



Autism in Wales: Diagnostic regimes and the governance of care under scarcity

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1. Introduction

Autism diagnosis today occurs in an institutional field shaped not only by medical judgement but by bureaucratic thresholds and resource scarcity. Across the UK, rising diagnostic demand has placed autism services under increasing strain, often surpassing institutional capacity. In Wales, recent policy innovations, notably the unified Neurodevelopmental (ND) pathway, have sought to standardise access and reduce regional disparities by aligning health and education services. Yet these ambitious reforms have not resolved persistent systemic challenges, including extensive waiting lists, stringent triage thresholds and procedural bottlenecks. Wales thus provides a critical site for examining how diagnostic systems function under conditions of scarcity and devolved governance.

This paper examines autism diagnosis as a complex classificatory regime embedded within public service infrastructures. Building on but moving beyond medicalisation theory, I use the concept of *diagnostic regimes* to show how diagnostic categories are operationalised through structured assemblages of institutional rules, professional norms and administrative technologies (Bowker & Star, 1999). Traditional models of medicalisation emphasise the expansion of medical authority into new domains of life (Conrad, 2007) or the role of grassroots advocacy in extending diagnostic recognition (Furedi, 2006). By contrast, the lens of diagnostic regimes reveals how such expansions are mediated, and often curtailed, by governmental practices of triage and standardisation, and how classificatory authority is distributed across a wider ecosystem of institutional actors (Eyal et al., 2010).

In this view, diagnosis is not a discrete clinical act but an institutional mechanism that can both enable and restrict access to care. Studies in the sociology of diagnosis show how diagnostic categories mediate between individual experience and institutional order, promising both explanation and entitlement while simultaneously constraining other forms of recognition (Armstrong, 2011; Jutel, 2009; Jutel & Nettleton, 2011; Rosenberg, 2002). Building on this lineage, the paper conceptualises diagnosis as an infrastructural mechanism that governs the

circulation of care. Drawing on qualitative data from health and education professionals, frontline support workers and third-sector practitioners within one Welsh health board, I examine how diagnostic pathways function as engines of inclusion and exclusion. These pathways promise fairness and consistency yet also generate institutional delay, produce “patients-in-waiting” (Timmermans & Buchbinder, 2013) and compel families into evidentiary labour to render their children institutionally visible. Integrating insights from this literature with the logic of care (Mol, 2008) and biosocial perspectives on autism (Eyal et al., 2014), I specify *diagnostic regimes* as a framework for understanding how classificatory infrastructures govern care under conditions of scarcity.

2. From medicalisation to diagnostic regimes

Autism offers a particular vantage point for rethinking how diagnosis operates in contemporary healthcare. Classical theories of medicalisation emphasised the expansion of medical authority into everyday life, reframing social or moral problems as medical issues (Freidson, 1970; Zola, 1972). Later accounts recast medicalisation as a negotiated and multi-directional process shaped not only by professionals but also by patient and advocacy groups (Ballard & Elston, 2005; Conrad, 2005, 2007). Families, in this view, can act as vectors of “medicalisation from below” (Furedi, 2006), pursuing diagnosis to secure recognition and access to resources. Such strategies align with Rose’s (2007) notion of “biological citizenship”, in which individuals mobilise biomedical categories to claim rights and entitlements.

The concept of diagnostic regimes builds on but departs from this tradition. While medicalisation theory explains *why* categories expand, diagnostic regimes show *how* classification is enacted in specific institutional settings – through the interplay of bureaucratic routines, technical standards and governance structures. As Rosenberg (2002) argues, diagnosis operates as a bureaucratic and moral technology that links individuals to institutional systems by rendering experience administratively legible. Likewise, Armstrong (2011) shows that classificatory

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systems do not merely reflect medical reality but actively produce it, translating the contingencies of clinical practice into standardised forms of knowledge and accountability. Here, the sociology of diagnosis (Jutel, 2009; Jutel & Nettleton, 2011) provides an important bridge, emphasising that diagnosis is not simply a label applied to an objective reality but a process embedded in institutional logics, professional negotiations and socio-political contexts. Diagnostic regimes bring this insight into sharper focus by centring the material and procedural architectures – forms, checklists, data systems, eligibility criteria – through which classificatory authority is sustained.

Two complementary perspectives underpin this formulation. From Foucault (1980), diagnosis appears as a social technology of power: a means of rendering complex phenomena visible, knowable and governable. Classification, in this view, is inseparable from governmentality – a mode of ordering populations, distributing resources and shaping conduct. From Bowker and Star (1999), we learn that classification achieves this not in the abstract but through material infrastructures that standardise categories, embed them in work routines and carry them across contexts. Their analyses of systems such as the Diagnostic Statistical Manual (DSM) and International Classification of Diseases (ICD) show how classificatory schemes organise the very fields they describe, making some identities legible to institutions while marginalising others.

Autism's recent history illustrates these dynamics. Nadesan's (2005) genealogical analysis traces its emergence as a socio-political category intertwined with anxieties about child development, normalcy and social productivity. Silverman (2012) highlights the role of cultural narratives, showing how changing social imaginaries influence the category's scope and salience. Evans's (2017) historical epidemiology links shifting diagnostic thresholds to rising prevalence estimates, reframing autism as a population-level concern in public health policy.

Eyal et al. (2014) argue that autism's expansion is driven less by biomedical certainty than by *epistemic recalcitrance* – its resistance to definitive closure – and *biosocial productivity*, whereby indeterminacy allows diverse actors to adapt and repurpose the category. This recursive engagement resembles Hacking's (1995, 2006) concept of “looping effects”, in which classification changes the behaviour and self-understanding of those classified, prompting revisions to the category itself. Eyal and colleagues extend this to an expanded looping, understood as a recursive process operating across multiple institutional domains: clinicians refining diagnostic tools, educators adjusting special needs provision, policymakers setting eligibility thresholds and advocacy groups reshaping public discourse – all feeding back into the category's evolution. The result is a classification that is both elastic and institutionally durable.

Yet expansion has not brought unbounded access to services. In Wales, rising demand has been met with formal governance mechanisms regulating entry into diagnostic and support pathways. Timmermans and Buchbinder's (2013) concept of “patients-in-waiting” captures how diagnostic systems manage biomedical uncertainty – not merely as a lack of knowledge, but as an enduring organisational condition. In their analysis, uncertainty becomes institutionalised when indeterminate or contested cases are absorbed into procedural routines of triage, waiting and evidentiary verification. Such mechanisms convert the indeterminacy of diagnosis into a managed state of suspension, producing new liminal subjectivities whose care is indefinitely deferred. In this light, diagnostic regimes are less mechanisms of closure than infrastructures that stabilise and reproduce uncertainty. While designed to assure fairness and transparency, these systems can also generate procedural suspension, where care is promised but indefinitely deferred.

Here, Mol's (2008) *logic of care* offers a valuable counterpoint. In contrast to models of choice and standardisation, the logic of care privileges relationality, responsiveness and situated judgement. Mol's ethnography of diabetes care shows how practice involves ongoing adaptation, not rigid adherence to protocols. Applied to autism services, this highlights the disjuncture between procedural rationality and the

lived complexity of care. In Wales, efforts to standardise pathways have collided with rising demand and resource strain, forcing families and professionals into continual “tinkering” to address unmet needs.

Taken together, these frameworks situate autism diagnosis within a dynamic field of classificatory governance. Diagnostic regimes are neither neutral nor simply coercive; they mediate care, allocate resources and reproduce inequalities. In doing so, they render visible both the institutional architecture of diagnosis and the human stakes of classification.

3. Autism policy in Wales

Wales presents a distinctive policy landscape due to its devolved powers in health and education, which have enabled autism services to develop along a separate trajectory from other UK nations (Welsh Assembly Government, 2008). This distinctiveness was marked by the launch of the Autistic Spectrum Disorder Strategic Action Plan (ASD SAP) in 2008, the first national autism strategy in the UK. The plan aimed to create a coherent framework for raising awareness, improving diagnosis and expanding access to support across the life course.

The strategy was not simply a top-down initiative. It emerged from sustained biosocial mobilisation involving a broad coalition: Autism Cymru, the National Autistic Society Cymru, the Cross-Party Autism Group in the Senedd and grassroots parent-led networks such as Autism Parents Wales. These actors successfully framed autism as a legitimate object of public policy, generating both diagnostic demand and a normative commitment to institutional recognition (Welsh Assembly Government, 2008).

Following its introduction, the ASD SAP coincided with a steep rise in school-age autism diagnoses from under 0.2 % in 2003/04 to nearly 1 % by 2012/13 (Holtom & Lloyd-Jones, 2016). While the plan catalysed public recognition and professional responsiveness, outcomes were uneven. Commentators described a patchwork of provision, marked by “islands of good practice” rather than consistent, system-wide reform (Holtom & Lloyd-Jones, 2022). These developments illustrate the double movement that characterises diagnostic regimes: as classificatory categories become infrastructural gateways to services, their expansion often coincides with the contraction of institutional response.

In 2016, the Welsh Government launched the Integrated Autism Service (IAS) to address gaps in service provision, particularly for adults transitioning from paediatric care. This was followed in 2017 by a broader policy realignment: the establishment of regional neurodevelopmental (ND) teams tasked with delivering standardised diagnostic pathways for autism, ADHD and related conditions. These reforms responded to concerns about diagnostic overlap, fragmented services and inequitable access.

The ND pathways aimed to streamline referrals and reduce variation in practice across health boards. However, they also embedded mechanisms of triage and rationing: eligibility thresholds, waiting-list targets (e.g. the 26-week referral-to-assessment benchmark) and performance metrics became central tools for managing demand. Diagnosis thus acquired a dual role: as a tool for clinical understanding and as an instrument of bureaucratic governance. This shift exemplifies what I have elsewhere termed “governance-driven medicalisation” (Arribas-Ayllon, 2025): the use of diagnostic infrastructures to regulate access and monitor service performance.

Education policy also underwent significant reform. The Additional Learning Needs and Education Tribunal (Wales) Act 2018 replaced the Special Educational Needs (SEN) framework with a needs-based model. This allowed children with Additional Learning Needs (ALN) to receive support via a statutory Individual Development Plan (IDP), regardless of formal diagnosis. The intention was to decouple support from diagnostic status and embed a more inclusive approach across education and allied services (Welsh Government, 2021). Yet implementation remains uneven. Studies suggest that despite the statutory emphasis on needs-based provision, educational professionals continue to rely on diagnostic

labels when allocating support, revealing persistent tensions between policy aims and entrenched practices (Hurt et al., 2019; Milosevic et al., 2022).

A further milestone was the statutory Autism Code of Practice (2021), introduced under the Social Services and Well-being (Wales) Act 2014 and the NHS (Wales) Act 2006. The Code sets out minimum expectations for local authorities and health boards, including timelines for assessment, post-diagnostic support, professional training and service-user involvement. Its rights-based, person-centred vision is ambitious, but underfunding and staffing shortages have slowed delivery (Duggan et al., 2023).

Despite progressive legislation, families continue to face significant barriers to timely assessment and support. Many report long waits, inconsistent implementation and a tendency for services to engage only at crisis points. A government-commissioned review confirmed that demand for neurodevelopmental services had “outstripped the capacity” of the system (Holtom & Lloyd-Jones, 2022), with 16,812 children and young people in Wales waiting for assessment (Senedd Cymru 2023). The Welsh Government’s 26-week target from referral to first appointment remains largely unmet, eroding trust in the system’s ability to deliver equitable support.

Recent initiatives, such as the “Neurodivergence Wales” strategy and proposals for a centralised national assessment pathway, signal a commitment to reform (Welsh Government, 2022). Yet these face the same structural pressures as elsewhere in the UK: staff shortages, uneven regional implementation and budgetary constraints. A postcode lottery persists, mirroring disparities seen in England (Autistica, 2024; Holtom & Lloyd-Jones, 2022).

Chiri et al.’s (2022) analysis of U.S. federal autism policy provides a useful comparative perspective here. Examining over two decades of legislation, they show how statutory recognition and targeted funding have often prioritised biomedical research, surveillance and early detection over the expansion of service infrastructures, particularly for autistic adults. Their concept of autistic people as ‘deserving but not entitled’ captures a structural tension also evident in the Welsh context, where policy ambitions for inclusion outpace the resources and institutional capacity available to deliver them.

In sum, Welsh autism policy articulates an ambitious vision centred on inclusion, rights and integration. Yet the infrastructure to realise this vision remains fragile. Effective implementation will require not only legislative clarity but also sustained investment, workforce capacity and cultural change in how diagnosis, needs and parental knowledge are recognised across services.

4. Method

This study forms part of a wider investigation into health and social services within a South Wales health board, serving three county boroughs pseudonymised as “Cwm”, “Afon” and “Duffryn”. The region is socioeconomically diverse, combining densely populated urban centres with rural areas. Stark contrasts between affluence and deprivation reflect patterns of post-industrial decline and persistent health inequalities following the collapse of coal mining. At the time of fieldwork, referrals for neurodevelopmental assessment had more than doubled within two years, placing significant strain on diagnostic pathways and related services. This study examines how increasing demand for autism diagnosis interacts with structural capacity constraints, with particular attention to support provision for autistic children and their families.

A qualitative case-study design was adopted to explore how resource limitations shape diagnostic practices, triage processes and inter-agency coordination across health, education and third-sector services. Fieldwork took place over five months and combined semi-structured interviews, focus groups, site-based observation and documentary analysis. Participants were recruited purposively through NHS and education networks, local authorities and third-sector organisations involved in neurodevelopmental assessment and support. A total of 33

participants were recruited, including paediatricians, educational psychologists, local authority staff, third-sector practitioners and support workers operating within or alongside ND services (see Table 1). Interviews were conducted online and transcribed verbatim by the author or a professional service. Two focus groups were held: one with charity support workers in Cwm, the other with local authority professionals in Duffryn. Although participant observation was originally planned for all three boroughs, time constraints limited this component to two sites in Cwm – a behaviour training charity and an early intervention service – selected for their operational links to the health board and central roles in family support. Observations focused on inter-professional discussions and informal exchanges with parents during group sessions. Fieldnotes were taken contemporaneously, anonymised and used to contextualise interview and focus-group data. Documentary materials, including local ND referral protocols, diagnostic templates, educational planning documents and policy guidelines, were also analysed to contextualise findings. Ethical approval was granted by the University Health Board’s R&D Office (Ref. XXX/2071/24).

Data analysis followed an iterative engagement with both empirical material and relevant theoretical frameworks. Initial coding drew on established sociological theories of medicalisation (Conrad, 2007), the sociology of diagnosis (Jutel, 2009) and the biosocial dynamics of autism advocacy and support (Eyal et al., 2010, 2014). These frameworks structured early analysis, which combined deductive and inductive cycles to test and refine their explanatory power. As analysis progressed, however, patterns in the data – prolonged waiting times, procedural gatekeeping and the evidentiary requirement that needs be observed across multiple institutional settings – highlighted dynamics not fully captured by models centred on professional dominance or biosocial mobilisation. These findings suggested that diagnosis was as much an administrative and infrastructural achievement as a clinical determination, revealing the limits of medicalisation theory in highly bureaucratised service environments.

To address these limits, the analysis developed the concept of *diagnostic regimes*: structured assemblages of professional norms, institutional rules and administrative technologies through which autism is identified, legitimised and managed (Bowker & Star, 1999). This reconceptualisation extends medicalisation theory by situating classification within governance infrastructures that allocate resources, set eligibility thresholds and control the pace of access to care. Following Mol’s (2008) concept of the *logic of care*, the framework highlights how these infrastructures can displace relational, adaptive forms of support with procedural and evidentiary demands. In parallel, Timmermans and Buchbinder’s (2013) notion of “patients-in-waiting” captures how diagnostic regimes do not only delay care but actively generate states of suspended eligibility, institutionalising uncertainty. Together, these perspectives positioned diagnostic regimes as the most suitable analytic framework for examining the Welsh ND pathway, linking the governance of diagnosis to its everyday effects on professional practice and family navigation.

The following analysis is organised into three empirical themes. “Diagnosis and access to care” explores tensions between bureaucratic rationality and the relational practices of support, showing how procedural requirements can delay or misalign care. “Expanding and contracting regimes” examines how rising diagnostic demand is met by strategies of triage, standardisation and access restriction. “Navigating crisis and care” traces how families and frontline actors respond to institutional delays and diagnostic ambiguity through advocacy, information-gathering and strategic engagement. Together, these themes illuminate how structured, policy-mediated diagnostic regimes shape autism service provision, professional practice and family experience in the Welsh context.

5. Diagnosis and access to care

Diagnosis does more than categorise; it coordinates action. In Welsh

Table 1
Participant overview.

Domain	Role(s)	Number	Data Collection	Location(s)
Clinical assessment	Community Paediatrician	4	Interview	Cwm, Afon, Duffryn
	Consultant Psychiatrist	1	Interview	Cwm
	Clinical Nurse Specialist	1	Interview	Duffryn
	Speech & Language Therapist	1	Interview	Other
Care Coordination	Operational Manager	2	Interview	Cwm, Afon
Educational Assessment	Educational Psychologist	3	Interview	Cwm, Afon, Duffryn
	Specialist Teacher	1	Interview	Duffryn
Educational Governance	Clinical Lead Officer	1	Interview	All-Wales
Community-based support	Psycho-Ed Group	1	Focus Group	Cwm
	Early Intervention Group	3	Observation/Focus Group	Cwm
	Behaviour Support Group	6	Observation/Focus Group	Cwm
	Home-Help Group	2	Focus Group	Cwm, Afon
	Parent Support Group	1	Interview	Duffryn
Strategic Commissioning	Social Services	1	Interview	Afon
	Commissioning Officers	4	Focus Group	Duffryn
	Welfare & Resilience Service	1	Interview	Cwm

autism services, diagnostic classification operates as an organisational technology that links professional judgment to administrative procedure and moral expectation. As [Armstrong \(2011\)](#) shows, medical nosologies were constructed to render disorder administratively visible and governable, yet their application in everyday practice exposes a persistent tension between classificatory order and lived complexity. In Rosenberg's terms, diagnosis functions as a bureaucratic ritual: it legitimises claims, structures communication across services and authorises movement through the system ([Rosenberg, 2002](#)). Within the Welsh ND pathway, this ritual links the promise of inclusion to procedural thresholds that ration access; families pursue diagnosis not out of preference but because classification has become the principal means through which care is coordinated and distributed.

A senior health board representative captured the disjuncture between official policy ideals and the practical rationalities of families and professionals navigating the diagnostic regime:

Unfortunately, and I guess that's the inheritance from SEN, people still think very much from a medical model perspective. Therefore, there is this drive to refer children onto the ND service to get that diagnosis, and particularly parents believe, rightly or wrongly, that if they have that diagnosis, all of a sudden, a door will be open to a secret world of support. And to a certain degree, some of our school colleagues believe that too and will be ushering parents along. But in principle, that is not the case [...] Sometimes parents are of the belief that the needs of their child are such that a mainstream school cannot fulfil their needs, or they think that their child will just be better off in a designated unit [special school]. Therefore, they are driving that diagnosis because that diagnostic label is one of the important keys to get in.

The account shows how diagnostic regimes channel care through classificatory infrastructures that often constrain responsiveness. Classification makes problems administratively visible, but it also standardises their admissible forms, producing thresholds and triage logics that families must navigate. Rather than a preference for a "medical model", the pursuit of diagnosis appears as a rational response to the way bureaucratic order translates uncertainty into eligibility and obligation. What reads as parental "choice" is thus system-driven necessity: diagnosis is sought because it is the only route through which institutions can legitimately act.

Local authority staff in Duffryn described how institutional design structures diagnostic demand:

CM: The way our structures are set up is what's pushing families to want that diagnosis. If we didn't have these structures would we have this big drive?

SW: However, I think if having a diagnosis wasn't necessary ... everyone would be completely overwhelmed. It would totally collapse.

CM: ... you want to be needs-led, but how could you manage that demand with what we've got now? It comes down to the resources and the way we structure things based on what we have available.

These reflections show that diagnostic demand is structurally incentivised, not driven by parental misunderstanding. What [Armstrong \(2011\)](#) shows is that the classificatory logic of diagnosis is not merely descriptive but constitutive, organising how medical realities are rendered visible and actionable. In contemporary systems, this epistemic rationality has become administrative: diagnostic thresholds replace the relational flexibility of care, turning classification into a procedural means of governing scarcity. Diagnosis thus becomes less a clinical explanation than a bureaucratic prerequisite, deferring care until classificatory criteria are met. This dynamic reflects [Eyal et al.'s \(2014\) expanded looping](#): a recursive process across clinics, schools and policy whereby tying services to classification increases diagnostic pursuit, which in turn cements the category's bureaucratic centrality. As access to services becomes tethered to classification, families are structurally compelled to seek diagnosis, which in turn expands its scope and further entrenches its bureaucratic centrality. Here, medicalisation is less about expanding clinical jurisdiction than about preserving institutional functionality by "managing uncertainty" ([Timmermans & Buchbinder, 2013](#)).

As public pathways become congested, some families turn to private assessments to bypass delays. Yet these market-based alternatives do not escape bureaucratic authority. Their legitimacy remains contingent on public ratification, as an educational psychologist in Duffryn explained:

As an authority, we do ALNCO [Additional Learning Needs Coordinator] forums. They were reporting that they were overwhelmed with ND requests. They couldn't manage the paperwork, the bottleneck requesting input from the specialist teacher or the EP [Educational Psychologist]. Alongside that was a rise in private ASD assessments. So parents fed up of the time it'll take to go through the normal ND process or having the ways and means of paying for private ASD assessments. What do we do with those private assessments? [...] we've now got some private ASD diagnoses that we have to ratify or not [...] sometimes the evidence was very poor from private assessors. And they did not meet the All-Wales protocol and we rejected the diagnosis. And that in itself then causes problems

because then you have complaints ... So we feel quite strongly that if a private assessment is not robust enough, we can reject it. It just causes a whole heap of hassle ... It didn't feel right that you could pay for a private assessment and then jump the queue.

Here, marketised diagnosis creates new tensions between consumer choice and institutional legitimacy. Families may pay for classificatory recognition, but unless it conforms to public protocols designed to standardise and validate assessment, it may remain ineffective – showing that classificatory authority is distributed across a heterogeneous field of professionals and institutions (Eyal et al., 2010). As Armstrong (2011) observes, classification systems achieve authority only through institutional coordination: they depend on shared standards that translate individual assessments into administratively actionable categories. In this sense, diagnosis operates as what Rosenberg (2002) calls a bureaucratic ritual: a means of securing legitimacy by aligning professional judgement with institutional protocols. Private diagnoses thus occupy a liminal space: recognised by some actors, contested by others and subject to administrative triage. As Timmermans and Buchbinder (2013) note, classification regimes can generate new liminal subjectivities, producing “patients-in-waiting” whose care is indefinitely deferred while they remain under institutional observation. In the Welsh ND pathway, this state of suspended eligibility is sustained by procedural thresholds and rationing mechanisms, leaving families recognised by the system yet continually awaiting the confirmation or resources that diagnosis is meant to unlock.

These dynamics reveal how diagnostic regimes displace the relational flexibility of care with the procedural rationalities of governance-driven medicalisation. Diagnosis becomes less clinical insight than as institutional currency, translating need into eligibility through standardised pathways. By tracing the strategic adaptations of families and professionals, this section shows how the regime shapes not only who gains access to care, but also the forms of care that remain possible within its constraints.

6. Expanding and contracting regimes

The development of autism services in Wales has been shaped by two intersecting forces: the biosocial productivity of families and advocates, and governance-driven efforts to standardise neurodevelopmental services. Together, these dynamics have produced an infrastructure that simultaneously expands classificatory reach and constrains institutional response. This double movement is central to understanding how diagnostic regimes operate under scarcity: as classificatory categories become infrastructural gateways to services, their expansion is often accompanied by new forms of contraction through waiting lists, eligibility thresholds and gatekeeping practices.

Such tensions are visible in the accounts of frontline practitioners, who describe a system where the proliferation of diagnostic labels outpaces the capacity to deliver care, increasing pressure on families to demonstrate need and navigate fragmented services. The clinical lead of a regional ND service attributed rising autism diagnosis to “disproportionate demand from families” driven by the belief that “unless you get a diagnosis, you don't get help”. Of the children awaiting assessment, he estimated that only a quarter “really would benefit” from a diagnosis, for example, those needing special-school placement, language unit access or preventative mental health intervention. The remainder, he argued, could be supported pedagogically without formal labelling. Rather than expanding clinical jurisdiction, he advocated tightening diagnostic thresholds and redistributing interpretive authority to teachers, who are already managing many of these children's needs in situ:

Teachers understand their needs. They're a bit quirky and they just need a bit of help ... whether they are on the spectrum or not, that label wouldn't actually change the provision they need in class [...] So it's that whole pool that is really stressing the service [...] But it's very difficult, even for a politician, to tell people to pause, 'look,

there's no need to rush and get a diagnosis'. Then parents are told, 'unless you get a diagnosis, you don't get help'. There is some truth in that for some children, but for most children, no, there isn't.

Here, the tension between diagnostic expansion and institutional contraction is refracted through the problem of triage. Diagnosis remains a prerequisite for many forms of provision, affirming its role as a gatekeeping device (Conrad, 2007), yet its practical utility is increasingly questioned for children whose needs can be met through educational adaptation rather than medical intervention. This results in a form of diagnostic boundary-work (Gieryn, 1983) that both extends and limits medical authority. While medicalisation generates demand for diagnostic labels, governmental rationalities redirect this demand through calculative mechanisms (i.e. waiting lists, referral thresholds, performance targets) that distribute responsibility across families, clinicians, educators and local services.

A frontline view from a local authority commissioning team shows how this redistribution can culminate in a post-diagnostic vacuum, where classificatory recognition does not guarantee support. The case manager (CM) and social workers (SW) in Duffryn described the scale of the problem:

CM: We have huge waiting lists for services in my team and we're talking about families that are in total crisis, severely disabled children who literally cannot access anything else [...] I went to a meeting yesterday and I think there are sixteen children on the waiting list, and one child has been on there since 2020 [...] even if Covid hadn't have happened, the demand for services is just unbelievable and we just haven't got enough.

SW1: So even when you've got a diagnosis and we assess that there's a need for support ...

SW2: Yeah, you're still on a waiting list for three years.

SW1: ... quite often we can't meet that need [...] because we just haven't got the staffing and we haven't got the services to provide the support

These reflections expose a diagnostic regime in which symbolic recognition outpaces institutional response. Similar patterns are evident in comparative policy analyses, where autism legislation confers legitimacy while directing most resources toward research infrastructures rather than tangible supports (Chiri et al., 2022). Diagnosis functions as classificatory infrastructure (Bowker & Star, 1999) that renders identities legible and, as Jutel (2009) emphasises, legitimates suffering, establishes eligibility for care and operates as a bureaucratic act embedded in systems of governance. Yet under conditions of scarcity, this allocative function is hollowed out: eligibility is formally conferred but material support is rationed or absent, creating a form of inclusion that is symbolic rather than substantive. The result is a stratified system in which families are expected to “wait well” and absorb risk within the domestic sphere (Rose, 1999). What emerges is a regime oriented more toward managing demand than providing care, in which triage becomes the dominant institutional logic.

A further expression of diagnostic tension between expansion and contraction is captured by a parent-advocate and co-founder of a behaviour support charity in Cwm, describing how her child's difficulties were dismissed by school:

School were not on board. And that's one of the problems we both had and that's a current problem now, if the school are not seeing the issue with the child, they are not able to contribute to the assessment that ND would do [...] because it needs to be in two settings at least, and ND are quite unlikely to diagnose without having school support [...] especially with children with autism, they will appear absolutely fine in school, because they will mask ... and the parents then are dealing with the fallout. The schools are not willing to put anything in place because they don't see anything. But if schools would listen to parents more and believe that they see these behaviours at

home [...] they'd be less violent and less outbursts at home because things are being managed in school.

This exchange illustrates the jurisdictional friction that arises when medical and educational systems are made mutually accountable for diagnostic evidence. What appears as institutional resistance is also a consequence of diagnostic expansion: as health services require evidence from multiple settings, schools become obligatory partners in the production of clinical legitimacy. Autism diagnosis thus operates across institutional boundaries, issued within medicine but enacted within education, where it governs access to specialist placements, additional learning support and staff resources. This translation of clinical judgement into educational entitlement is rarely smooth: it generates continual negotiation over jurisdiction, accountability and evidence, revealing the interdependence of medical and educational systems in defining children's needs.

The account above illustrates how schools act as epistemic gatekeepers in a regime that demands corroboration across settings. The requirement that symptoms be observed in at least two contexts creates an epistemic hierarchy in which the school's perspective can override the parent's. When behavioural concerns are unrecognised in institutional settings, parental testimony is delegitimised, blocking access to assessment. The child's ability to mask symptoms further exposes the limits of behavioural epistemologies underpinning eligibility criteria, where visibility is both constructed and contested (Eyal et al., 2010). In such contexts, diagnostic ambiguity becomes an institutional impasse, responsibilising families without offering structural support. This dynamic exemplifies how the expansion of diagnostic rationalities into education simultaneously generates new sites of contraction, where bureaucratic requirements reproduce scarcity through evidentiary control.

This interplay of expansion and restriction demonstrates how diagnostic regimes extend medicalisation beyond the simple growth of medical authority. Here, classification is driven by biosocial advocacy while recalibrated by governance mechanisms such as triage and eligibility protocols. Inclusion and exclusion are not incidental outcomes but embedded features of the regime's operation.

7. Navigating crisis and care

In Wales, diagnostic regimes responsibilise families by shifting care, coordination and advocacy onto parents in conditions of institutional scarcity. Intervention is often deferred until bureaucratic thresholds are met, making support conditional on diagnostic visibility. Drawing on Mol's (2008) *logic of care*, I show how relational, adaptive practices essential to anticipatory support are subordinated to a triage-based infrastructure. Families must mobilise diagnostic categories and perform evidentiary labour to render their needs institutionally legible.

A support worker tasked on a "waiting list initiative" described how neurodevelopmental needs are reclassified as acute crises, and how bureaucratic and medicalised thresholds delay support until visible breakdown can no longer be ignored:

I've got one little boy who I really feel for because his mother is crying out for diagnosis and he goes to school, they say there's no issues, the police are called all the time because of his aggressive behaviour towards his mother, they told the parents that if you're in crisis you have to take them to A&E [Accident & Emergency], so you've got families in a meltdown you've got to say to them, "Right, I've got to take you now to A&E". This little boy went to A&E with his mum, and then they were told there's no doctor so he has to wait there overnight. So the system is letting the children and the parents down.

This reflects a system governed by crisis thresholds, where services intervene only at the point of failure. Instead of early or preventative care, families are redirected to emergency services ill-equipped for

neurodevelopmental needs, signalling a breakdown of the logic of care in which adaptive, relational responses are displaced by procedural deflection. The instruction to attend A&E functions as a bureaucratic workaround that relocates responsibility without delivering care. Without classificatory recognition, needs remain structurally invisible (Bowker & Star, 1999). For Mol, this is not merely inefficiency but a failure of attunement – a system unable to synchronise with the tempo, urgency or situatedness of care.

As statutory support becomes more conditional, families take on the labour of navigating opaque, fragmented systems. Responsibility is both emotional and logistical: learning procedures, gathering documentation, challenging refusals and managing inter-agency breakdowns. Charities interviewed during fieldwork reported that the burden of proof shifts decisively onto parents – those seeking help must first prove their deservingness by performing bureaucratic competence. A children's services manager in Duffryn noted that many families, after repeated deflection to generic parenting programmes, arrive at voluntary sector organisations "exhausted" from years of convincing schools that "there's something else" – a phrase signalling a biosocial framing that locates problems in neurodevelopment rather than parenting.

A charity worker in Cwm explained the evidentiary burden this entails:

When schools are saying, we don't see anything ... as a parent we always tell parents keep a diary, keep notes if anything happens, make a paper trail, they have to show on such and such date we were called to go and pick up Cole because for example they couldn't manage his behaviour or there was an incident in the classroom [...] a lot of our parents don't know the process, so in that situation they're really left in the dark.

Here, an asymmetry emerges: schools "don't see anything", yet parents must prove their claims. Charities coach families to produce documentation, exemplifying what Eyal et al. (2014) call *biosocial productivity*: the mobilisation of collective capacities to generate the navigational infrastructures (i.e. diaries, records, procedural know-how) that enable families to engage with the diagnostic regime. While these practices equip parents to pursue recognition, they also supply the administrative labour that keeps the system operational under scarcity. Diagnosis thus becomes an administrative process, outsourcing classificatory work to lay actors through forms, timelines and records – a form of administrative medicalisation in which recognition depends less on care than on procedural compliance. Instead of relational responsiveness, care is displaced by proceduralism, demanding that families convert crises into admissible proof.

Third-sector organisations increasingly operate as *parainstitutional* actors: filling the void left by under-resourced services yet lacking the permanence or authority of formal institutions. The co-founder of a behaviour support group in Cwm described the origins of their non-diagnosis-specific model:

The reason we decided to be a non-diagnosis organisation was because when my son wasn't diagnosed ... I didn't have any support and I had nowhere to go, so it was quite important to us that people without a diagnosis get support ... ten years ago there wasn't an organisation about to support me, because they were very autism specific organisations ... we started with that premise of being non-diagnosis specific and we have found that the other support groups around us have adapted and they've made it not diagnosis specific [...] and it just kind of grew and grew and grew, and then the local authority kept asking us to do things and other people were interested and it just kind of went from there, and now it's insane.

By refusing to condition support on formal diagnosis, the group challenges gatekeeping and reorients care around lived need. Rather than reproducing the rigid entry criteria typical of a logic of choice, it reflects a logic of care: ongoing adjustment, attentiveness and responsiveness to families' circumstances (Mol, 2008). At the same time, its

growth illustrates the productivity of biosocial movements (Eyal et al., 2014), where lived experience becomes the basis for alternative infrastructures that supplement, and sometimes circumvent, the formal diagnostic regime. While such groups provide vital navigational resources, their proliferation reflects a deeper responsabilisation of care: the state relies on voluntary networks to absorb unmet need without guaranteeing stability or support.

These practices show how diagnostic regimes extend beyond formal institutions, enrolling families and third-sector actors into their everyday functioning. Lived experience is transformed into documentary evidence and alternative infrastructures that sustain the regime despite scarcity. Far from existing outside the classificatory system, these adaptive strategies become integral to its reproduction, reinforcing diagnosis as both the gateway to, and the condition of, care.

8. Discussion and conclusion

This analysis contributes to the sociology of diagnosis by showing how classificatory systems function as infrastructures of coordination across institutional domains. Following Armstrong (2011) and Rosenberg (2002), diagnosis can be understood not as a discrete clinical act but as a bureaucratic and moral technology that organises visibility, legitimacy and obligation. In the Welsh neurodevelopmental (ND) pathway, these classificatory infrastructures are extended across health and education, where medical categories are repurposed to govern access to support. The concept of *diagnostic regimes* captures this dual process: the extension of diagnostic authority beyond medicine and its simultaneous recalibration through bureaucratic mechanisms of triage and rationing. Within Wales, this dynamic takes a distinct cross-sectoral form: although diagnosis is produced within health, its effects are enacted primarily in education, where it structures eligibility, resources and accountability. This transfer of classificatory authority across domains illustrates how diagnostic regimes function as intersectoral infrastructures, binding together systems with divergent logics of care, evidence and governance.

The Welsh case shows how contemporary diagnostic regimes for autism function simultaneously as infrastructures of inclusion and exclusion. On one hand, the classificatory apparatus of diagnosis renders needs visible and institutionally legitimate; children's struggles often do not officially "exist" until named by a medical institution. This act of naming and standardising autism through clinical definitions and assessment pathways actively shapes the social world it purports to describe. Diagnosis does not merely reflect a pre-existing reality but participates in its constitution, producing what can be understood as a social ontology (Bowker & Star, 1999; Hacking, 1995, 2006). Like other codified systems, the Welsh ND pathway brings certain behaviours into view while excluding others that fall short of evidentiary thresholds.

Seen through the lens of medicalisation theory, the Welsh case complicates linear narratives of expanding medical authority. Classical accounts emphasised professional dominance and the encroachment of medical jurisdiction into everyday life (Freidson, 1970; Zola, 1972). Later formulations, particularly those foregrounding "medicalisation from below" (Furedi, 2006), recognised the role of families and advocacy groups in pressing for diagnostic recognition and access to resources. Autism in Wales reflects this negotiated model: families mobilised to raise awareness and demand reform. Yet biosocial mobilisation alone cannot explain the current regime's structure. Demand "from below" has been met not by unbounded expansion, but by governance mechanisms that formalise rationing. As Bowker and Star (1999) note, classificatory systems exert "torque" when categories and thresholds fail to align with lived realities, creating friction where personal experience meets institutional recognition. In Wales, this misalignment is acute when diagnostic thresholds exclude those whose needs are genuine but not institutionally legible. Governance tools such as eligibility checklists, standardised forms, panel reviews, act as bureaucratic filters, narrowing thresholds through administrative

oversight. The ND pathway's pre-assessment checklists, for example, aim to ensure only the most clear-cut cases are evaluated. Such measures enhance procedural consistency but also entrench reliance on diagnostic labels as the *sine qua non* of support, rendering autism visible to institutions only through a classificatory infrastructure that institutionalises rationing.

This paradox of expansion under scarcity was evident across the empirical themes of this study. Participants described how broadened diagnostic criteria and heightened awareness increased referrals, only to be met by limited service capacity, a pattern not unique to Wales. In the United States, for example, Chiri et al. (2022) report a similar paradox, with symbolic recognition expanding faster than service capacity, as resources are channelled into research and surveillance rather than direct provision. In both contexts, the expansion of classificatory visibility is tempered by the contraction of material response. The response was not expansion, but triage – tightening thresholds and slowing access. Diagnostic regimes thus serve not only classificatory functions but also as instruments of biopolitical rationing, distributing scarce resources through evidentiary burdens, formal eligibility and procedural delay. Such infrastructures often displace the logic of care with a logic of choice, substituting relational practices with procedural gatekeeping. This tension was echoed by the clinical lead of the ND pathway in Cwm, who noted that while a minority of children clearly require a diagnosis to access specialised provision, a much larger group are referred on the basis that "unless you get a diagnosis, you don't get help", even though many receive support without a formal label. In practice, categories become compulsory currencies of eligibility, undermining needs-led provision and embedding care within bureaucratic thresholds.

While diagnostic regimes offer an institutional language for recognising neurodevelopmental differences, they often conflict with the relational and situated demands of care, as families and professionals encounter needs that do not map cleanly onto standardised categories or eligibility thresholds. The ND pathway formalises diagnosis through standardised assessments and evidentiary requirements, including the demonstration of functional impairment across multiple settings: a stipulation consistent with DSM-5's requirement that autism symptoms show "pervasiveness". Yet many children's difficulties are episodic, masked in certain environments or poorly captured by school reports. This creates a tension between the procedural rationality of the system and the lived complexity of care, producing diagnostic latency, where the absence of a label delays both recognition and intervention.

These tensions are compounded by institutional pressures to manage risk, perform accountability and control system flow. As Timmermans and Buchbinder (2013) argue, efforts to manage uncertainty through standardisation often produce "patients-in-waiting": individuals whose clinical status is unresolved and whose care is suspended within bureaucratic processes. This figure is echoed in participants' descriptions of children "waiting for a diagnosis", navigating the Welsh ND pathway, where delays and diagnostic ambiguity leave families in limbo – neither eligible for services nor fully excluded. Rather than resolving uncertainty, the diagnostic regime defers it, converting it into wait times, referral loops or demands for further evidence. In this sense, diagnosis functions less as an instrument of closure than as a mechanism of deferral and filtration. What disappears in this process is the responsiveness that care requires – what Mol (2008) describes as ongoing attunement and adjustment. In a system oriented toward procedural justice and rationed access, such flexibility gives way to the demands of standardisation, documentation and categorical fit.

A striking feature of this study was the resourcefulness of families and frontline professionals in navigating ambiguities and delays. Interviewees, including support officers and third-sector representatives, some of whom were themselves parents, described how families often undertook advocacy and evidentiary labour to make their children legible to overstretched systems. These collective efforts reflect the mobilisation of community knowledge, lay expertise and peer support to secure care. This resonates with Eyal et al.'s (2014) notion of biosocial

productivity, in which the experience of diagnostic uncertainty or delay catalyses new forms of social collaboration. In Wales, participants cited parent-led networks as examples of how families mobilise biological citizenship (Rose, 2007), claiming rights and resources through affiliation with diagnostic categories and advocacy discourses.

One expression of these dynamics involved commissioning private assessments to bypass public wait times. While promising faster diagnosis, these often occupied an ambiguous status: accepted by some actors, questioned by others. Institutional recognition, rather than clinical opinion alone, determined whether a diagnosis translated into support. This reflects what Eyal et al. (2010) describe as the distributed nature of classificatory authority within contemporary regimes. Although the state no longer holds a monopoly over diagnostic expertise, it retains gatekeeping power through administrative triage. In this context, private diagnosis becomes provisional capital: it may strengthen a referral case or accelerate recognition, but its efficacy depends on alignment with public protocols. These dynamics reveal how diagnostic practices risk being treated as consumer transactions – purchasable solutions that obscure their dependence on institutional infrastructures of validation and care. At the same time, private diagnosis operates within a secondary “moral economy”, where the legitimacy is judged not only by content but by provenance – a process that risks reinforcing social inequality by privileging those who can afford to navigate both markets and bureaucracies.

Such dynamics expose the asymmetries embedded in diagnostic regimes. While ostensibly neutral adjudicatory systems, they often reward those able to navigate institutional logics while marginalising those who cannot. As Chiri et al. (2022) show for U.S. federal policy, even well-intentioned frameworks can privilege research and surveillance while leaving autistic adults and caregivers “deserving but not entitled” – a comparative pattern that clarifies why diagnostic proof, rather than need, so often becomes the effective currency of support. This comparative lens highlights how the Welsh ND pathway’s emphasis on diagnostic proof over responsive care reflects a wider politics of deservingness. The labour of making autism visible is unevenly distributed and under-recognised, often falling to families who must align their experiences with institutional vocabularies of need. At the same time, such practices contribute to the elasticity of the diagnostic category itself. As more families adopt and circulate the language of autism, often under guidance from advocacy networks and professional intermediaries, the category gains institutional traction. This recursive dynamic reflects a broader shift in the ecology of diagnosis, where classificatory authority is co-produced through advocacy, institutional response and infrastructural constraint. The result is not simply a regime that classifies, but one that enlists families into its operation – extending its reach while redistributing its burdens.

The Welsh case offers a critical vantage point for understanding how classificatory regimes operate under conditions of institutional fragility. While progressive in its ambitions, integrated pathways and statutory rights have struggled to deliver a coherent system of autism diagnosis and support. Rather than resolving diagnostic fragmentation, the ND pathway has reassembled it within a new bureaucratic architecture, codifying eligibility while amplifying strain. This contradiction illustrates what Eyal et al. (2010) describe as a “network of expertise”: a dispersed field in which clinicians, educators, parents and policymakers interact with categories that are simultaneously expansive and contested. Within such networks, categories like autism are not only sites of medical authority but objects of negotiation, struggle and adaptation.

This negotiation is especially pronounced in contexts of devolution. Since 1999, Wales has held devolved powers over health and education, enabling policies that diverge from those in England. This autonomy has fostered innovation, such as integrated neurodevelopmental pathways, but limited resources, workforce shortages and administrative scale have constrained their delivery. Wales therefore occupies a distinctive position in the UK landscape: despite pioneering the first national autism strategy, the implementation of diagnostic reform has been uneven,

shaped by geographical disparities and path-dependent legacies in education and health (Duggan et al., 2023). These constraints give classificatory systems a compensatory function: in the absence of universally available care, diagnosis becomes a means of prioritising cases, managing demand and signalling institutional responsibility. As such, diagnostic regimes in Wales exemplify what Rose (2007) describes as a form of biological citizenship, where individuals are enjoined to make themselves visible to the state through medical categories in order to secure recognition and resources.

Yet visibility through classification is not synonymous with care. The Welsh experience reveals the limits of systems that rely on diagnosis as a proxy for need. While the ND pathway has introduced consistency and formalisation, it has also entrenched a logic in which support is conditional on diagnostic confirmation. This tension between aspirations for inclusive, needs-led provision and the realities of bureaucratically managed diagnosis points to a broader challenge for autism governance. As this paper has argued, classificatory regimes are not inert structures but dynamic infrastructures of inclusion and exclusion. They mediate access, shape subjectivities and redistribute responsibility. In doing so, they reveal the stakes of diagnosis not only as a clinical act but as a political and ethical process, one that requires critical scrutiny as health and education systems confront rising demand with limited capacity.

This study has several limitations. First, it does not include direct interviews with parents or autistic individuals, meaning the analysis is based primarily on the perspectives of frontline professionals and third-sector practitioners. Although some participants occupied dual roles as both practitioners and parents, the findings reflect institutional and professional interpretations, which may not fully capture families’ own experiences or forms of knowledge. Second, the study focuses on a single health board serving a cluster of socioeconomically deprived boroughs in South Wales, which limits generalisability. However, national reports (Holtom & Lloyd-Jones, 2022; Senedd Commission, 2024) suggest that long diagnostic wait times and service bottlenecks persist across Wales, not only in disadvantaged areas. Moreover, the governance structures analysed here, such as eligibility protocols, assessment thresholds and the ND pathway, are embedded within a nationally coordinated policy framework. This suggests that the mechanisms of governance-driven medicalisation identified here likely extend beyond the immediate setting. While resource constraints and institutional pressures may be intensified in deprived regions, the standardisation of diagnostic practices under the ND pathway structures autism diagnosis across the nation. Future research might explore how these dynamics play out across different health boards and demographic contexts, refining our understanding of how local variation interacts with national frameworks in shaping diagnostic regimes.

In sum, autism diagnosis in Wales is less an endpoint than a mode of governance. It operates through infrastructures of classification that mediate deservingness, redistribute responsibility, and redefine what care can be under constraint. This analysis extends medicalisation theory by showing how diagnostic regimes work not only to expand or contract access, but to manage scarcity through bureaucratic routines and evidentiary thresholds. By tracing these dynamics, the paper foregrounds the political and ethical stakes of diagnosis in contemporary public systems.

Declaration of competing interest

None to declare.

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