BRIDGING THE RECOGNITION GAP:

A Neurodisability Framework to promote access to support for Learning Disability, Neurodevelopmental Conditions, and other Neurological Disabilities.

A discussion paper presenting a practical proposal for health, education, and social care.

SEPTEMBER 2026



THE ENABLEMENT HUB
NEURODISABILITY SUPPORT: ENABLED

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This paper is intended as a discussion document to support debate, testing, and co-production with people with lived experience, families, practitioners, commissioners, and system leaders.

ABOUT THE ENABLEMENT HUB:

The Enablement Hub works with partners across health, social care, and education to improve the lives of people with support needs connected with neurological disabilities. We provide expert consultancy, training, and intensive support.

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EXECUTIVE SUMMARY:

People with learning disabilities continue to experience poorer access to services, worse health outcomes, and shorter lives. Despite years of policy attention, reviews, inquiries, and learning after deaths or serious concerns, the same pattern persists: needs are recognised too late, specialist support is often unavailable, families end up coordinating care, and support often arrives only at crisis point.

Alongside increasing rates of neurodevelopmental diagnosis and the growing policy alignment of learning disability with autism, questions have emerged about the breadth of diagnostic categories and the pressures these place on public systems. Here we propose an alternative to this debate by using a neurodisability framework to identify functional need, as an alternative to diagnosis-led support.

- **Core argument:** Systems have invested heavily in equitable access, but the term "learning disability" is still widely misunderstood and the specialist support needed to make equity real is often not recognised. It is regularly confused with "learning difficulty", educational underachievement, or broader neurodivergence. Recently progress has been made to reduce associating learning disability with mental health services, which is welcome, but it also risks leaving some people with less leverage when advocating for the support they need. As a result, some people with complex lifelong needs become less visible to health, care, and education systems.

- **Public system challenge:** rising demand for autism, ADHD, SEND, disability-related benefits, and neurodevelopmental assessment is increasing pressure across education, health, social care, and welfare systems. This paper suggests that diagnosis alone is not a sufficient basis for organising publicly funded support. Systems need a fair and transparent way to distinguish recognition and reasonable adjustments from targeted and specialist support for people with the greatest functional impact, complexity, coordination need, and risk.

- **Definition:** in this paper, a neurodisability framework means organising pathways, commissioning, and workforce around long-term functional need linked to neurology and neurodevelopment, rather than around one diagnosis. The vision is to develop systems that are responsive and effective for largely predictable needs, rather than waiting until people reach crisis.

- **Why this matters to system leaders:** it offers a practical way to align governance, commissioning, and escalation routes around life course need, reducing avoidable harm and high-cost demand while improving access.

- **Critical gap:** learning disability pathways are unclear beyond early childhood and there are no consistent diagnostic pathways. Families may receive time-limited labels, such as global developmental delay, without further follow up. Many are pushed towards autism or ADHD routes because these appear to be the recognised gateway. Yet the breadth of these diagnoses is further challenging recognition of need.

- **Proposal:** use a neurodisability framework as the organising principle for pathways, commissioning, and workforce planning. Use language that services and the public understand more easily, while protecting learning disability and neurodivergent identity and rights.

- **Operational model:** the neurodisability framework can be applied by assessing three interacting elements: breadth of functional impact across life domains, impact upon independence, and coordination/risk. Together, these can provide a shared basis for deciding whether the response should be universal, targeted, or specialist.

- **What this is not:** it is not about relabelling people, weakening rights, or medicalising difference. It is about creating a clearer and more accountable system.

- **What would change:** people and their families would have clearer pathways to access support. Services would recognise complexity earlier, take clearer responsibility for coordination, reduce repeated reassessment and handoffs between children's and adult systems, and intervene before crisis points.

- **Current debate:** recent debate about autism and neurodevelopmental diagnosis often focuses on whether diagnostic categories have become too broad. This paper argues that the deeper system issue is that diagnosis alone does not tell services enough about functional impact, support intensity, coordination need, or risk. A neurodisability framework offers a needs-led way to retain the value of diagnosis and identity while organising support more fairly and transparently.

THE NEURODISABILITY FRAMEWORK AT A GLANCE:

MOVING FROM DIAGNOSIS-LED SYSTEMS TO NEEDS-LED SUPPORT

1 Recognition:

- **Diagnosis**
- **Identity**
- **Rights**
- **Reasonable Adjustments**

Examples:

- Learning Disability
- Autism
- ADHD
- Cerebral Palsy
- Acquired Brain Injury
- Other Neurodevelopmental & Neurological conditions

Whilst recognition matters, it is only the first step. It does not tell services what support a person requires.

2 Understanding Need:

Three factors need to guide decision-making

Breadth of Functional Impact

How many areas of life are affected?

Level of Support Need

How much support is needed for everyday life?

Coordination & Risk

How complex is coordination? What happens if support is delayed or fragmented.

3 System Response:

Universal:

- Inclusive Services.
- Reasonable Adjustments
- Accessible communication

Targeted Neurodisability Support:

- Coordinated Planning
- Multi-agency support
- Clear Pathway ownership.

Specialist /High-Level Neurodisability Support

- Specialist leadership
- Intensive Coordination.
- Proactive risk management

Outcomes

- **Earlier Recognition**
- **Clearer Pathways**
- **Better Coordination**
- **Reduced Crisis**
- **Improved Outcomes**
- **More Transparent Decisions**

CORE PRINCIPLE

Diagnosis helps with description and recognition.

The Neurodisability Framework helps identify and organise what support people may need.

DEFINITIONS (AS USED IN THIS PAPER):

This paper uses several terms that are often used interchangeably in policy and public debate. As language, recognition, and system design are central to this discussion, the definitions below are given to clarify what each term means when used in this paper, whilst respecting that there may be different views to these definitions.

Learning disability:

A lifelong condition characterised by (1) significant impairment of intellectual functioning (commonly indicated by IQ below 70), (2) significant impairment of adaptive functioning (everyday independence and social functioning), and (3) onset in childhood (before age 18). Its significance lies in the long-term effects on understanding, adaptive functioning, and support need. With the right support, people can and do develop skills and thrive, yet their learning disability is consistently present.

Learning difficulty:

A term commonly used to describe specific learning differences (for example dyslexia). It is not an intellectual disability that has a global impact on a person's life. The term is often used for learning needs that do not meet the clinical definition of learning disability.

Neurodiversity:

The concept that describes differences in how people think, learn, communicate, and process information as part of normal human variation. It is not, by itself, a diagnosis or a service eligibility category.

Neurodivergent / neurodivergence:

Umbrella terms that are often used (including by individuals and communities) to describe people whose neurocognitive functioning differs from what is considered typical. In policy contexts, it is sometimes used to refer to people with diagnosed neurodevelopmental conditions, but it is not consistently defined and may be used with or without reference to disability or support needs.

Neurodevelopmental conditions:

Conditions that arise from differences in brain development and typically present in early life (for example autism, ADHD, developmental language disorder, tic disorders, and intellectual disability/learning disability). Individuals may have single or multiple conditions. Support needs can vary widely and change over time.

Neurodisability:

A lifelong disability associated with neurological and/or neurodevelopmental differences that results in functional support needs across multiple life domains (health, education, daily living, participation, and safety). In this paper, the term is used as a service-organising concept, not as a replacement identity label.

Complexity / most complex needs:

In this paper, complexity describes the interaction between functional impact across life domains, impact on independence, coordination requirements, family or system burden, and risk. A person may be "most complex" because their needs cut across several systems, change over time, require specialist interpretation, or carry significant risk if support is delayed or fragmented.

INTRODUCTION:

There are around 1.5 million people in England who have a learning disability, approximately 2% of the population (Mencap, n.d.). The term "learning disability" is used to describe a very broad range of people with varying strengths and different levels of need and disability. Diagnoses do not describe these differences.

It is often said that the term "learning disabilities" is not understood, which also contributes to the needs of people with learning disabilities not being understood. This paper explores why that recognition gap persists and proposes a neurodisability framework to better align lifelong need with the support people require.

Despite years of policy attention, legal protections, and workforce initiatives, people with learning disabilities continue to experience poorer access to services, worse health outcomes, and much shorter life expectancy than the general population (LeDeR, 2026). These inequalities persist in a context of growing pressure across health, social care, and education, and alongside reductions in some specialist learning disability services and in specialist professions, including the learning disability nursing workforce.

The primary focus of policy attention has been on rights-based approaches, reasonable adjustments, accessible information, and procedural inclusion. These are essential factors in learning disability support. They have strengthened self-advocacy and legal protection. But they do not, on their own, create the proactive, specialist, and coordinated support needed by people whose needs are lifelong, complex, and difficult to advocate for without support. When access measures are treated as the whole answer, responsibility can drift between services. Families can then be left to hold risk until crisis forces recognition.

> ***If you're in a wheelchair then people can see your disability and know how to help you. When it's a hidden disability like learning disabilities can be, then that can make it hard to get the right support as people don't understand.***

Person with lived experience, reflecting on their experience of accessing support.

FRAMING THE CURRENT DEBATE: DIAGNOSIS IS NOT ENOUGH

Recent public debate about autism diagnosis often focuses on whether the diagnostic category has become too broad, whether assessment thresholds are right, and whether the growing numbers of people seeking recognition can be sustained by existing services. These are important questions, but they can also lead systems into an unhelpful argument about where the boundary of a diagnosis should sit.

This paper takes a different position. The central issue is not whether autism, ADHD, learning disability, or other neurodevelopmental labels are too broad. The deeper problem is that diagnosis alone does not tell systems what they most need to know: what support a person requires, how wide-ranging their functional needs are, how this impacts on independence, who should coordinate that support, and what risk may arise if support is delayed or fragmented.

Diagnostic labels can be valuable. They can help people understand themselves, provide access to rights and reasonable adjustments, help connect with communities, and receive diagnosis-specific support. Diagnoses should not be dismissed or weakened. However, two people with the same diagnosis may need very different types and levels of support. Equally, a person without a clear diagnosis may have substantial needs across communication, learning, daily living, health, participation, safety, or family life. A different approach is therefore needed to identify who needs support, and what support they need.

This is why a needs-led framework is required alongside diagnostic recognition. A neurodisability framework offers a way to separate three questions that are often treated as one:

- Does the person have a recognised diagnosis, identity, difference, or long-term condition?
- What is the functional impact across everyday life, health, learning, communication, participation, safety, and family life?
- What level of response is proportionate: universal inclusion and reasonable adjustments, targeted support, or specialist/high-support input?

> **Most people don't even know what a learning disability is.**
>
> *Person with lived experience, discussing the misunderstanding of the term 'Learning Disability'*

ORIGINS OF THE RECOGNITION GAP:

The term "learning disability" came into use in the 1990s to replace "mental handicap", a term that had become widely regarded as offensive. This change was necessary, but over time the link between this term and the current terminology has faded. As a result, "learning disability" is now often confused with "learning difficulty" and used to describe educational underachievement or specific learning needs such as dyslexia, rather than a lifelong intellectual and adaptive disability.

This confusion affects whether people's needs are recognised as lifelong, complex, and requiring coordinated support. Professor Sara Ryan's distinction between "the wise" (those with lived experience) and "the collective" (the wider population) captures this recognition gap well (Ryan, 2025). Families and people with lived experience often describe the same frustration: no matter how clearly they explain what is happening, others do not seem to understand. They are left repeating their story, fighting for support, and trying to coordinate care across a fragmented system that does not properly recognise them.

Additionally, in England, policy positions from public bodies like NHS England have paired the needs of people with learning disabilities with the needs of autistic people. Yet there are significant differences in the lives and needs of

people with learning disabilities and autistic people who do not have learning disabilities.

The growth in co-production with lived experience has been warmly welcomed and is long overdue. However, the lived experience typically used to shape policy is often that of people who can participate in formal engagement processes, usually autistic people without learning disabilities and people with mild or moderate learning disabilities. This generally includes people who can communicate verbally and live with greater independence. The experiences of people with severe and profound learning disabilities may therefore be less visible, resulting in those who need support most being heard least.

Growing awareness of neurodiversity, autism, and ADHD has created clearer routes for some people to seek recognition and adjustments. However, it has also contributed to a perception that these labels are now the most visible route to support, while learning disability itself has become less visible as a diagnostic and service pathway.

Another cultural shift is the distancing of learning disability from mental health. Historically, learning disability and mental health services have often been positioned alongside each other, but this alignment is weakening.

Specialist secure learning disability hospitals have significantly reduced, and current Mental Health Act reforms are clarifying that a person should not be detained under the Mental Health Act on the basis of learning disability or autism alone.

This is welcome, but it raises a strategic question: where should specialist learning disability support sit within contemporary health, care, and education systems?

> ***I find that when I go to hospital they don't really understand what learning disability is. It would be nice if they [health and social care professionals] took more time to listen.***
>
> ***Person with lived experience, reflecting on their experience when accessing healthcare***

OUR PROPOSITION:

If diagnosis alone is insufficient, systems need an alternative organising principle. We propose that a neurodisability framework may provide that organising structure required because it starts with functional need rather than diagnostic category.

One in six people in the UK are living with a neurological condition (Neurological Alliance, 2022). This includes people with learning disabilities. A learning disability is typically the result of neurodevelopmental or neurological differences that affect cognition, communication, physical health, emotional wellbeing, daily living, education, and social participation.

The link between neurology and learning disability can be seen when reviewing the incidence of epilepsy, which affects around one in three people with learning disabilities. That incidence increases with severity of learning disability, and for people with severe learning disabilities the incidence of epilepsy is 50% (NHS England, 2023).

> *They [Health and Social Care] need more experience and training. If more people had the right experience and understanding, then I would receive the support I really need.*
>
> *Person with lived experience, reflecting on accessing support*

This paper proposes that learning disability support should be better aligned with neurodevelopmental and neurological pathways, while retaining its social, rights-based, educational, and community foundations.

Specialist support for people with learning disabilities could sit within a wider neurodisability umbrella where this helps systems recognise and respond to complex lifelong need.

This framing would support clearer articulation and response to the complex needs of people with learning disabilities, alongside people with other neurological disabilities that are not a learning disability.

This framing should not take anything away from the identities of people with learning disabilities or autistic people who rely on these identities for recognition, adjustments, and rights.

The framework is therefore proposed as a way to help publicly funded systems make fair and transparent decisions about the intensity of support required. Universal inclusion and reasonable adjustments should be widely available. Targeted and specialist support should be matched to functional impact, complexity, coordination need, and risk.

- We propose a neurodisability framework as a practical organising principle for systems. Its purpose is to help services recognise complex lifelong need earlier, understand when reasonable adjustments are not enough, and bring access to specialist support before crisis.

- The framework would organise pathways, commissioning, and workforce planning around three interacting questions: how many life domains are affected, how this affects independence, and what level of coordination or risk is present. These questions provide a shared basis for deciding when support should be universal, targeted, or specialist.

- This paper invites leaders in health, commissioning, education, local authorities, providers, and workforce to test whether this framing could improve recognition, reduce the burden on families, strengthen pathway ownership across the life course, and prevent avoidable harm and costly escalation.

DEFINING A NEURODISABILITY FRAMEWORK

A widely used UK consensus definition, developed through a Delphi survey with health professionals and parents, describes neurodisability as:

> a group of congenital or acquired long-term conditions that are attributed to impairment of the brain and/or neuromuscular system and create functional limitations. A specific diagnosis may not be identified. Conditions may vary over time, occur alone or in combination, and include a broad range of severity and complexity. The impact may include difficulties with movement, cognition, hearing and vision, communication, emotion, and behaviour.
> (Morris et al., 2013)

This definition is useful for system design because it starts with long-term functional impact rather than a single label, includes both congenital and acquired conditions, and does not require a firm diagnosis before support is justified. This definition fits learning disability well, while also extending its reach beyond IQ thresholds and childhood onset.

NEURODISABILITY IS NOT A NEW TERM:

In the UK, “neurodisability” is already used to organise services. The General Medical Council–approved Royal College of Paediatrics and Child Health “neurodisability syllabus” recognises it as a subspecialty based on long-term functional impact and complex co-occurring need, and this includes learning disability practice within a wider neurodisability field (RCPCH, 2023).

In practice, there are existing paediatric neurodisability services that already provide long-term, coordinated support for children with complex and often lifelong needs, including cerebral palsy, learning disability, and acquired brain injury (RCPCH, n.d.; NHS England, 2013).

In existing neurodisability services, the following can be seen:

- A function-first orientation: needs are framed across communication, cognition, mobility, health complexity, behaviour, participation, and safeguarding. This is in contrast to relying on a single diagnosis.

- Recognition that conditions and needs can co-occur, for example epilepsy, sensory needs, mental health, feeding, sleep, and pain, and care must be coordinated rather than “handed off” between siloed pathways.

- A multidisciplinary approach, combining medical, therapies, nursing, and educational perspectives and integrating family knowledge into planning.

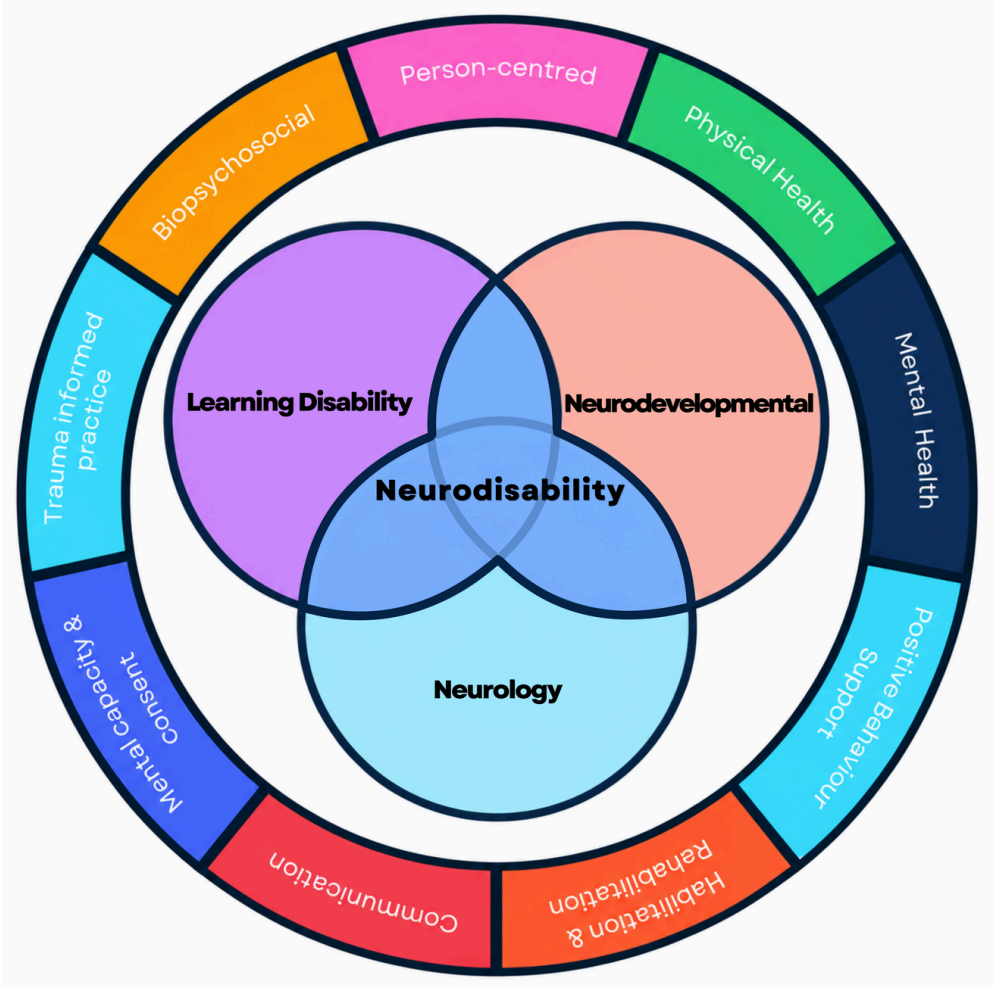
- Use of shared care models: specialist expertise supports local teams, rather than replacing them, building capability and reducing repeated reassessment cycles.

- A strong emphasis on developmental trajectories and the predictable pressure points of transition, ensuring consistency of support across the lifespan.

THE PROPOSED NEURODISABILITY FRAMEWORK:

In practice, the framework organises pathways, commissioning, and workforce around long-term functional needs linked to neurology and neurodevelopment. Its purpose is to keep complex lifelong needs visible across health, social care, education, and wider system design.

It considers where learning disability, neurodiversity, and neurology practice overlap, and where shared interventions and philosophies already exist.



A model for understanding neurodisability practice.

This framework may be useful in providing practical support to system leaders in three practical ways. First, it could support the design of pathways around life stages and function, from early years to adulthood, rather than around service

settings alone. Second, it could enable specialist neurodisability expertise to be commissioned into mainstream services through consultation, shared care, training, and proactive planning. Third, it could support the development of regional needs-led escalation models, with agreed triggers, ownership, and response times so that complexity is recognised before things break down.

The framework can be operationalised through three interacting elements: breadth of functional impact across life domains, impact upon independence, and coordination/risk. Together, these provide a shared decision-making basis for determining what level of response is proportionate: universal inclusion and reasonable adjustments, targeted neurodisability support, or specialist/high-support neurodisability input. This does not replace legal duties or local eligibility criteria, but it can make thresholds more consistent, transparent, and defensible.

- **Needs-led, not IQ or diagnosis-led:** IQ and diagnoses remain relevant clinically, but the framework is triggered by functional need, risk, and coordination complexity, instead of a single score threshold.

- **Prevents threshold gaps:** the framework helps identify people with mild learning disabilities, co-occurring needs, or significant functional difficulties who may otherwise fall between learning disability, mental health, education, and social care pathways. Support is triggered by functional impact, coordination need, and risk, not by whether someone meets a single diagnostic threshold.

- **Identity protected:** the framework is about system architecture, not relabelling individuals or weakening rights.

- **Broad enough to include other neurological disabilities:** the framework explicitly includes conditions such as cerebral palsy and acquired brain injury, where an intellectual disability diagnosis threshold may not be met. It has scope to include other neurological conditions across the lifespan, such as Parkinson's disease and stroke, where these are resulting in disability and limitations to independence. It recognises that needs may be physical, cognitive, communicative, behavioural, sensory, or mixed.

- **Narrow enough to be useful:** some people with learning disabilities live independently with minimal specialist input. This is particularly relevant for people with mild learning disabilities. The framework does not assume specialist services are always required; it ensures that when complexity, risk, or coordination needs arise, the system recognises and responds earlier and more consistently. The same applies to those who have other neurodevelopmental diagnoses or identify as neurodivergent.

> ***I like the inclusion that the neurodisability model gives. I have communication problems. People don't understand me and what I mean, so I get upset. I think this framework would help me to be recognised.***
>
> *Person with lived experience, discussing the potential benefits of the framework.*

VISUALISING THE FRAMEWORK:



Breadth, independence and risk indicators together determine the level of support and coordination required.

The framework can be described in practical terms by starting with the person's lived experience, strengths, and support needs, then considering functional impact across life domains. The domains themselves may benefit from further consultation and debate, but eight domains have been presented here to support conceptualisation:

- **Communication**
- **Cognitive and learning**
- **Daily living and independence**
- **Physical and health needs**
- **Behaviour and emotional regulation**
- **Sensory processing**
- **Participation and social inclusion**
- **Safety and vulnerability**

Tier	Who it includes (illustrative):	What the system should do:	Basis for prioritisation:
Universal	People with disabilities or long-term conditions using mainstream services, including people with learning disabilities who do not usually require specialist pathways.	Consistent reasonable adjustments, accessible communication, and discrimination-free services; plus reliable recognition of when functional impact extends across multiple domains and requires escalation beyond reasonable adjustments.	Recognition of difference, diagnosis, disability, or long-term condition; need for accessible mainstream services and reasonable adjustments.
Targeted neurodisability support	People with significant functional impact across two or more life domains, whether congenital or acquired. This includes, but is not limited to, many people with learning disabilities, autism, ADHD, cerebral palsy, acquired brain injury, complex epilepsy, and combinations of neurodevelopmental conditions with high support needs.	A coordinated pathway with clear ownership, multidisciplinary capability, proactive care planning, and needs-led access to support (with diagnosis where it adds value). Typically includes coordinated, multi-agency support.	Functional impact across two or more domains, significant support need, and need for coordinated planning.
Specialist / high-support neurodisability	People with widespread functional impact that impacts independence across multiple life domains, combined with high coordination needs and elevated risk. This includes, for example, profound and multiple learning disabilities (PMLD), significant learning disability with complex health needs, repeated placement breakdown, acute admissions, high-risk transitions, or safeguarding concerns.	Specialist leadership, intensive coordination, and proactive risk management across settings (health, social care, education), reducing avoidable crisis and harm.	Widespread functional impact, high coordination need, elevated risk, repeated crisis, safeguarding concern, placement instability, or need for specialist interpretation and leadership.

The functional impact across these domains can be reviewed to identify what a person's support needs are and how they impact upon the person's independence.

The tiers above describe levels of system response, not a fixed categorisation of people. Utilisation of the tiers is shaped by breadth of impact, impact upon independence, and coordination/risk. This makes complexity visible through observable support needs, not diagnosis alone.

The model does not replace local eligibility criteria, but it can support more consistent thresholds and clearer escalation. A person may need support from more than one tier at the same time, and the aim is to recognise complexity earlier, before crisis defines need.

> **I have always wondered why they don't make a clearer path for support services. I began in children's services and then I was pushed into adult services where people had to assess my needs again. A framework that focuses on independence might help improve that.**

Person with lived experience, reflecting on accessing support throughout their life.

CHILDREN LOST IN THE SYSTEM

Misunderstanding of needs begins in childhood. In education, learning disability and other neurological disabilities may not be recognised in early years and there is inconsistency in how they are identified. Support is often tied to labels and thresholds, and families can face adversarial processes to have needs recognised and support agreed.

The SEND (Special Educational Needs and Disabilities) system remains under heavy strain. Children and young people with neurodevelopmental needs are often expected to fit into mainstream provision that is neither designed nor resourced to meet them. The education system is expected to meet its educational purpose, whilst supporting young people with complex biopsychosocial needs. Early help can depend on statutory processes, with Education, Health and Care Plans (EHCPs) serving as rationing tools in an overstretched system.

Rising EHCP numbers, increasing tribunal activity, and local authority overspends all point to structural failure. The Department for Education's 2026 white paper, Every child achieving and thriving, sets out reforms intended to move towards earlier intervention, tiered support, and stronger mainstream capability (DfE, 2026).

Those reforms are necessary, but they will work best if they are grounded in a life-course understanding of learning disability as a neurological long-term population need, not only as an education pressure. Too often, learning disability is held as an education issue in childhood and a social care issue in adulthood, without a stable life-course framework for people whose needs remain clinically and functionally complex. A neurodisability framework could help connect early years identification and SEND support to adult health and care pathways, enabling each transition to be better aligned.



The white paper's focus on tiered, needs-led support for children and young people with the "most complex needs" is an important opportunity. However, "most complex" cannot be left as an intuitive or crisis-defined category. If systems do not define complexity transparently, children may be prioritised only after exclusion, placement breakdown, family exhaustion, safeguarding escalation, or acute crisis. A neurodisability framework could provide a clearer basis for identifying complexity earlier, using functional impact across life domains, impact on independence, coordination complexity, and risk as gateways for targeted or specialist support.

This argument is strengthened by recent population-level evidence. Cant et al. (2026) used linked education and hospital data from England to compare educational attainment among more than 2.3 million children, including children with hospital-recorded neurodisability before starting Reception. The study found that around 2.2% of children had a recorded neurodisability before school entry; that fewer than half met expected levels in Maths and English at each national assessment point; and that by age 10/11, 31% of children with neurodisability were not participating in national assessments despite being enrolled in school. This reinforces the need for education, health, and care systems to use functional progress and support need, not standard attainment alone, as the basis for planning and accountability.

The alignment with this paper is important. The findings do not simply show lower attainment; they show that a recognisable population of children with neurodisability is already visible in health data before school, experiences multi-year educational disadvantage, and may fall outside the usefulness of standard educational assessment. This supports the proposition that neurodisability should be treated as a shared health, education, and care concern across the life course, rather than as a problem held by schools alone.

There is also a significant gap for children and young people whose needs are substantial but who do not meet learning disability criteria and do not have a mental health diagnosis that would bring them into CAMHS remit. In many areas, these children can fall between education, neurodevelopmental, mental health, and social care thresholds. Their needs may be recognised by families and schools, but without a clear diagnostic or pathway "home", support can remain fragmented, delayed, or unavailable until crisis whilst they fall through recognition gaps.

SHIFTING FOCUS

The Learning Disabilities Mortality Review (LeDeR) continues to show that people with learning disabilities die too young from causes often described as "preventable" or "avoidable". Whilst these terms matter in public health, they can soften the reality of what is happening. They can make repeated failures in community support, recognition, assessment, treatment, and follow-up sound more distant than they are. They can make negligent acts or omissions that result in death sound like "one of those things" rather than lives being unnecessarily lost.

The focus is often directed towards what happens at the point of acute care, such as hospital passports, flagging systems, reasonable adjustments, and staff training. This only addresses the final point of failure. It does not address the missed opportunities before the person was admitted to acute care. It is akin to giving a smoker cough syrup to address deaths by smoking. Reasonable adjustments cannot compensate for poor recognition of learning disability, limited community support, weak clinical ownership, or a lack of professionals with the right skills and confidence to respond to complex need.

LeDeR also repeatedly identifies diagnostic overshadowing, missed deterioration, poor management of long-term conditions, and unclear clinical ownership. These systemic errors cannot be addressed by accessible approaches or awareness training alone. Failing to look beyond this creates the risk of minimising the complexity of these situations and the need for specialist input.

A neurodisability framework would shift attention upstream: towards earlier recognition of complexity, clearer accountability across pathways, better community support, and specialist capability before crisis. It also helps clarify that learning disability is a lifelong neurodevelopmental and functional support need.

INCREASED NEURODIVERGENCE AWARENESS

Many parents of children currently in the education system have never known older terms used for learning disability, such as “mental handicap”. So the term “learning disability” itself is unclear for them and is easily confused with learning difficulty. Some children receive an early diagnosis of global developmental delay, which should only be used until around age five, but then have no obvious route into learning disability pathways. There are no consistent, visible diagnostic pathways for learning disability across childhood and adulthood. At the same time there has been a rise in awareness of autism and ADHD.

Families can understandably conclude that autism or ADHD are the best routes to support. They appear to carry clearer clinical pathways, service recognition, and legitimacy than learning disability itself. Increased public and media attention on autism and ADHD has also made these labels more visible and more readily understood than learning disability. These identities are often perceived to receive better responses from services, networks, and communities. That dynamic adds to waiting lists and delays recognition of learning disability as the primary need.

Neurodivergence is not a diagnosis; it is broad social language for different ways of thinking, learning, communicating, and processing information. In this paper, neurodisability refers more specifically to disability-linked functional impact and support need.

Put simply:

Neurodivergence describes difference.

Neurodisability describes disability-related support need.

A neurodisability framework recognises and respects increased awareness of diagnoses and identities, and supports policy direction of access to support not being dependent on diagnoses. It adds to this the personal impact of these and helps organise what support is needed.

> **Learning Disability Nurses are needed so that people with learning disabilities are listened to.**
>
> *Person with lived experience, reflecting on the importance of learning disability nurses*

THE LEARNING DISABILITY NURSING CRISIS

Registered learning disability nurses are a highly specialised workforce, with expertise in neurodevelopmental conditions, communication, behaviour, and long-term support. Yet their numbers have fallen steeply, and the training pipeline is shrinking.

This crisis reflects a wider misunderstanding of where this profession's expertise fits, and what the needs of people with learning disabilities are. Learning disability nursing does not sit neatly within hospital-centred workforce models and often spans commissioning boundaries. Without a clearer organising framework, the specialist workforce associated becomes easier for systems to overlook.

Nursing is the largest workforce in the healthcare system. A neurodisability framework could help position learning disability nursing expertise within a wider population health agenda while preserving its specialist focus.

Change could be applied at point of registration, skilling these nurses to work across a broader range of neurological conditions, whilst protecting roles for

specific conditions, such as learning disability nurses. A registered nurse in neurodisabilities could work as a community learning disability nurse, or as a charge nurse on a neuro-rehab ward for example.

This moves us from seeing learning disability nursing as relevant only to the one in 50 people with a learning disability (Mencap, n.d.), to recognising its contribution to the wider 1 in 6 people living with neurological and neurodevelopmental needs (Neurological Alliance, 2022) where communication, cognition, behaviour, health inequality, and coordination are central concerns. It would strengthen the identity and purpose of the profession while maintaining its unique contribution to the lives of people with learning disabilities.

It is important to stress this suggestion is not advocating for the removal of learning disability nursing roles - they are essential. But change at the point of registration could increase the career opportunities, improve where the field of nursing is positioned, and therefore appeal to more potential nurses, which could secure the roles in learning disability nursing, where their future currently appears fragile.

> ***Less people are taking the jobs needed to help people, so maybe using a different title, like Neurodisability Nurses, would get more nurses to join.***
>
> *Person with lived experience, discussing the lack of support available.*

A neurodisability framework would make the relevance of this expertise more visible across pathways, positioning learning disability nursing as central to prevention, coordination, and long-term support rather than as a marginal specialist add-on.

PROTECTING IDENTITY WHILE MODERNISING FRAMEWORKS:

A neurodisability framework is not intended to change or broaden the identities chosen and valued by neurodivergent people or people with learning disabilities. These terms provide recognised and meaningful social identity with its own history, culture, and rights-based movements. Any system-level reframing must respect that and avoid obscuring lived experience.

The same applies to specialist workforces. Their roles should not be diluted or redefined without consent and support. The aim is coherence: keeping complex lifelong support needs visible to the systems that plan, commission, and deliver care, while preserving distinct expertise and identity.

Historically, learning disability services have been aligned with mental health services, despite learning disability not being a mental illness. As that alignment weakens, systems need a clearer way to locate specialist learning disability support. A neurodisability framework offers one route by placing lifelong cognitive, communicative, behavioural, physical, and health needs within neurodevelopmental and neurological pathways.

A neurodisability framework must not medicalise difference, weaken social models of disability, dilute specialist expertise, or sideline lived experience. Its purpose is not to rename people, but to strengthen system responsibility where needs are complex, cross-domain, and long term.

The framework must also avoid being used as a blunt rationing tool. Its purpose is not to deny support to people who do not meet a specialist threshold. Universal inclusion, anti-discrimination duties, reasonable adjustments, and early help remain essential. The purpose is to make sure that more intensive publicly funded support is allocated transparently to people whose functional impact, complexity, coordination need, or risk require it.

Co-production, transparent governance, and explicit commitments to rights and equity are essential safeguards.

CONCLUSION: BRIDGING THE RECOGNITION GAP

Persistent inequalities in outcomes for people with learning disabilities reflect problems in system design, not just isolated operational failures. When services are organised mainly around access, thresholds, and diagnostic gatekeeping, they struggle to respond to predictable lifelong need. Support then arrives late, and complexity is too often recognised only in crisis.

Reasonable adjustments remain essential, but they are not enough on their own. They must be backed by proper recognition, accountability, specialist skill, and clear pathway ownership, especially where needs are complex, lifelong, and difficult to advocate for without support.

Systems need a better way to keep complex lifelong neurodevelopmental need visible within planning, commissioning, and clinical support. A neurodisability framework offers a practical way to realign system thinking, pathway design, workforce, and investment towards prevention, coordination, and sustainability. It can help leaders connect what is currently fragmented: life-course planning, needs-led access, and specialist capability embedded within mainstream pathways.

In a context of rising neurodevelopmental recognition and public system pressure, the question is how systems can match the intensity of publicly funded support to functional impact, complexity, coordination need, and risk. A neurodisability framework offers one way to do this fairly, transparently, and without losing sight of people with learning disabilities whose needs have too often been misunderstood or minimised.

Whether the Neurodisability Framework ultimately proves to be the right model is a matter for further debate, testing and co-production. What is clear is that continuing to organise support predominantly around diagnostic labels will not, on its own, resolve the inequalities this paper describes.

> ***At the moment, people haven't got the time to listen to us [people with learning disabilities]. I think it's a good idea. This [Neurodisability Framework] would make it easier to get support.***
>
> *Person with lived experience, commenting on the proposed framework.*

WHAT LEADERS CAN DO NEXT:

The steps below are suggested starting points for local discussion. They should be shaped with people with lived experience, existing services, and the realities of local governance and delivery.

Map the crisis areas in your area using a small number of real journeys, identify where needs are repeatedly missed or rediscovered, and where earlier action could have prevented escalation.

Consider the adoption of a shared complexity model *across partner organisations. Can you use the three-part framework (life-domain impact, how this affects independence, and coordination/risk) to support earlier recognition, more consistent thresholds for response, and clearer multi-agency accountability?*

Separate recognition from prioritisation across local pathways. *Agree which support should be available universally through inclusive practice and reasonable adjustments, and which support should be triggered by functional impact, coordination need, and risk.*

Define escalation triggers and responses *using the model. Agree what combination of multi-domain functional impact, support intensity, family or provider burden, coordination need, and risk should trigger targeted or specialist support. What specialist input should follow, who is responsible, and how quickly action should happen.*

Build shared outcome measures with education partners *that go beyond attainment alone. Use the evidence from Cant et al. (2026) to test whether local systems can track functional progress, participation, communication, health, family burden, and coordination need for children whose development is not meaningfully captured by standard school assessment.*

Clarify pathway ownership *at each life stage, especially during transition. Make it clear who coordinates when needs cut across health, social care, education, and provider settings, and how responsibility changes when coordination need or risk increases.*

Define the workforce offer*, including how learning disability nurses and other specialist roles support mainstream teams. Set clear expectations for consultation, shared care, training, and proactive planning.*

Run a time-limited pilot in one pathway, *such as transition or acute escalation, and test the model in practice. Agree a small set of measures, such as family burden, time to the right support, unplanned admissions, placement stability, and whether complexity is being recognised earlier using the shared model.*

Learn from existing neurodisability models, *especially in children's services, and explore what could be adapted into adult pathways. For example, leaders could draw practical lessons from established teams such as the Tulip Neurodisability Team in Croydon. Some providers and networks are already beginning to use neurodisability framing, including PBS4 and the Neurodisability Network. What can be learned from these examples?*

Engage lived experience early, *including people with learning disabilities and others who may benefit from a neurodisability framework. Use co-production to test language, safeguards, and what good support looks like in everyday life.*

Work with current learning disability services and professionals*, especially learning disability nurses, to understand what capability already exists, what has been lost, and how specialist expertise could be embedded into mainstream pathways and escalation routes.*

Explore workforce and education partnerships *where universities and employers are testing neurodisability-aligned offers. For example, the University of Wolverhampton is exploring describing pre-registration learning disability nursing routes as "Neurodisability and Learning Disability Nursing", while Kingston and Winchester are exploring neurodisability-focused post-registration modules.*

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