcome. Clinicians acknowledge that a lack of observable autistic traits in school does not rule out autism. However, if evidence is insufficient, withholding a diagnosis often invites parental frustration and potential appeals, demonstrating how medical authority is both constrained and challenged in the pathway. As Furedi (2006) observes, medicalisation from below pressures professionals not by rejecting medicalisation itself but by contesting expert authority. In practice, ND teams must justify a non-diagnosis as rigorously as a diagnosis.

In sum, the multidisciplinary assessment process is both a medical and an administrative exercise, ensuring that any diagnostic conclusion is clinically valid and institutionally defensible. ND pathways shape the construction of an autism diagnosis through tools and practices that mediate professional discretion, formalise accountability and structure how medicalisation unfolds within organisational constraints.

3.2.3. Post-diagnosis

The post-diagnostic stage of the ND pathway reveals how governance-driven medicalisation structures access to services by reinforcing diagnostic dependency. While assessments claim to identify clinical need, access to support remains contingent on formal diagnosis, creating institutional barriers for children below the diagnostic

threshold. This reflects broader contradictions in medicalisation governance, where services aspire to be needs-led, yet continue to be rationed through bureaucratic categories.

A clinical nurse responsible for disclosing diagnoses at Duffryn, described the emotional stakes of this process – especially when informing families that their child will not receive a diagnosis:

I often get a pit in my stomach if I'm telling them they haven't got a diagnosis, because it's such a long-winded process, and so many parents are struggling. They know they might not meet the threshold, but they still need support, and they know full well that if there's no diagnosis, they're going to struggle to get it. And that can be awful, parents can get angry and upset. Some parents are relieved, but that's not always the case, because they know something isn't right. 'Okay, it doesn't meet the threshold, but what do I do now? How do I get support for my child?'

Post-diagnosis clinics are held within six weeks of the panel's decision, and of the twelve sessions conducted each month, one or two typically result in a non-diagnosis. The binary nature of diagnosis reinforces institutional exclusions, as categorical thresholds fail to capture the dimensionality of neurodevelopmental traits (Thapar, Cooper & Rutter, 2017). Families left without a diagnosis remain in a liminal state, unable to access services despite evident difficulties.

The Welsh service model thus exhibits an institutional dependency on diagnosis, where access to care is structured around meeting formal criteria. Even though policymakers acknowledge that children's needs do not always align neatly with diagnostic boundaries (NHS, 2015), reliance on diagnostic categories reflects historically entrenched patterns of "path dependence" (Mahoney, 2000). As the clinical nurse lamented, "*diagnosis still opens a lot of doors, which it shouldn't*" – yet it does. Medical labels continue to dictate what help a child can receive.

Rather than dismantling this dependency, the ND pathway has effectively entrenched it by embedding medical classification into governance frameworks that determine support. Governance structures regulate medicalisation not by straightforwardly expanding or denying access, but by imposing administrative thresholds, institutional gatekeeping and standardised protocols that define whose needs are officially recognised. As Bergey (2024) observes, diagnostic categories become not just clinical tools but products of bureaucratic standardisation, professional negotiation and policy constraint that collectively shape service provision. Within this framework, clinicians must balance their medical judgment with regulatory imperatives, working in a system where a diagnosis serves both as a clinical determination and as a strategic key for unlocking resources (Decoteau and Daniel, 2020).

4. Discussion and conclusion

Classical theories of medicalisation (e.g. Zola, 1972) conceive the expansion of medical jurisdiction largely as a product of professional dominance, while alternative accounts emphasise bottom-up pressures such as parental advocacy movements demanding recognition and services (Furedi, 2006). The Welsh case, however, reveals a shift toward a governance-driven model of medicalisation that diverges from these patterns. In Wales, ND care pathways orchestrate medicalisation through administrative and policy mechanisms rather than arising solely from medical professionals or grassroots activism. These pathways were introduced as a form of clinical governance that actively structures diagnostic access and decision-making. Medicalisation here is not the result of unchecked professional expansion but is *administratively curated* by formal tools (standardised referral forms, diagnostic checklists), eligibility thresholds (DSM-5) and procedural protocols (NICE guidelines, codes of practice) that regulate who can receive an autism diagnosis.

This governance-driven approach adds a new dimension to medicalisation theory, extending beyond Conrad's (2005) "engines" of biotechnology, consumer demand and managed care as key forces

driving medical expansion. The Welsh ND pathway shows how the state itself becomes an engine of medicalisation by embedding diagnostic practices within regulatory technologies and oversight. As a result, obtaining a medical label becomes less about individual clinical discretion and more about navigating a structured pathway governed by policy guidelines. Crucially, this yields a paradox: on one hand, standardising the diagnostic process through governance improves consistency and accountability in who is diagnosed; on the other hand, it entrenches dependency on the diagnostic label, since formal classification remains the gateway to services and support. In short, Wales demonstrates that medicalisation can be driven as much by governance and administrative imperatives as by market dynamics, pushing Conrad's framework into the realm of state policy and clinical governance.

A hallmark of the Welsh approach is its heavy reliance on standardisation. This reflects broader trends in evidence-based medicine identified by Timmermans and Berg (2003a), where clinical practices are codified into formal procedures to enhance reliability. The ND pathway uses such standardisation to ensure uniform assessments across regions. However, as Timmermans and Berg argue, standardisation transforms rather than eliminates professional discretion. This study supports that view: clinicians described tools like the ADOS as a "grid of perception" (Foucault, 1973) that sharpened their awareness of autism while also constraining their flexibility. In practice, practitioners did not follow these protocols blindly but negotiated their use. For example, some assessment teams would override procedural rigidity when clinical judgment deemed a diagnosis obvious, showing that medicalisation remains a negotiated process even under high standardisation. This interplay confirms that while the *form* of expertise is reshaped by protocols, the *substance* of decision-making still relies on professional interpretation and tacit knowledge.

Autism diagnosis in Wales thus operates as a site of negotiated expertise within an interdisciplinary network. Eyal (2013) describes how expertise around autism has become distributed across "networks of expertise" including not only doctors but also psychologists, educators and other allied health professionals. The Welsh ND pathway institutionalises this distributive model: multi-agency panels and cross-sector teams collectively contribute to the diagnostic process. Diagnostic authority is no longer monopolised by any single profession – it is shared among different experts and stakeholders. In this study, for instance, educational psychologists and specialist teachers played an integral part in referral and evaluation decisions, effectively sharing gatekeeping roles with clinicians. Autism diagnosis emerged from an interdisciplinary dialogue, supporting Eyal's notion of autism as a "boundary" domain intersecting multiple fields. At the same time, these findings refine Eyal's thesis by showing that these networks operate under governance constraints. Eyal anticipated that distributed expertise might democratise decision-making; in Wales it broadened participation but also introduced new bureaucratic checks and balances. Professionals had to justify decisions in panel meetings, adhere to pathway criteria and negotiate disagreements. In other words, expertise was negotiated not just socially, but in a distinctly institutional arena: clinicians, educators and administrators collectively interpreted standardised criteria and decided a child's diagnostic fate. This kind of managed network of expertise contrasts with models of medicalisation that credit either physicians alone or parent activists as the decisive forces. Instead, medicalisation is co-produced by an ensemble of actors operating under policy guidance.

The Welsh case also invites a comparative perspective on how different governance regimes shape autism's medicalisation. In the United States – where healthcare access is often mediated by private insurance and fragmented funding – medicalisation follows a somewhat different path. Insurance mandates and reimbursement policies are powerful drivers of diagnosis; in effect, an autism label becomes a ticket to therapy coverage or educational resources. Medicalisation in the U.S. is intertwined with legal and financial frameworks. As Chiri et al. (2022) note, U.S. federal policy discourse solidified autism as a neurobiological

disorder worthy of medical attention, yet paradoxically those same policies often limit support, rendering many children “deserving but not entitled”. The result is a landscape where parents may vigorously pursue a medical label as a rational strategy to access scarce services in an insurance-dependent system.

In the UK, a different governance logic is at work: a state-managed, universal healthcare system that allocates resources through centralised planning rather than market competition. Here, the expansion of autism diagnosis has been guided by national strategies, clinical guidelines and pathway standards rather than market forces. The Welsh Government implemented the ND pathway as part of a policy response to rising demand for autism assessments, under the banner of improving consistency and “prudent” use of resources. This state stewardship makes the rationing and standardisation of diagnosis more explicit. Instead of insurance companies determining coverage, the NHS and local health boards decide how many assessments can be done and under what criteria, using tools like waiting-list targets, referral checklists and multi-step triage. A key comparative difference emerges: in the U.S., medicalisation often grows organically at the intersection of clinical innovation and advocacy, only later to be reined in by payers; in Wales, medicalisation is preemptively structured by governance to proceed in an orderly, resource-conscious way. Despite these differences, the end result in both contexts is strikingly similar – the centrality of the diagnosis. In short, American autism medicalisation might appear more demand-driven and Welsh medicalisation more supply-regulated, but both reinforce the “credentialing” function of medicalisation (Conrad and Schneider, 1980). This comparison shows how different governance structures (market-based vs. state-based) shape the trajectory of medicalisation, even if both ultimately extend the reach of medical definitions in everyday life.

Amid these structural forces, one might ask about the influence of cultural discourses such as the neurodiversity movement, which advocates viewing autism as a natural variation of human neurobiology. In theory, the rise of neurodiversity could counteract medicalisation by shifting focus toward acceptance and accommodations outside the medical model. Indeed, in both the US and UK, neurodiversity rhetoric has increasingly appeared in policy documents and professional dialogue, stressing person-centred, strengths-based approaches and warning against pathologising neurodevelopmental differences. In Wales, for example, recent initiatives (the Children’s Commissioner’s “No Wrong Door” report and new inclusive education reforms) explicitly embrace neurodiversity principles. However, the analysis presented here suggests that these discourses have been absorbed into existing frameworks without fundamentally altering the dependence on diagnosis. This exemplifies Decoteau and Daniel’s (2020) concept of “subsumptive orthodoxy”: dominant institutions respond to challenges by incorporating elements of the critique, thereby preserving their core framework. In Wales, neurodiversity advocacy has been co-opted in a way that leaves the requirement of a medical diagnosis intact. Governance frameworks now acknowledge neurodiversity, but they operationalise it within the same bureaucratic logic of standardised assessment and eligibility criteria. As a result, despite increased awareness and neurodiversity-informed training, professionals and families remain locked into pursuing the diagnostic label – partly because services are still tethered to that label. In effect, the impact of the neurodiversity movement has been refracted through the prism of governance-driven medicalisation.

One critical insight from the Welsh case is the prominent role of schools as gatekeepers, especially in socioeconomically deprived communities. Under the ND pathway, referrals for an autism assessment often originate from, or require confirmation by, educational professionals. Teachers and school-based staff (such as Additional Learning Needs coordinators and educational psychologists) are tasked with providing observational evidence and completing standardised referral forms about a child’s behaviour and development. This positioning makes schools both facilitators and filters in the diagnostic process. In

practice, strict referral criteria at the school level sometimes marginalised parental concerns. Parents in disadvantaged areas often reported feeling dismissed or “looped out” of the pathway when schools were unsupportive; for instance, if the school did not observe extreme behaviours in the classroom, the referral was not endorsed and parents were instead directed to general parenting courses on the assumption that parenting strategies were the issue.

In such situations, educational policy and resource constraints intersect with medicalisation. As Tomlinson (2017) notes, the education market incentivises schools to avoid or exclude pupils who are difficult to teach, or to demand additional resources for those they must accommodate. Under-resourced schools may therefore be hesitant to initiate a diagnosis that could obligate support they cannot readily provide, whereas others strategically seek diagnoses to access extra funding or specialist services – an ambivalence evident in Welsh referral patterns (Hurt et al., 2019). In practice, medicalisation is tightly interwoven with the logics and inequalities of the education system. Middle-class families are more likely to secure autism labels (Tomlinson, 2017), while poorer families must navigate formal pathways and are more exposed to gatekeeping. The Welsh data thus contribute to a broader understanding of diagnosis as a multi-institutional process, co-governed by education and health policy. By foregrounding the discretionary power of schools, this study extends medicalisation theory: educational institutions can amplify or constrain the reach of medical categories depending on how they collaborate with medical services. This finding resonates with Eyal’s (2013) account of the “networks of expertise” surrounding autism, where teachers and school administrators function as key nodes shaping clinical trajectories.

This study of Welsh autism pathways demonstrates that medicalisation today is a complex process shaped by the interplay of professional practices, policy frameworks and material infrastructures. The Welsh case extends Conrad’s theory by highlighting the state’s active role in managing medicalisation – reinforcing arguments that policy and bureaucracy function as central engines of medicalisation alongside medical professionals and consumer demand (Conrad, 2007). While this case study focuses on a single health board serving three socioeconomically deprived boroughs, national reports (Holtom and Lloyd-Jones, 2022; Senedd Commission, 2024) indicate that long diagnostic wait times persist across Wales. These findings suggest that while deprivation may exacerbate these challenges, they are not unique to poorer areas but reflect broader systemic constraints. Nonetheless, the governance structures analysed are embedded within a nationally coordinated policy framework, suggesting that the core mechanisms of governance-driven medicalisation extend beyond the immediate research setting. Resource constraints, workforce shortages and institutional gatekeeping may be more pronounced in deprived areas, but the standardisation of diagnostic pathways structures autism diagnosis across Wales. Future research could explore how ND pathways operate in different Welsh health boards, particularly in more affluent areas where service capacity and referral processes may vary. Comparative analyses of these variations would provide clearer insight into how governance structures interact with local resource conditions to mediate medicalisation, further refining the concept of governance-driven medicalisation within state-managed healthcare systems.

Finally, the way neurodiversity discourse has been handled in Wales provides a cautionary tale about the limits of ideological change in the face of institutional inertia. It exemplifies how even well-intentioned moves toward a needs-based, de-medicalised approach can be subsumed into existing orthodox structures (Decoteau and Daniel, 2020). In sum, the medicalisation of autism in Wales is revealed to be an intricately governed phenomenon. It advances our theoretical understanding by illustrating how governance structures, professional networks, comparative policy contexts and cultural discourses intersect to shape the trajectory of a medicalised condition. This synthesis of theory and evidence suggests that the evolution of diagnostic practices is embedded in a wider matrix of power and governance – a critical insight for future

studies of medicalisation and for policymakers striving to balance standardised care with individual needs.

Declaration of competing interest

None to declare.

Acknowledgements

I would like to express my gratitude to Emily Payne and Charlotte Thomas for their invaluable support in facilitating access to the participants who made this study possible. Charlotte was co-applicant on this project, and her contributions were instrumental to the completion of this work. This project was funded by the Research and Development Department, NHS Wales (Ref. JG/RB).

Data availability

The data that has been used is confidential.

References

- Allen, D., 2009. From boundary concept to boundary object: the practice and politics of care pathway development. *Social Science & Medicine* 69 (3), 354–361.
- Allison, G.T., Zelikow, P., 1999. *Essence of Decision: Explaining the Cuban Missile Crisis*, second ed. Addison Wesley Longman, New York.
- American Psychiatric Association, 2013. *Diagnostic and Statistical Manual of Mental Disorders*, fifth ed. Arlington.
- Aylward, M., Phillips, C., Howson, H., 2013. *Prudent Healthcare: Securing the Future of Wales*. NHS. Bevan Commission.
- Bergey, M.R., 2024. Medicalization in global context: current insights, pressing questions, and future directions through the case ADHD. *Sociology Compass* 18, e13257.
- Children's Commissioner for Wales, 2023. *A no wrong door approach to neurodiversity: a book of experiences*. Available at: <https://www.childcomwales.org.uk/a-no-wrong-door-approach-to-neurodiversity-a-book-of-experiences/>.
- Chiri, G., Bergey, M., Mackie, T.I., 2022. Deserving but not entitled: the social construction of autism spectrum disorder in federal policy. *Social Science & Medicine* 301, 114974.
- Clarke, A.E., Shim, J.K., Mamo, L., Fosket, J.R., Fishman, J.R., 2003. Biomedicalization: technoscientific transformations of health, illness, and US biomedicine. *American Sociological Review* 68, 161–194.
- Conrad, P., 2005. The shifting engines of medicalization. *Journal of Health and Social Behavior* 46 (1), 3–14.
- Conrad, P., 2007. *The Medicalization of Society: on the Transformation of Human Conditions into Treatable Disorders*. Johns Hopkins University Press.
- Conrad, P., Bergey, M.R., 2014. The impending globalization of ADHD: notes on the expansion and growth of a medicalized disorder. *Social Science & Medicine* 122, 31–43.
- Conrad, P., Schneider, J.W., 1980. *Deviance and Medicalization: from Badness to Sickness*. Temple University Press.
- Crane, L., Chester, J.W., Goddard, L., Henry, L.A., Hill, E.L., 2016. Experiences of autism diagnosis: a survey of over 1000 parents in the United Kingdom. *Autism* 20 (2), 153–162.
- Decoteau, C.L., Daniel, J., 2020. Scientific hegemony and the field of autism. *American Sociological Review* 85 (3), 451–476.
- Degeling, P.J., et al., 2004. Making clinical governance work. *BMJ* 320 (18 September), 679–681.
- Eyal, G., et al., 2010. *The Autism Matrix: the Social Origins of the Autism Epidemic*. Polity Press, Cambridge.
- Eyal, G., 2013. For a sociology of expertise: the social origins of the autism epidemic. *American Journal of Sociology* 118 (4), 863–907.
- Foucault, M., 1973. *The Birth of the Clinic: an Archaeology of Medical Perception*. Translated by A.M. Sheridan. Pantheon Books, New York.
- Freidson, E., 1970. *Profession of Medicine: a Study of the Sociology of Applied Knowledge*. Harper & Row, New York.
- Furedi, F., 2006. The end of professional dominance? *Sociology Compass* 3 (6), 1126–1134.
- Hacking, I., 1996. The looping effects of human kinds. In: Sperber, D., Premack, D., Premack, A.J. (Eds.), *Causal Cognition: a Multidisciplinary Debate*. Clarendon Press, Oxford, pp. 351–383.
- Holtom, D., Lloyd-Jones, S., 2016. *Outcome Evaluation of the Autistic Spectrum Disorder Strategic Action Plan: Final Report*. Welsh Government, Cardiff.
- Holtom, D., Lloyd-Jones, S., 2022. *Review of the Demand, Capacity and Design of Neurodevelopmental Services: Full Report*. Welsh Government, Cardiff.
- Hunter, D.J., Segrott, J., 2007. *Reconfiguring governance, rethinking health policy: the role of care pathways in health service reform*. *Sociology of Health & Illness* 29 (1), 1–15.
- Hurt, L., Langley, K., North, K., Southern, A., Copeland, L., Gillard, J., Williams, S., 2019. Understanding and improving the care pathway for children with autism. *International Journal of Health Care Quality Assurance* 32 (1), 208–223.
- Knight, C., Crick, T., 2022. Inclusive education in Wales: interpreting discourses of values and practice using critical policy analysis. *ECNU Review of Education* 5 (2), 258–283.
- Mahoney, J., 2000. Path dependence in historical sociology. *Theory and Society* 29 (4), 507–548.
- Maynard, D.W., Turowetz, J., 2019. Doing abstraction: autism, diagnosis, and the social theory. *Sociological Theory* 37 (1), 89–116.
- NHS, 2015. *Together for children and young people: framework for action*. NHS Wales. Available at: <https://executive.nhs.wales/functions/strategic-programme-for-mental-health/together-for-children-and-young-people-2/>.
- Pinder, R., et al., 2005. What's in a care pathway? Towards a cultural cartography of the new NHS. *Sociology of Health & Illness* 27 (6), 759–779.
- Russell, G., 2021. *The Rise of Autism: Risk and Resistance in the Age of Diagnosis*. Routledge, London.
- Senedd Commission, 2024. *Neurodevelopmental services in Wales: research briefing*. Available at: <https://research.senedd.wales/research-articles/neurodevelopmental-services-in-wales/>.
- Silverman, C., 2012. *Understanding Autism: Parents, Doctors, and the History of a Disorder*. Princeton University Press, Princeton, NJ.
- Singer, J., 1999. Why can't you be normal for once in your life? From a 'problem with no name' to the emergence of a new category of difference. In: Corker, M., French, S. (Eds.), *Disability Discourse*. Open University Press, Buckingham, pp. 59–67.
- Thapar, A., Cooper, M., Rutter, M., 2017. Neurodevelopmental disorders. *Lancet Psychiatry* 4, 339–346.
- The National Institute for Health and Care Excellence, 2011. *Autism Spectrum Disorder in Under 19s: Recognition, Referral and Diagnosis* (Clinical Guideline, 128).
- Timmermans, S., Berg, M., 2003a. *The Gold Standard: the Challenge of Evidence-based Medicine and Standardization in Health Care*. Temple University Press, Philadelphia.
- Timmermans, S., Berg, M., 2003b. The practice of medical technology. *Sociology of Health & Illness* 25 (Silver Anniversary Issue), 97–114.
- Timmermans, S., Epstein, S., 2010. A world of standards but not a standard world: toward a sociology of standards and standardization. *Annual Review of Sociology* 36, 69–89.
- Tomlinson, S., 2017. *A Sociology of Special and Inclusive Education: Exploring the Manufacture of Inability*. Routledge, London.
- Welsh Government, 2008. *Autistic Spectrum Disorder Strategic Action Plan*.
- Welsh Government, 2021. *Code of practice for the delivery of autism services in Wales*. Available at: <https://www.gov.wales/code-practice-delivery-autism-services>, 08/06/2024.
- Welsh Government, 2022. *Neurodivergence improvement programme: engagement events November 2022*. Available at: <https://www.gov.wales/neurodivergence-improvement-programme-engagement-events-november-2022.html>.
- Zola, I.K., 1972. Medicine as an institution of social control. *The Sociological Review* 20 (4), 487–504.