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Learning Disability Service Model
For Northern Ireland

August 2025



Introduction

We welcome your views on this draft Learning Disability Service Model, which sets out how we will improve outcomes for people with a learning disability who use Health and Social Care (HSC) services in Northern Ireland.

A Learning Disability Service Model is a strategic framework that defines what good support should look like — including the values, outcomes, and service approaches that should shape how care is designed, commissioned, and delivered.

This document proposes a new approach to supporting adults with a learning disability through Health and Social Care services in Northern Ireland. It sets out the key outcomes we want to achieve, the principles that will guide delivery, and the actions needed to improve services across the system.

While the Model focuses on HSC services, it recognises the vital role of other public services. People's lives span education, housing, employment, justice and more — not defined by service boundaries.

Successful implementation will require strong leadership and coordinated action across government. This Model provides a platform for joined-up delivery, supported by a Memorandum of Understanding, shared outcomes, and participation in joint governance structures.

Implementation of the Learning Disability Service Model

Implementing the Learning Disability Service Model will be a significant, system-wide undertaking. It will be inclusive, cross-sectoral, and rooted in co-production — building on existing structures and lived experience.

Not all actions can begin at once. As part of this consultation, we are seeking your views on the proposed outcomes and actions to help inform how implementation should be phased and prioritised.

A **Learning Disability Collaborative Leadership Board**, chaired by the Department of Health, will oversee delivery, track progress, and publish annual reports. Each Trust will establish a **Local Implementation Group**, including people with lived experience and family carers, to coordinate local action and monitor impact.

A **Regional Outcomes Dashboard** will be developed to publish baseline data and track annual progress across areas such as service access, transitions, supported living, and hospital admissions.

This implementation structure provides clear accountability and reflects best practice, drawing on successful models such as NHS England's *Transforming Care* and the HSE's *National Clinical Programme*.

Successful delivery will depend on workforce development, transformational investment, and — where necessary — legislative change to enable new models of support and rebalance existing provision. These dependencies will be reviewed annually, and mitigations developed with partners across government and the independent sector.

Following this consultation, and after the Model is finalised, a detailed costings exercise will be undertaken to ensure the delivery plan is robust, prioritised, and financially realistic. This will include an assessment of current spend, the level of investment required to deliver new priorities, and potential savings from reduced reliance on high-cost placements.

The Delivery Plan will be kept under review and adapted in line with available resources, emerging evidence, and stakeholder feedback, ensuring that progress remains both ambitious and achievable.

Impact Screening

The proposals contained in the consultation paper have been screened for potential equality, human rights, data protection, regulatory and rural impact, and a preliminary

decision has been taken that no full impact assessments are required at this stage. The preliminary decision is subject to change following analysis of feedback received during this consultation.

How to Respond

We are seeking views on the draft Learning Disability Service Model and invite written responses by no later than 5pm Tuesday 25 November 2025.

You can respond online by accessing the Northern Ireland Government Citizen Space website and completing the online survey there. A link to the Citizen Space website can be found on the Department's consultation website: <https://www.health-ni.gov.uk/consultations/learning-disability-service-model>.

We would prefer responses using Citizen Space, however, if you wish to send an email please send it to ldsm@health-ni.gov.uk or if you want to post a hard copy of your response, please send it to: Department of Health, Learning Disability and Autism Unit, D2, Castle Buildings, Stormont, Belfast BT4 3SQ.

When you reply, it would be very useful if you could confirm whether you are replying as an individual or submitting an official response on behalf of an organisation. If you are replying on behalf of an organisation, please include:

- your name.
- the name of your organisation; and
- an e-mail address.

If you have any queries or wish to request a copy of the draft Learning Disability Service Model in an alternate format, please contact the Department by email at: ldsm@health-ni.gov.uk.

An Easy Read of the Learning Disability Model and questionnaire is available online available and can be requested at: ldsm@health-ni.gov.uk.

It was made by TILII Translates, a group of adults with a learning disability, autism and other support needs who are experts at making information easier to understand. TILII Translates is part of Telling It Like It Is (TILII), an advocacy group that supports people to speak up for themselves.

TILII is one of the lead projects within the Association for Real Change (ARC), a leading umbrella body representing the learning disability community and is a key partner for DoH in helping to deliver services in the learning disability sector. Their purpose is to improve the quality of life for people who have a learning disability, autism and other support needs.

For further information on how we will process data, and your rights, see our Privacy Notice at **Annex A** below and at the following link: <https://www.health-ni.gov.uk/publications/learning-disability-service-model-consultation-privacy-notice>

The Department will be hosting a series of regional engagement events during the consultation and details will be published on the Department's website and social media channels.

What Happens Next

Following the close of the consultation on 25 November 2025, all responses and feedback will be collated for review by the Department of Health, and a consultation summary of responses report will be produced.

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Ministerial Foreword

People with learning disabilities have the same rights as everyone else — to live with dignity, to be included in their communities, and to access the support they need to lead full and meaningful lives.

Despite progress over recent decades, people with learning disabilities in Northern Ireland still face significant inequalities across many areas of life — in health, education, housing, employment, and access to services. Too often, systems are fragmented, slow to respond, and difficult to navigate. These challenges affect not only individuals, but also families and carers, who often find themselves filling the gaps with limited support.

Since my first day as Minister of Health, I have been committed to addressing and reducing health inequalities. Tackling the deep-rooted inequities faced by people with learning disabilities is a critical part of that mission.

Over the past year, I have visited a range of Health and Social Care (HSC) services that support people with learning disabilities, and I have been consistently impressed by the dedication of staff, the determination of families, and the potential that shines through when services work well. I have seen what is possible when people are supported at the right time, by the right person, in the right place. These are the moments where we get it right — and they must become the norm, not the exception.

We cannot ignore the serious failings that have occurred in our system. The abuse of patients at Muckamore Abbey Hospital represents a profound breach of trust and has caused lasting harm to individuals, families and public confidence. A public inquiry has concluded, and its findings will be critical in shaping how we move forward — not only in ensuring accountability, but in making sure such failings can never happen again.

This document is a platform for change. It sets out a proposed Learning Disability Service Model for adults in Northern Ireland — a new vision for how HSC services can better support people with a learning disability to live the lives they choose.

A Learning Disability Service Model is a strategic framework that defines what good support should look like. It brings together the values, outcomes and approaches that should guide how care is designed, commissioned and delivered. It also signals the kind of system change required to improve people's experience of services — from improved transitions and accessible housing to more responsive mental health care and better support for carers.

Crucially, this Model was developed through genuine co-production. Over 3,600 people with lived experience, family carers, practitioners, community partners and professionals contributed to the thinking, values and content of this work. Their insights have shaped the direction of the Model and the detail of its ambitions.

At its heart, the Model focuses on six key ambitions:

1. **Life Changes** – Ensuring people receive the right support through key transitions and life stages.
2. **Health and Wellbeing** – Tackling avoidable health inequalities and improving access to care.
3. **Families and Carers** – Strengthening emotional, practical and respite support for those who care.
4. **Meaningful Lives and Citizenship** – Expanding opportunities for education, employment and community inclusion.
5. **Home** – Supporting people to live in their own homes, with the right support around them.
6. **Mental Health and Behaviours of Concern** – Delivering timely, specialist and integrated support, including alternatives to hospital admission.

These ambitions are supported by a clear set of outcomes and a three-year Delivery Plan that identifies the actions needed, who is responsible, and how progress will be measured through a Regional Outcomes Dashboard.

While this is a model for HSC services, it is not a job for the health and social care system alone. People's lives span education, housing, employment, transport, and justice — and successful delivery will require a collective effort across government.

We will formalise this through a cross-departmental Memorandum of Understanding, shared outcomes, and participation in joint governance structures.

We also recognise the scale of change required. Implementation will be phased and prioritised in partnership with service users and families. It will depend on sustained investment, workforce development, and — where appropriate — legislative reform to unlock new models of support and rebalance existing provision.

This consultation marks a key milestone. We are asking for your views on the Model's ambitions, the outcomes we want to achieve, and the practical steps needed to get there. Your feedback will directly inform the final version of the Model and how we deliver it together.

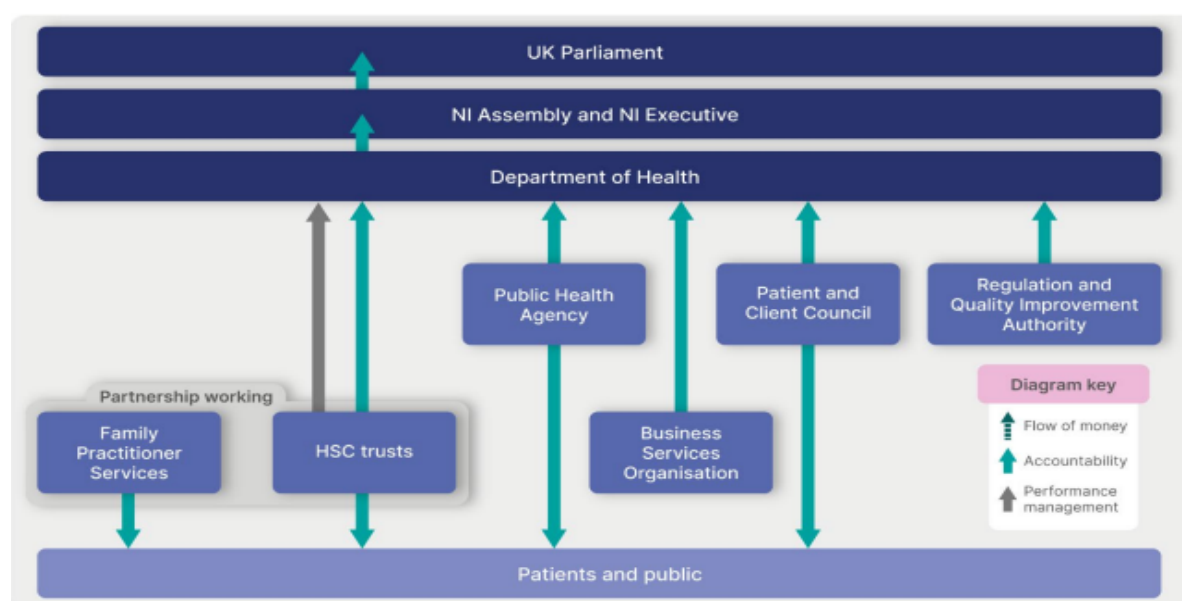
Thank you to everyone who has contributed to this work so far. The voices of people with learning disabilities and their families have been at the heart of this process — and they must remain central as we move forward.

Together, we can build a system that truly reflects what people need and value. One that says, clearly and confidently: *We Matter*.

MIKE NESBITT
Minister of Health

1.1 Background and Strategic Context

Northern Ireland Health and Social Care (HSC) services are overseen by the Department of Health, who have responsibility for policy, leadership and oversight of health, social care and public health services. The Strategic Planning and Performance Group (SPPG) was established under the Health and Social Care Act (Northern Ireland) 2022 (the 2022 Act) and has responsibility for planning; improving and overseeing the delivery services. Services are delivered by the five main HSC Trusts and the Northern Ireland Ambulance Service, both directly, and in partnership with a range of external independent sector providers. Regulatory responsibility of HSC services and settings sits with the Regulation and Quality Improvement Authority (RQIA).



Reference: HFMA introductory guide to NHS finance - Health and Social Care in Northern Ireland

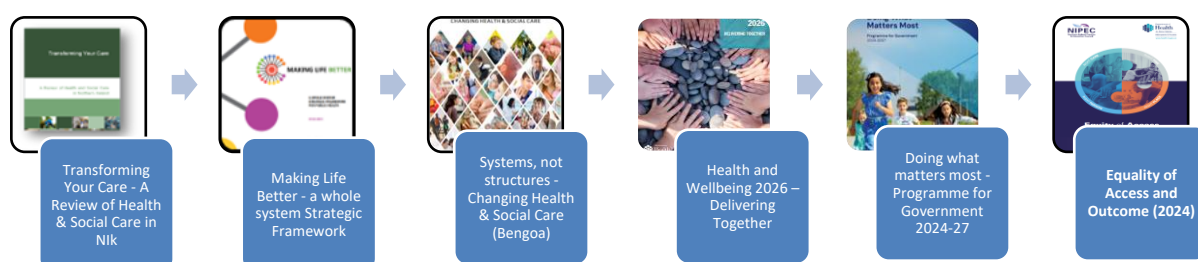
The Northern Ireland Assembly and the Department of Health (DoH) provide strategic direction for health and wellbeing in Northern Ireland through legislation, policy and strategy. In 2011 DoH published Transforming Your Care, which aimed to re-shape and optimise HSC services to ensure that they are safe, resilient and make the best use of available resources. The operationalisation of this policy is outlined in Making Life Better. This document set out a framework which aimed to improve health and

wellbeing, reduce health inequalities, and support individuals and communities to achieve their full health potential. Implementation of the framework is overseen by the Public Health Agency.

The Northern Ireland Health and Social Care Board (HSCB) was dissolved on 31 March 2022, following the passage of the Health and Social Care Act (Northern Ireland) 2022. The Board's functions were transferred to the Department of Health. This closure was part of a wider transformation agenda to streamline HSC services.

From 1 April 2022, former HSCB staff are now undertaking their functions under the direction of the Department as part of SPPG.

In addition to key policy and strategic frameworks, DoH have also commissioned a number of independent reviews to evaluate service delivery and guide service design. These include the Donaldson Report (The Right Time, The Right Place, 2014), which reviewed governance arrangements; and the Bengoa Report (Systems not Structures, 2016) which outlined recommendations for transforming health and social care focused upon sustainability and improved outcomes.



In order to translate over-arching HSC Policy in practice, there have been a number of policies and strategies which have provided strategic direction for the development of Learning Disability services. These include *People First* which was published in 1990; *Valuing People* White Paper which was published in 2001; and the *Equal Lives Report* from the Bamford Review of Learning Disability services which was published in 2005. A review of the implementation of the *Equal Lives Report* was completed in

2016. This review identified that progress had been made in a number of areas but noted that further steps were required in order to support people to live full and independent lives in the community.

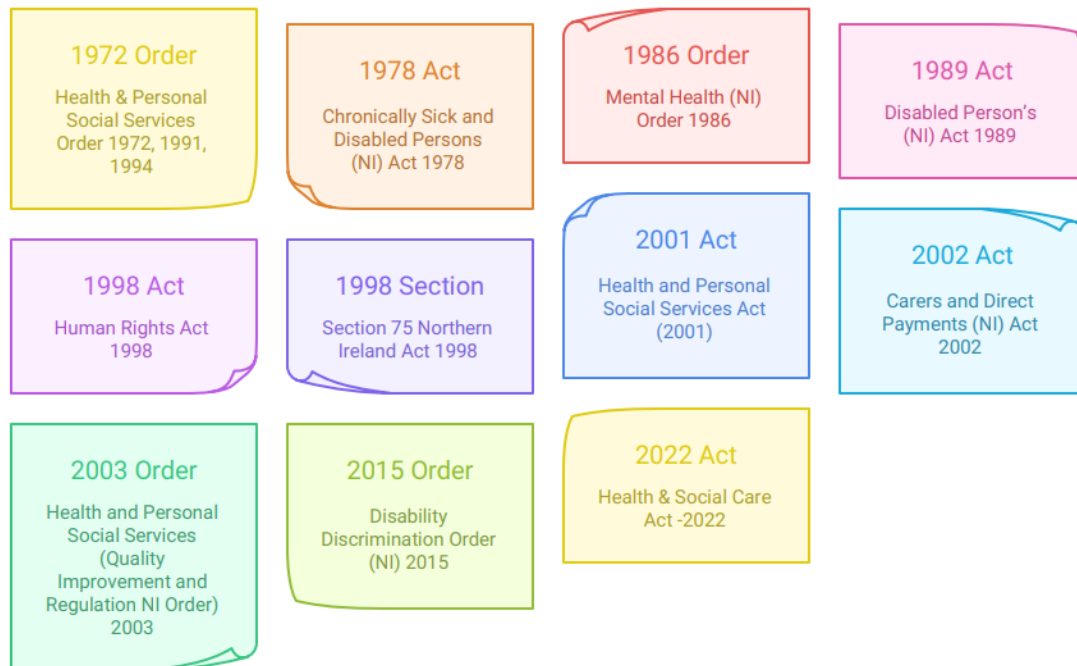
In addition to key Learning Disability strategy and reviews, there are a number of other publications which have direct relevance for people with learning disability. These include the *Mental Health Strategy 2021-2031*; the *Autism Strategy 2023-2028* and the *Autism Strategy Delivery Plan 2023-2025*.



Legislative Context

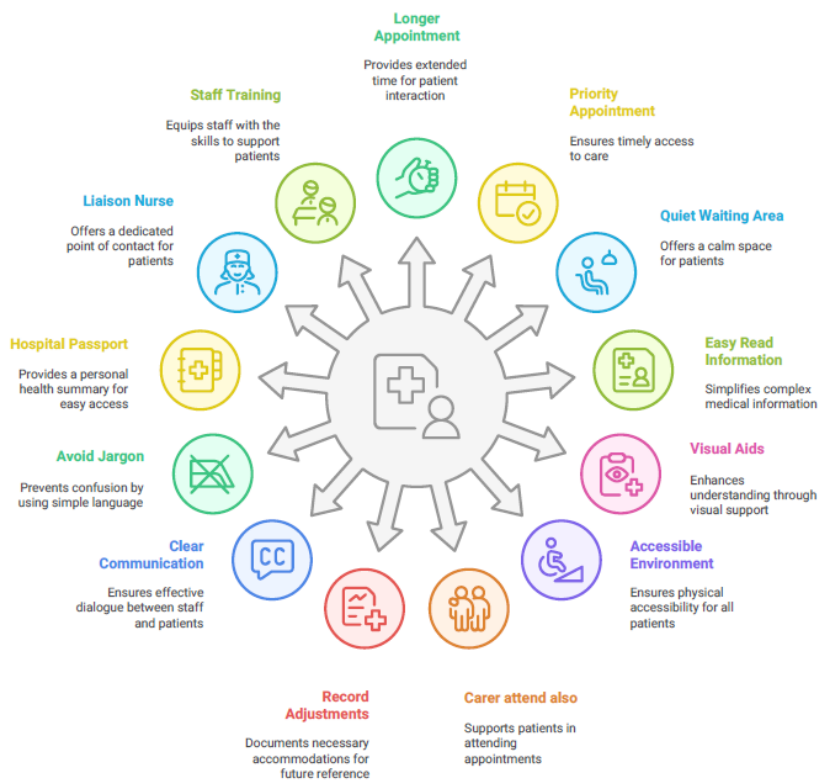
HSC Services in Northern Ireland are delivered in accordance with a comprehensive range of legislation.

Northern Ireland Legislation



Of note, equality legislation places a legal requirement on all public authorities to ensure services are accessible to all persons with disabilities. This is facilitated through the implementation of 'reasonable adjustments' which are intended to reduce and/or mitigate barriers in accessing services. Examples of reasonable adjustments are outlined in the infographic below.

Reasonable Adjustments in Healthcare can include:



In addition to the above legislation, the introduction of Phase 1 of the Mental Capacity Act (NI) 2016, in 2019, and the planned introduction of Phase 2 of the Act (date to be confirmed) provide a progressive framework to people supported to optimise their capacity to make decisions about their lives, and to provide safeguards where an individual lacks capacity.

Delegated Functions

The Health and Social Care Act 2022 amended previous legislation and provided the legislative basis for the exercise of statutory functions by HSC Trusts by the addition of Article 10A and 10B to Health and Personal Social Services (Northern Ireland) Order 1991. The arrangements for the exercise of statutory functions related to social care and children are specified in Departmental Circular (OSS) 01/2022: Social Care and Children's Functions (Statutory Functions) and Circular (OSS) 02/2022: Social Care and Children's Functions (Statutory Functions), Management and Professional

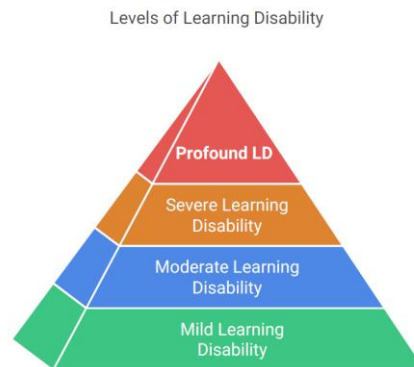
Oversight. Circular (OSS) 03/2022 sets out roles and responsibilities of lead social work staff within the HSC system in Northern Ireland.

With the dissolution of the HSCB by the Health and Social Care Act (Northern Ireland) 2022, the responsibility for the exercise of functions is placed directly onto HSC Trusts with direct accountability to the Department. DoH confers responsibility for the exercise of social care and children's functions on to an HSC Trust by a Delegation Direction. DoH's Strategic Planning and Performance Group monitor Trust performance in accordance with the Statutory Function process and other parallel related processes, as appropriate.

What is Learning Disability?

The World Health Organisation (WHO) defines learning disability as 'a state of arrested or incomplete development of mind' and identifies 4 levels of learning disability:

- Mild learning disability
- Moderate learning disability
- Severe learning disability
- Profound learning disability



Learning disability is diagnosed based upon the presence of 3 concurrent criteria:

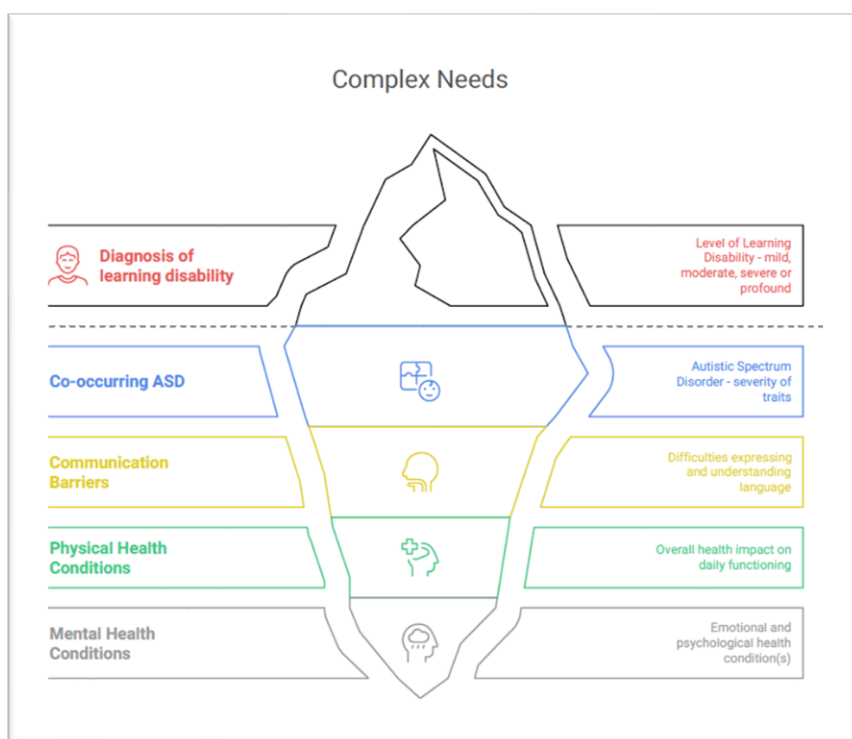
- Significant impairment in intellectual functioning, and
- Significant impairment in adaptive functioning, and
- Onset during the developmental period (i.e. first 18 years of life)

Learning disability is diagnosed by psychologists who complete an assessment of the individual's cognitive and practical skills. This diagnosis identifies the individual's strengths and needs and facilitates access to services.

Every individual with a learning disability is unique and each person has their own preferences and aspirations.

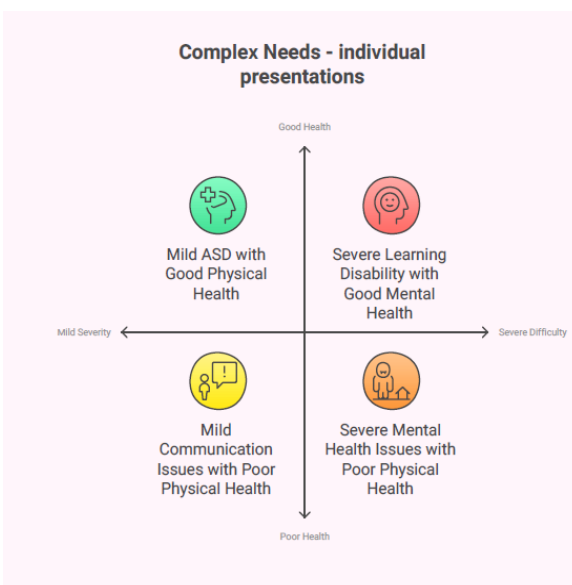
The needs of individuals who have a learning disability are also unique and varied and can cover a wide spectrum of areas. These needs can relate directly to the person's learning disability or can be due to associated co-occurring difficulties that the person may experience. For example, the person with learning disability may experience multiple difficulties that co-exist and overlap. This can intensify the individual's needs and create added challenge in the provision of services.

The individual's multiple conditions can also intersect with their life circumstances and environment, thus adding to the complexity of the situation. Finally, the individual's needs may change over



time, for example with increasing age or during periods of ill-health. As such it is essential that support is flexible and tailored to the individual and their unique circumstances.

Individuals who have needs across multiple domains and/or those whose needs span across multiple service areas are often referred to as having 'complex needs'. Individuals with complex needs will have a unique profile of strengths and challenges related to their circumstances. People with complex needs often experience social exclusion, health inequalities and barriers to accessing support. This necessitates co-ordinated multi-agency support.



Prevalence of learning disability

Overall, 2.16% of the population are estimated to have a learning disability¹, which includes 0.5% of the population who would have a severe or profound learning disability. Based upon the population of Northern Ireland (1.910 million), it is estimated that 42,000 people who would meet the criteria for a diagnosis of learning disability. This would include 25,000 adults aged 18-64 years; 6,000 adults aged over 65 years and 11,000 children and young people aged 0-17 years.

However not all persons who meet the criteria for diagnosis of learning disability will present to community and specialist learning disability HSC services. This can be due to a number of factors including:

- Some people will have their needs met by their families and extended networks and will not require diagnosis or additional support.
- Some people will have limited or delayed access to diagnostic services and thus only present to services in middle or older age.

¹ Based upon normal distribution curve or bell curve which represents probability of the incidence of learning disability in the population

- Some people's needs may be over-shadowed by other factors and their learning disability may not be identified.

It is noted that in the last 20 years there has been an increase in the number of people with learning disability accessing specialist and community learning disability HSC services. This increase is due to a number of factors including:

- Increased survival of very pre-term and low weight babies who have a range of complex needs.
- Increased life expectancy - In 2000 life expectancy for adults with learning disability was 52 years. This has increased to 62 years in 2025², although it continues to remain on average 20 years younger than the general population.
- Improved recognition and better access to diagnostic services.
- Resettlement of people supported in long stay hospitals such as Muckamore Abbey Hospital.

Adult learning disability services currently supports approximately 9,000 adults and their families that are known to social services. HSC Trusts note a continuous rise in referrals for assessment. The learning disability service is the third largest programme of care by cost, equating to £500 million per annum. It is expected that the learning disability programme of care will continue to grow, reflecting the increasing rates of disability and changing profile of need amongst children who are now surviving into adulthood, and the increased likelihood of people with learning disabilities living to older age with associated health complexity and comorbidities.

The majority of people with learning disability share the same aspirations as people without learning disability – for example:

- Stable and meaningful relationships with other people
- A safe and comfortable place to live
- Access to meaningful pursuits such as training, employment and daytime activities
- Hobbies and interests which provide joy and relaxation

² Mencap (2025)

- Good health and financial stability

While aspirations for our lives may be shared, every person with learning disability is different, and individuals may require different levels of support to live a life of their choosing. The level of support required may also change or intensify over time for example as people grow older or if they have periods of poor physical or mental health.

The medical model of disability considers the impairments and difficulties that people experience and aims to provide interventions to reduce the impact of the difficulty. In contrast, the social model of disability emphasises societal barriers and attitudes which can have a disabling effect. People with a learning disability will often benefit from aspects of the medical and social models of disability to help them stay healthy, flourish and achieve.

This proposed Model seeks to acknowledge the additional needs of adults with learning disabilities while placing emphasis on developing services which preserve an individual's human rights and which prioritise the dignity, choice and wellbeing of the individuals we serve. Services must be person-centred and address the unique additional needs of people supported.

People with learning disability can experience a range of additional needs including communication challenges, sensory impairments and a range of co-occurring conditions such as autism and ADHD. There is also a consistent body of evidence across the UK that highlights those adults with learning disability experience increased rates of physical and mental ill health conditions and poorer access to appropriate evidence-based health care assessment and treatment.

In 2024 a review of the health needs of approximately 800 adults accessing services across Northern Ireland identified the following rates of current physical health conditions: - epilepsy (29%); bowel difficulties (18%); cardiovascular difficulties (15%); obesity (15%); diabetes (11%) and thyroid dysfunction (12%). In addition, 37% of adults experienced an anxiety disorder, 19% depression; 11% psychological trauma; 8% psychosis and 9% deliberate self-harm.

Within this review, the needs of adults with learning disability and co-occurring autism were specifically assessed. 32% of the adults in the study had co-occurring autism. Individuals were more likely to be male (75%); under 35 years of age (61%); and have a severe learning disability (40%). 68% of individuals also experienced sensory processing difficulties and 35% experienced difficulties with dental health.

Identifying the physical and mental health needs of individuals with co-occurring autism can be impeded if individuals are unable to self-report symptoms, and if services do not make reasonable adjustments to facilitate the individual’s additional needs. Within the study the following rates of physical and mental health needs were identified:

Physical Health Needs	Mental Health and Behavioural Needs
Epilepsy – 29%	Anxiety disorders – 29%
Sleep difficulties – 23%	Depression – 19%
Swallowing difficulties – 20%	Psychological trauma – 11%
Bowel difficulties – 18%	Deliberate self-harm – 9%
Cardiovascular problems – 15%	Psychosis – 8%
Obesity – 15%	Aggression to others – 57%
Thyroid problems – 11%	Self-injurious behaviour – 57%

Access to Health and Social Care Services

In 2025 there are approximately 9,000 adults with learning disability accessing specialist and community learning disability HSC services (prevalence rate 0.47%) with a current growth rate of 1.6% per annum. The number of people who may require services in the future will likely increase due to people with previously unidentified learning disability presenting more frequently to services in the context of pressures in other support structures, e.g. access to Mental Health services; reduction in family support due to societal pressures; etc.

As noted, there are currently approximately 9,000 adults with learning disability accessing a range of HSC services. Services are commissioned by SPPG through the five HSC Trusts and delivered in partnership with a range of external providers, such as independent sector organisations. Some services, such as day centres, domiciliary care agencies and residential care homes, are required by law to be regulated. RQIA complete this role by registering, inspecting and monitoring these services as appropriate. All regulated and non-regulated services are subject to governance and monitoring arrangements, which are overseen by SPPG.

Services for adults with learning disability are typically centred upon:

- (1) Social care – which includes a broad range of support to help people to live as independently and safely as possible (for example community support services; provision of aids and equipment; safeguarding services; etc.); and
- (2) Health care – which includes a comprehensive range of services to meet people’s medical and health care needs. Services include Primary Care services (e.g. General Practitioners); Secondary Care (e.g. Hospitals); Emergency Care (e.g. Emergency Departments), Allied Health Professionals, and Public Health services (e.g. vaccinations and screening services).

Services can be accessed directly from the Trust or independent provider; or can be funded through Self-Directed Support (SDS) which is a flexible way of funding social care support in lieu of statutory provision. An assessment of the individual’s social care needs is completed, and a personal budget is agreed to meet these needs. Funding is provided by the individual’s local HSC Trust in order to organise and purchase the assessed care and support. There is a choice of arrangements for funding which include:

- Direct payment
- Managed Budget
- Trust Arranged Service
- Combination of the above

Factors which enable the delivery of services

There are a broad range of factors which enable the effective delivery of Learning Disability services. This includes ensuring key structures are in place to drive policy, ensure responsive commissioning, and provide oversight and monitoring of service delivery. It is also essential to ensure that processes and systems of working are fit for purpose, both now and into the future. Services need to keep pace with digital and technological innovations and ensure that developments in relation to assistive technologies and digital tools are integrated to transform future service delivery.

In addition to the above factors, there are three core enablers which are the bedrock of service delivery:

- Families and carers
- Workforce and staffing
- Funding and resource allocation

Family and carers

Families can include parents, siblings and extended family members. They often play a central role in the lives of many adults with learning disability. Families can play multifaceted roles including being a source of support and security; a conduit for learning and development; and an enabler for social integration and relationships.

Families can also play an important role in advocating for the rights of their family member.

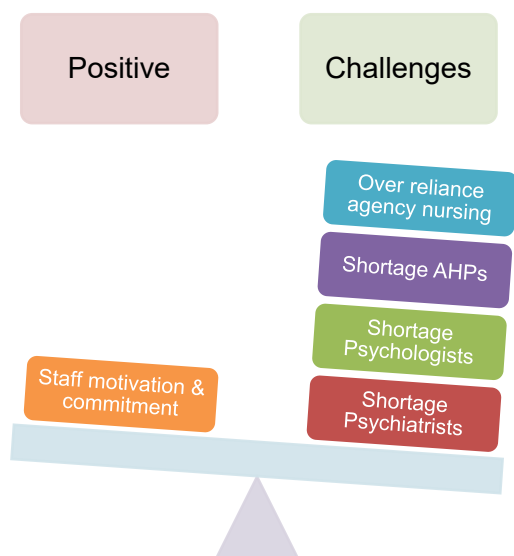
Caring for a family member with learning disability can be hugely rewarding. However, it is also acknowledged that providing care for a family member with learning disability can be challenging. It can create reduced employment opportunities and financial hardship; the intensity of care can lead to emotional distress and burnout; and the time-consuming needs of the person with disability can contribute to isolation and loneliness.

As noted above, family members can complete a very broad range of roles in supporting the person with learning disability. In order to be able to fulfil all these roles, it is essential that family members and carers receive support and guidance. This can include access to information regarding responding to the needs of their family member; information regarding available services and information regarding how to support their own health and wellbeing. Access to this information is particularly essential during periods of transition and when planning for the future.

HSC Trusts also provide and commission a range of services such as day opportunities, short breaks and support within the family home. These services are for the benefit of the individual with learning disability, while also providing brief short breaks for families. It is recognised that demand for these services has outstripped supply, and an increase in service provision is urgently needed.

Workforce

Staff across the statutory and independent sectors provide a crucial role in supporting adults with learning disability. Many staff pursue a career in Specialist Learning Disability services as they have a strong commitment to support people with disabilities. However, there can be significant pressures in respect of remuneration, safety and job security. There is a notable disparity in pay, terms and conditions between statutory and independent sector HSC. Staff are also required to undertake regular training and development to ensure that they can effectively complete their expanding job roles. These challenges have led to a significant shortage in the workforce for staff across all roles (for example support worker roles, staff in multi-disciplinary teams, etc.).



In October 2021 DoH commenced a baseline review of the Learning Disability services workforce across both the statutory and non-statutory sectors. This review identified a number of challenges in meeting workforce requirements. The review has been paused pending completion of the Model. Pending agreement of the Model, details of the required workforce composition and skill mix will

be identified. This will include consideration of 'hard to fill posts', standardisation of recruitment processes and paths to career progression. This information will be used to draft a Workforce Action Plan, which will be developed in collaboration with other ongoing workforce planning exercises including Professional Body Reviews (for example the Learning Disability Nursing Review).

Funding and resource allocation

DoH carried out a financial review of adult learning disability services in 2024 to better understand how funding was used and to inform the development of a costed implementation plan for the service model following public consultation. At the point of review, adult learning disability services accounted for 8% of the total Health budget, equating to £500 million per annum and sitting as the third largest programme of care. For comparison purposes, the average cost of providing services to persons in the Older People's programme of care is £4,255 per person, in comparison to £55,555 per person in the Adult Learning Disability programme of care. It is also noted that the overall level of expenditure has increased significantly since 2019 and has exceeded the growth rate of the Northern Ireland block grant.

The majority of learning disability funding (80%) is used to provide personal social services, including day activity, short breaks, domiciliary care, self-directed support, and accommodation (residential, nursing and supported living). 10% of expenditure is

on hospital care, inclusive of Muckamore Abbey Hospital and other specialist learning disability inpatient units in Northern Ireland. Across all HSC Trusts, supported/other accommodation is the leading area of spend, which has increased in line with resettlement from long stay hospitals. It should be noted that people with learning disabilities will access general healthcare services such as GPs and hospitals, which forms part of a wider programmes of care.

High-cost placements (placements valued at over £100k per annum), inclusive of Extra-Contractual Referrals, now account for 20% (£100 million) of the total programme of care spend and learning disability now accounts for over half of all high-cost placements across all programmes of care in HSC in Northern Ireland.

Overall, while the programme of care has grown at a rapid rate, it is recognised that money has not been distributed equitably across services and there is a financial rationale to recalibrate how services are commissioned and provided.

Challenges in delivering Health and Social Care services

As noted above, there is a very strong commitment from families and staff to support persons with learning disability. However, there is significant variation in the range and delivery of some services across Northern Ireland. This variation, coupled with the changing profile of people supported needs, and the increasing demand for services, have created a significant pressure on the delivery of care. For example:

- Children's Disability services have experienced a significant increase in the number of children and young people supported and changing profile of need. There are approximately 5,600 Children with Disabilities known to social work teams, largely comprising of those with learning disabilities or autism.
- Approximately, 300 young people are scheduled to transition to Adult Learning Disability services in the next two years.
- The gap in Prevention and Early Intervention, and treatment services for children and young people can lead to significant negative impact on an individual's development, which can persist and intensify in adulthood.

- There is a shortage of short break beds due to their temporary re-configuration for emergency placements and due to workforce constraints.
- Demand for the provision of day services and short breaks exceeds the supply of available placements.
- There has been a notable increase in the demand for bespoke placements for persons with complex needs. This has both financial and workforce implications.
- Access to hospital inpatient care has significantly reduced in the last five years due to a planned shift in the model of care to the community. This has resulted in regional variation, and pressure in ensuring timely access to specialist inpatient beds, when needed.
- The development of Community Treatment services, including prevention and crisis intervention, has not kept pace with demand for these services.
- Within the United Kingdom there has been a longstanding policy to resettle people with learning disabilities from long stay hospitals to community-based settings. This policy is based upon the principle of 'betterment' for the individual. Within Northern Ireland the majority of people who were 'resident' in long stay hospitals have been resettled. A small number of individuals with highly complex needs continue to await resettlement.

1.2 Responding to the Challenge – how the Model was developed

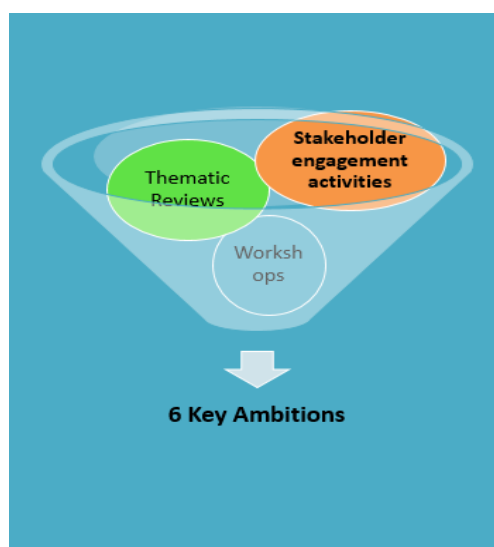
In 2018, the HSCB secured funding to develop a roadmap for transforming Learning Disability services across Northern Ireland. This transformation commenced through the establishment of a Communications and Engagement Plan to harness the commitment, views and recommendations of key stakeholders. This led to an extensive programme of engagement which included workshops, meetings and surveys. Between February 2019 and March 2020, the views of 3,600 people supported, carers, and providers were elicited.

In addition to the stakeholder engagement exercises, DoH also commissioned the completion of thematic reviews regarding six core themes which were emerging from

the stakeholder engagement exercises, and a review of services for Adults with Learning Disability and co-occurring autism.

A content analysis was completed to synthesise information obtained from these sources of information and details are outlined in Annex 2.

This information has been used to further refine the six Key Ambitions for services and has been incorporated into the draft **We Matter** Service Model. A Strategic Delivery Plan (SDP) has also been developed to translate the Model’s strategic vision into actionable steps and identifies how outcomes will be measured.

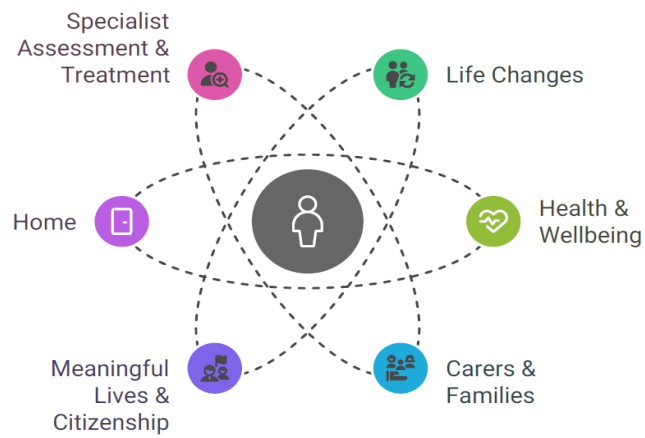


Key Ambition: Health and Wellbeing

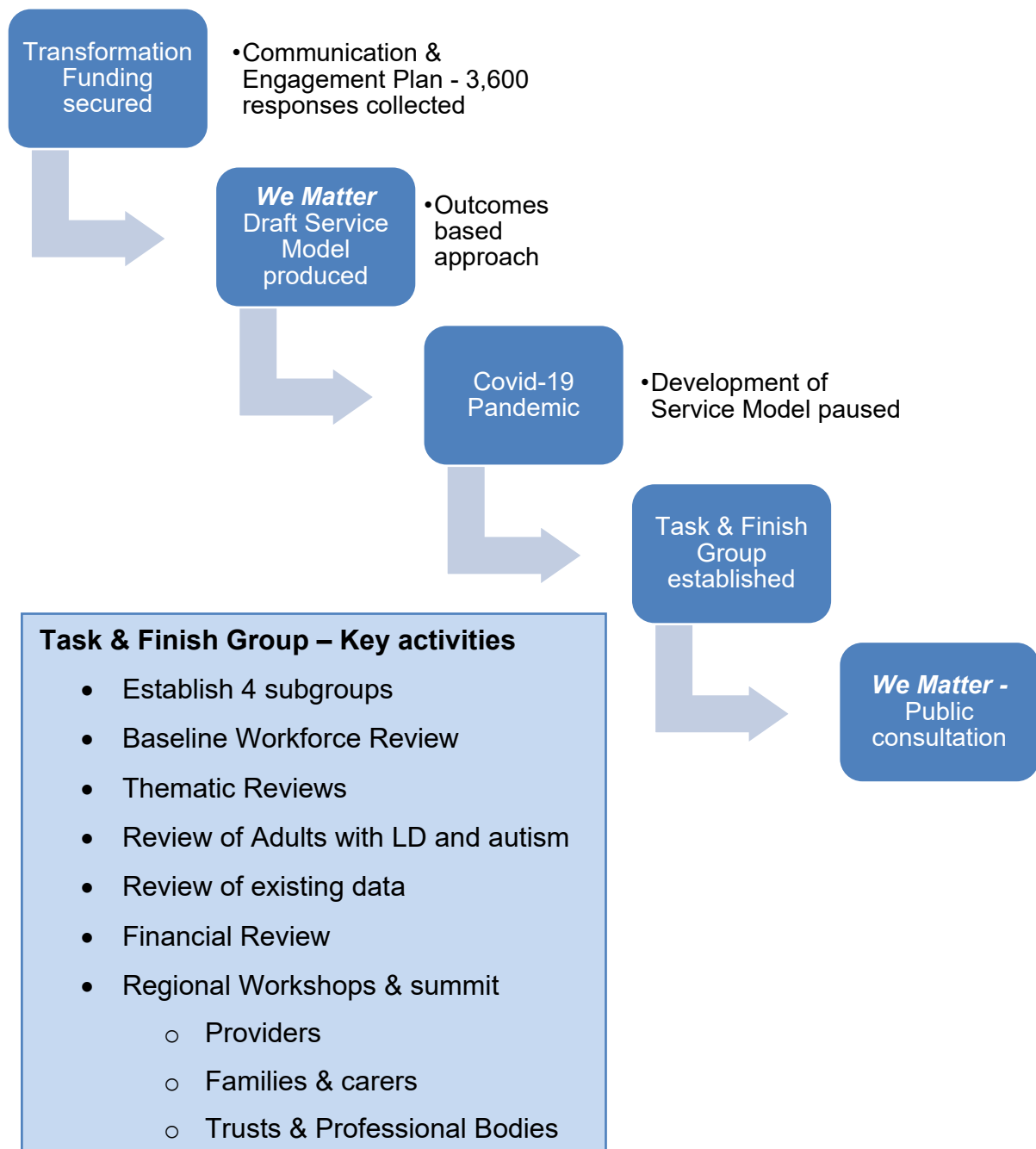
	Thematic Review	Stakeholder Engagement	LD & ASD Engagement
General issues			
Higher rate of physical health difficulties/health inequalities	X	X	X
Need to reduce preventable death	X		X
Deficiencies in the system e.g. difficulties accessing appointments; inappropriate environments, access to out-of-hours appointments, discharged if not follow advice etc.	X	X	X
Difficulty accessing dental Services	X	X	X
Service challenges & gaps			
Delaying in diagnosing conditions/diagnostic over-shadowing/ diagnosis errors	X	X	X
Limited uptake screening Services/improve access to health screening	X	X	X
Opportunities for health promotion e.g. diet & exercise; sport	X	X	X
Reduce poverty, poor housing, unemployment	X		
Reduce over-medication e.g. STOMP initiative	X		X
Staffing issues			
Communication challenges between service user and professional	X	X	
Confusion/duplication regarding roles & responsibilities	X	X	X
Lack of professional confidence & skills/need for staff awareness and advanced training	X	X	X
Health facilitators provide localised support	X	X	X
Difficulty identifying people with LD in mainstream services	X	X	
Lack of accessible transport	X	X	
Need skill mix in staff teams; need more diverse staff in GP Practices		X	
Enablers			
Improve access to reasonable adjustments e.g. longer appointments	X	X	X



Key Ambitions



In March 2023, the Department revisited the transformation project **We Matter** and established a Task and Finish Group and a number of sub-groups to progress development of the Model and focus on the ongoing delivery of services. A significant body of work has been completed, and highlights are outlined in the diagram below:



Next Steps

This draft Service Model is being circulated for consultation across a wide range of stakeholders to elicit their feedback. When feedback has been integrated and the Model finalised, there will be a number of actions to be completed. These will include:

- HSC Trusts will be required to produce local implementation Action Plans, the delivery of which will be subject to performance management.
- DoH will complete a financial costing exercise of the agreed SDP. This information will be used to support future funding bids.
- Cross-departmental structures and initiatives will be enhanced, and extended to ensure opportunities are maximised to deliver public services more effectively.
- Partnership working with third sector providers and key agencies, across a range of departmental and statutory agencies) will be strengthened.

1.3 The Scope of the Model

The Model has been designed for all people who access, develop and deliver services for individuals with learning disabilities and their families and carers. It outlines key responsibilities for the HSC, DoH and HSC providers, including the independent and private sector providers.

The Model will provide a platform for all partner agencies and organisations to work together to enhance and continually improve the quality of life, and life outcomes for adults with learning disability.

The intention is to ensure that care and support to individuals and their families is available consistently across Northern Ireland based on the assessed needs of both individuals themselves and their carers, to enable individuals to live full and meaningful lives.

The Model sets the direction for a system which encourages personalised support. This means that individuals with learning disabilities, their families and carers should have more choice and control over the high-quality services they use.

The Model will focus upon the following key groups:

- **Individuals diagnosed with a learning disability:**
 - who live in Northern Ireland; and

- who may have mild, moderate, severe or profound learning disability; and
- who require support from community and specialist HSC and partner organisations.
- **Family members and Carers**
- **Staff who provide care to individuals with a learning disability from:**
 - HSC Trusts; and
 - local communities; and
 - Independent sector and private organisations.

People with learning disabilities without an assessment of need may benefit from elements of this model where reasonable adjustments are made to address barriers to general access to services.

While the Model does not specifically relate to children and young people, planning and delivery of services is predicated upon consideration of individuals across their life span. Legislation, such as the Children’s Services Co-operation Act (2015), and the Special Educational Needs Disability Act (NI) 2016 provide a framework for joined up working between Children and Adult’s services. In practice, there has been enhanced alignment and co-working between these services in areas such as the development of the Transitions Protocol, and the Emotional Health and Wellbeing Framework.

The ambitions of the Model are aligned to priorities within the Programme for Government:

- Better Support for Children and Young People with Special Educational Needs;
- Provide More Social, Affordable and Sustainable Housing;
- Reform and Transformation of Public Services; and
- Cut Health Waiting Times.

1.4 Service Model Vision

"I have the same rights as everyone else.

I want to be safe and happy in my community.

I should be included in everything, not left out or left behind.

One day, I hope we won't need to keep asking to be included, it will just be normal.

With the right support, I can live the life I want and make my own choices.

I've abseiled down the Europa and play wheelchair basketball, so don't tell me I can't!"

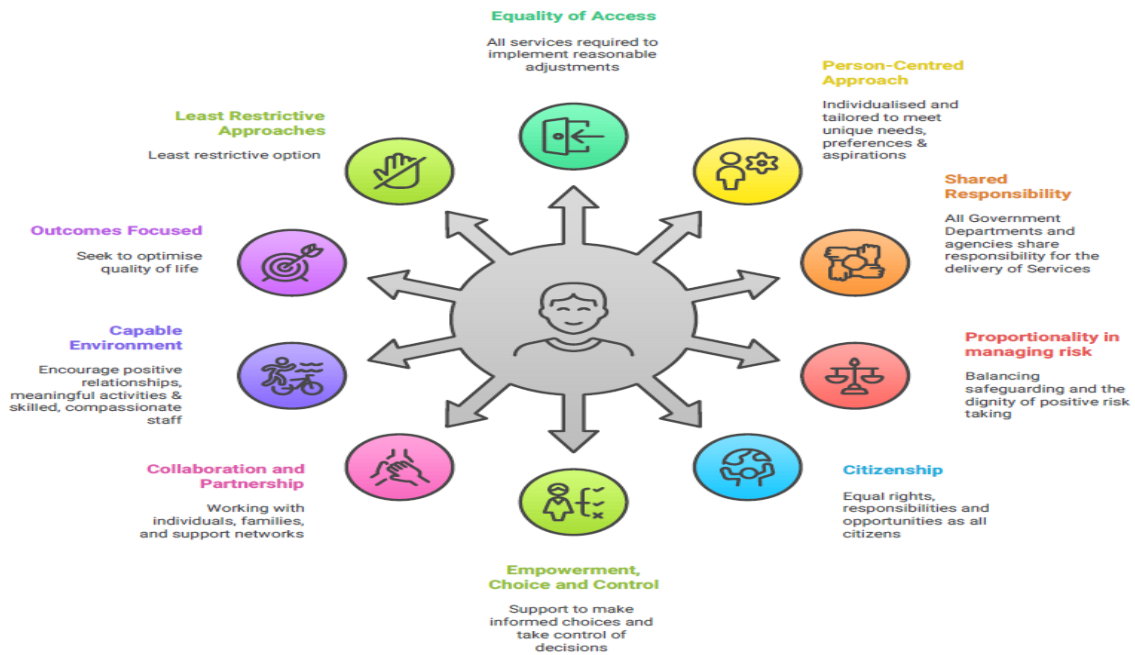
Bethany Meneary TILII

Delivering our Model will be inextricably influenced by the values and principles which underpin the Model. The Model is grounded in HSC values of working together, excellence, compassion, and being open and honest.

Principles

The Model has identified 10 key principles which will drive our service delivery. These principles were consistently identified in the stakeholder engagement activities and reviews which were completed throughout development of the Model.

Service Delivery Principles



Shared language

Services are delivered across Northern Ireland by a range of organisations and are shaped by local needs and practices. This has resulted in a range of different language being used, often for the same or similar purpose. The following terms have been used in this document to reflect the broader range of terms:

Term	Incorporates following terms
Named Worker	<ul style="list-style-type: none"> • Named worker • Keyworker • Case manager • Care manager • Representative from Community Learning Disability Team
Intensive Support service	<ul style="list-style-type: none"> • Intensive Support service • Behaviour Support service • Intensive Behaviour Support service • Positive Behaviour Support service

Standardisation and avoidance of duplication

Social Care services across Northern Ireland deliver services in accordance with the Health and Social Care Act (Northern Ireland) 2022. Following an individual's assessment of need, a care planning process is undertaken, which results in the development of a Care Plan/Care and Support Plan. In addition to a Care Plan, people supported may also complete a number of assessments and processes which can lead to the development of a range of additional plans, for example a Transition Plan, Health & Wellbeing Plan, Future Plan, Promoting Quality Care (PQC) risk assessment and management plan, etc.

The development of the Encompass System within Northern Ireland provides a platform for a single, digital electronic care record. This aims to provide a standardised approach to collating information regarding individual people supported and the range of services that they access. The goal of this system is to streamline processes and improve efficiency; and enhance patient care through improved access to information. It is anticipated that this system will improve standardisation and reduce duplication of information. The regional roll-out of Encompass across the five HSC Trusts was completed in June 2025. The implementation of this system will be monitored, and further action taken, as required.

2 Our Key Ambitions and Outcome Measures

2.1 Key Ambition 1 - Life Changes

Key Ambition Statement 1: People with learning disabilities will be prepared and supported throughout important changes in their lives.

2.1.1 Introduction

Everyone will experience changes throughout their lives. Some changes can be anticipated and planned, for example becoming an adult, while other changes can occur unexpectedly or abruptly without time for adequate planning. One of the most important changes for people with learning disability is when they first transition into Adult Learning Disability services, although transition can occur at a number of life stages.

People can be referred to Adult Learning Disability services at different stages of their lives:

- Move from Children's Disability to Adult Learning Disability service when the young person attains age 18 years.
- Adults referred from other services such as Mental Health services, Probation services, etc. if learning disability is suspected and/or confirmed.
- Adults who have come to Northern Ireland under asylum or immigration status with a pre-existing learning disability.
- Adults who have lived with ageing parents, or other family circumstances, which can no longer be sustained.

Transition into Adult Learning Disability services can be challenging and stressful for both the individual and their family. This can be eased by ensuring the following practices are in place:

- Early planning – transition planning should begin as early as practical to ensure a smooth introduction.
- Person-centred approach – plans must focus upon the individual’s needs, preferences and aspirations. Plans must promote independence, community integration and optimal quality of life.
- Information sharing – providing accessible information to the individual and their family about the range of potential options is crucial.
- Multi-agency co-ordination – joint working between all agencies involved with the individual and their family must be timely and effective.
- Transition link worker – access to staff who have a dedicated role in the co-ordination of transitions can help individuals navigate the system and ensure continuity of care.

In addition to transition into services, adults with learning disability often encounter other changes throughout the course of their lives. This can include changes in employment and day opportunities; moving home; developing personal relationships including intimacy, and getting married etc. For many people these changes also need to be carefully planned to ensure that the individual can retain their network of support with family and friends; they feel ready and prepared to embrace their new life, and that there are supports available to optimise success.

2.1.2 Outcome Measures – What does Success Look Like

In order to achieve our Key Ambitions, the Model has identified a number of outcomes which will be used to measure our success. These outcomes have been translated into key actions in the SDP. The Department will monitor progress in achieving these actions to ensure that we remain focused and accountable in delivering our Model.

- Individuals with a learning disability who require community and specialist health, and social care services will be offered a lifelong, coordinated, and proactive transitions programme, which is flexible and responsive to their needs.

- Individuals, families, and carers can **access clear information and support** on policies, procedures and processes regarding transitions. This will include information on available HSC and other Services, such as day services, domiciliary care and accommodation-based services.
- Every individual will have their needs and strengths assessed using a regionally consistent, rights based and **person-centred model**. This will ensure that services are targeted according to the assessed needs of individuals and will be informed by a regionally agreed and standardised approach.
- Individuals and their families and carers, will be involved in co-producing a comprehensive and holistic **Care Plan**. Transition planning will commence at age 14 years for young people transitioning from Children’s services and individual’s Care Plans will be reviewed throughout transition and adulthood. People supported who complete transitions for other life events (for example moving to live outside the family home) will also receive timely assessment and care planning. Each **Care Plan** will include a holistic understanding of the needs of people supported, including their physical and mental health needs.
- Transition Handover Plans to support effective care planning and service delivery from children to adult services will be developed with **multidisciplinary input** to ensure that both health and social care needs are adequately addressed.
- All Care Plans and Transitions Handover Plans will be developed, implemented, and reviewed through **inter-agency collaboration**, and an understanding of **local intelligence and community services**.

Every individual in receipt of services and who is encountering a life change, will have a named staff member who will offer support as needed. This named staff member will co-ordinate with the **Trust Transition Link Worker** for young people moving from

Children to Adult Services. This will ensure the provision of appropriate support and/or signposting to other agencies that can help individuals to achieve their goals

2.1.3 Actions for HSC Trusts and SPPG

- In collaboration with the independent sector, HSC Trusts (with consent) will maintain a dynamic register of children and adults with a learning disability who are in receipt of HSC services. This will be used to enable long term planning and facilitate inter-agency working with non-HSC agencies, for example the Northern Ireland Housing Executive.
- In collaboration with the independent sector, Trusts will co-produce a regionally consistent pathway and planning process for life transitions, which will include accessible information regarding policies, procedures and processes. Information on the transitions process and relevant HSC Services will be made publicly available to signpost individuals and caregivers in advance of transition.
- HSC Trusts will ensure the availability of multidisciplinary input during transitions planning and review.
- Some children and young people will have long-term accommodation needs after the age of 18. HSC Trusts will commence planning at an early stage and consideration will be given to extending the transitions window, and pooling funds, assets and staffing between Children and Adult services.

HSC Trusts will ensure the availability of Transition Link Workers within Children and Adult Disability services. Transition Link Workers will listen to, actively involve, and value key members of the person's support network and family, in the planning and management of transition.

2.1.4 Relevant guidance and standards:

National Institute for Health and Care Excellence (NICE) website.

NCEPOD (2023) *The Inbetweeners- A Review of Barriers and facilitators in the Process of the Transition of Children and Young People with Complex Chronic Health conditions into Adult Care Services*

NICE, [Care and support of people growing older with learning disabilities](#) (2018).

NICE Guideline. *Transition from Children's to Adults Services for Young People Using Health or Social Care Services*. (February 2016). [Transition from children to adults' services for young people using health or social care services \(nice.org.uk\)](#)

2.2 Key Ambition 2 – Health and Wellbeing

Key Ambition Statement 2 : People with learning disabilities will have improved health outcomes and experience reduced health inequalities through equal access to general healthcare and wellbeing services.

2.2.1 Introduction

Good physical health and wellbeing are crucial for living a long, healthy and happy life. Supporting people to make healthy lifestyle choices, engage in self-management activities and access screening services, are all important to maintaining our health and wellbeing.

However, adults with learning disability are at increased risk of developing physical health conditions, have poorer access to healthcare and have a reduced life expectancy. It is essential that all adults can access the full range of physical health and wellbeing services. This should include (1) access to services to support prevention and early intervention where possible; and (2) to prioritise early identification and timely access to assessment and treatment Services, if health conditions are suspected or diagnosed.

As noted above, the Equality Act 2010 requires all services to implement reasonable adjustments to ensure services are accessible to all people with disabilities.

Stepped Care Model



Health and Wellbeing Services are delivered across a range of settings which can be considered within the Stepped Care Model. Health and Wellbeing Services are primarily delivered at Step 1, Step 2 and Step 3 of the Model. This includes services delivered by Primary Care services and Primary Care Multi-Disciplinary Teams, and programme of Care Specialist services such as Community Learning Disability Teams. Specialist Assessment and Treatment services are delivered at Step 4 and Step 5, and further information will be outlined in Section 6.

2.2.2 Outcome Measures – What Success looks like

- Individuals will have access to the same general healthcare and wellbeing services as all citizens. Focus will be placed upon the implementation of **reasonable adjustments** and access to relevant support.
 - HSC Services will be reviewed to ensure that they are **accessible** and meet the needs of people with learning disability.
 - Individuals, families, and care givers can access **Information and Guidance** on self-care and self-management.
 - Individuals will receive a comprehensive **Annual Health Check** from the **age of 14 years** by a GP and will be offered a **Health Passport**. This Health Check will be holistic and will review the physical, psychological and mental health needs of the individual.

Individuals will have access to **Healthcare Facilitation** to support them to access mainstream health services. Healthcare Facilitation is a process involving a range of professionals and programmes of care as opposed to a service. The process will include the offer of **clear, accessible and practical information** about keeping fit and healthy, and will facilitate access to suitable health and wellbeing programmes available through general HSC services and community partners. This will form a key part of the individual's overall **Care Plan**.

- Individuals will have a **Health and Wellbeing** section in their **Care Plan**. This section will focus upon prevention, such as health screening programmes, and early intervention activities. The Care Plan will also include a section to outline **Physical Health assessment and treatment needs**, as required. This will focus upon any specialist treatment and support for long term health conditions. The plan will be **person-centred**, flexible and be supported by **multidisciplinary teams** who are appropriately trained.
- The development of a **Learning Disability Physician** role is currently being reviewed. This professional would manage routine physical health conditions and coordinate care with other healthcare services, such as cardiology, oncology, neurology, etc.
- Individuals will be supported to access all healthcare appointments, when required. This will include access to an up-to-date **Health Passport** which facilitates healthcare professionals to provide the right care, communicate effectively and make any necessary reasonable adjustments. Individuals may also have access to an acute **Hospital Liaison Service**. This service is currently being piloted, and learning will be implemented, as appropriate.

- Individuals will receive evidenced based holistic assessment and care from Registered Nurses in Learning Disability. RNLDs will support timely discharge from hospital.
- Individuals will experience timely access to RNLD's intervention from RNLDs with appropriate skills and level of expertise, working as part of the wider interdisciplinary team.

2.2.3 Key Actions for SPPG and Trusts

- Several elements of this ambition will be delivered by the full implementation of the [Equity of Access and Outcome Review](#), which was launched by the Minister of Health on 1 November 2024.
- HSC Trusts will review access to general primary and secondary care HSC services in line with Section 75 duties. The review will evaluate the implementation of reasonable adjustments, healthcare facilitation, and health passports.
- HSC Trusts will ensure that individuals, families and caregivers can access information and guidance on the health and wellbeing supports available for people with learning disability.
- SPPG, PHA and HSC Trusts will ensure that people with learning disability are offered an Annual Health Check. This will include the development of a database which will monitor delivery and uptake of health checks and review their outcomes.
- HSC commissioners will ensure that all people with learning disabilities have access to a Health Passport and that Health and Wellbeing assessments, and action plans are routinely completed.

- HSC Trusts will ensure the availability of regionally consistent Health Facilitation.
- SPPG will undertake an evaluation of the Hospital Liaison Service. Learning from this evaluation will be rolled out accordingly.
- SPPG will explore opportunities to develop a **Learning Disability Physician** role.

2.2.4 Relevant guidance and standards

National Institute for Clinical Excellence (NICE) (2015) Challenging Behaviour and Learning Disabilities: Prevention and Interventions for People with Learning Disabilities

National Institute for Health and Care Excellence. Care and Support of People Growing Older with Learning Disabilities. (April 2018). [Care and support of people growing older with learning disabilities \(nice.org.uk\)](https://www.nice.org.uk/guidance/CG138)

National Institute for Health and Care Excellence. How our Work Affects People with a Learning Disability. (2021).

National Institute for Health and Care Excellence (NICE) Website. NICE impact people with a learning disability | Reviewing the impact of our guidance | Measuring the use of NICE guidance | Into practice | What we do | About | NICE [NICE impact people with a learning disability \(csp.org.uk\)](https://www.nice.org.uk/impact)

2.3 Key Ambition 3 - Carers and Families

Key Ambition Statement 3: The needs and views of families and carers of people with learning disability are fully understood and accessible support is available.

2.3.1 Introduction

It is important to recognise that family and carers play a pivotal role in the health and wellbeing of people with learning disabilities. Families provide emotional support, love and a sense of belonging. Caring for a family member across their lifespan provides stability and security for the individual, and families often provide an economic safety net for people supported who are dependent upon state benefits.

Individuals and their families often choose for the person supported to remain living in the family home well into their adult years. This experience can be enhanced through the provision of services for the individual such as day care or day opportunities, short breaks and home care.

In addition to support for people supported, it is important to acknowledge that family members may also require support to fulfil their role as carers. Access to carers' assessment, training and support, are important in assisting carers to maintain their own wellbeing, while supporting their family member.

Finally, some adults with learning disability live independently or in congregate settings. This does not diminish the importance of being facilitated to maintain contact with family members. Families continue to have a vital role in supporting the emotional wellbeing of the person supported and advocating for their needs and preferences.

2.3.2 Outcome Measures – What Success Looks Like

- Families and carers will be offered the flexible, practical and emotional support that they need to support individuals to live in the community and have a meaningful life. Practical support may include the provision of day opportunities

or short breaks for the person supported. Emotional support should include access to a carer's assessment, advocacy services, and support and training to assist the carer fulfil their role.

- Families and carers can access a **single point of contact** for all advice and information about services, carer's assessment and independent advocacy services.
- Carers will have local access to an **independent advocacy service**, when required.
- Family and carers will be offered a **Carer's Support Assessment** of their own needs using a standardised Regional Assessment Tool e.g., the **Carers' Northern Ireland Single Assessment Tool** or the **Carer's Conversation**. A **Carer Support Plan** will be developed which will outline the carer's needs and the support that they will receive.
- **Accessible training, information and support** will be provided to staff, families and carers to enable them to be actively involved, understand and respond effectively to the physical health, mental health and behavioural needs of people supported.
- Families and carers will be involved in **planning and decision making** and supported to carry out their role effectively. Families and carers will be offered support by HSC staff to plan for future life changes for themselves and their family member.
- When a **short break** is required, carers will be offered a flexible choice, based upon assessed need, and clear, transparent, regionally agreed, standardised criteria.
- Families and carers can access **self-directed support, direct payments, and managed budgets** aligned with assessed need. This

will be underpinned by **clear information, advice and support** on the options and process to be followed.

2.3.3 Actions for SPPG and Trusts

- In collaboration with the independent sector, HSC Trusts should develop regionally consistent registers of those caring for people with a learning disability (this should include, age, relationship, living arrangement, and level of HSC support received now and anticipated requirements over the next 5-10 years).
- In collaboration with the independent sector, HSC Trusts will provide an accessible single point of contact for families and carers to access information and support.
- Families and carers will be involved in the planning and decision making process.
- In collaboration with the independent sector, HSC Trusts will ensure the availability of a range of supports for families and carers, including training, information and social care support. The level of service will reflect assessed need, current living arrangements and the demographics of those with caring responsibilities.
- In collaboration with the independent sector, HSC Trusts will ensure that families and carers are aware of the range of options such as self-directed support, direct payments, and managed budgets available to them in order to facilitate choice and control. Trusts will provide support to families and carers to access the best support to meet the needs of their loved one.
- In collaboration with the independent sector, HSC Trusts will ensure the availability of local access to independent advocacy services.

- In collaboration with the independent sector, HSC Trusts will ensure that all families and carers are offered the opportunity to develop a future plan. Future plans help to anticipate and prepare for both planned and unexpected changes for the individual. Future Plans will include an emergency plan, consideration of housing options, financial planning, and making a will. These plans should take into account the contribution of siblings and wider family members, as relevant (family centred approach) and should establish a circle of support for the person with learning disability and their family carers, as they age.

2.3.4 Relevant guidance and standards

Mental Capacity Act (NI) 2016

NICE - Supporting adult carers – January 2020 [Supporting adult carers \(nice.org.uk\)](https://www.nice.org.uk/guidance/CG146)

NICE guidance on challenging behaviour and learning disabilities, sections on parent-training programmes and proactive and reactive strategies. [Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges \(nice.org.uk\)](https://www.nice.org.uk/guidance/CG146/chapter/1-3)

NICE- Guideline 3 Advocacy services for adults with health and 4 social care needs 5 Draft for consultation, June 2022 [1 \(nice.org.uk\)](https://www.nice.org.uk/guidance/CG146)

2.4 Key Ambition 4 - Meaningful Lives and Citizenship

Key Ambition Statement 4: People with learning disabilities will have greater opportunities to learn, engage in communities, make friendships and pursue meaningful activity.

2.4.1 Introduction

All citizens have the right to lead lives rich in meaningful activities, which provide a sense of purpose, fulfilment and engagement. Meaningful activities are unique to each individual and support will be available to help individuals identify their interests and preferences.

Engaging in our local community fosters inclusion, skill development and a sense of belonging. Individuals with a learning disability will be supported to build meaningful connections and friendships which aim to enrich their lives.

Friendships are vital for our mental health and wellbeing. At times it can be difficult to maintain friendships when individuals move from school to adult services. This can lead to social isolation and loneliness. Focus will be placed on assisting individuals to build and maintain friendships which will enhance their overall quality of life.

Many individuals will also wish to develop personal and romantic relationships across the full spectrum. Support and education will be available to help individuals make informed decisions, and to address limiting societal attitudes. Individuals may also require additional support if they choose to marry or have children.

2.4.2 Outcome Measures – What Success Looks Like

- Individuals will be supported to access a range of community based services and supports to lead full meaningful lives, have access to a wide range of social, work and leisure opportunities, and to form and maintain friendships and relationships.

- An Individual's **Care Plan** will be reviewed with them on an **annual basis** to ensure access to a range of community based services, activities, and training and/or employment opportunities, as appropriate.
- Individuals will have access to activities and **services in the community** that are meaningful and purposeful. They will have **choice and control** over the activities in which they participate. Individuals will be offered a range of options such as self-directed support, direct payments, and managed budgets to facilitate choice and control.
- Individuals, and where appropriate families/carers, will have access to **information, advice and support** to help them understand the choices available to them, exercise these choices, and help them plan to use a **managed budget**.
- Services will be planned and delivered on the basis of **inter-agency working** and an understanding of **local intelligence and community opportunities**.
- Individuals will have local access to an **independent advocacy service**, when required.

2.4.3 Actions for SPPG and Trusts

- HSC Trusts, working with independent sector providers, will ensure the availability of a wide range of community-based day services through the expansion of Day Opportunities and Shared Lives. It is recognised that those with complex physical, mental health or behavioural needs may be better supported in a buildings-based setting, and efforts will be made to deliver these services in an inclusive and individualised manner.
- HSC Trusts and independent sector providers, will ensure the availability of day services beyond the current standard hours of provision (9am-3pm).

- HSC Trusts will continue to offer managed budgets to enable choice and control.
- HSC Trusts will collaborate with transport providers to meet statutory duties, ensure continuity of care with other HSC services (e.g. short breaks) and utilise local services (e.g. Community Transport).

2.4.4 Relevant guidance and standards

[Recommendations | Learning disabilities and behaviour that challenges: service design and delivery | Guidance | NICE](#)

https://www.adviceni.net/sites/default/files/202105/Draft_Policy_for_Developing_Advocacy_Services.pdf

Regional Learning Disability Day Opportunities Model - Post Consultation Report – April 2014 (HSCB & PHA) [december-2013-consultation-response-to-the-regional-learning-disability-day-opportunities-model.pdf \(copni.org\)](#)

2.5 Key Ambition 5 – Home

Key Ambition Statement 5: People with Learning Disability will be supported to live with the highest level of independence possible

2.5.1 Introduction

Access to a home which is stable, secure and comfortable is an important foundation for a good life. It enables people to maintain their independence and have a sense of control over their lives. Individuals should be supported to manage daily activities and make their own decisions, without undue interference.

More than two thirds of adults with learning disability currently live in the family home. This can reflect a conscious decision to maintain the support from family, although can also be influenced by the availability and quality of alternative options.

Adults with learning disability will require a range of supports to live as independently as possible. This will include those living in the family home and those living in alternative settings. Supports required will include the provision of services ranging from floating support to accommodation-based services. Developments in housing adaptations and assistive technology can also enable individuals to manage daily tasks, build life skills and maintain choice and control over their living situations.

It is important to recognise that HSC does not provide housing, but will work with other agencies to ensure access to appropriate accommodation, when required.

2.5.2 Outcome Measures – What Success Looks Like

- Individuals will be supported to remain in their own home for as long as possible or as long as they wish. When a change of home is being considered, the individual, with their family and/or their advocate, will play a key role in the decision-making process about where they live and with whom. This can include wishing to live in an urban or rural area, wishing to live with other people or alone,

and wishing to move to another part of Northern Ireland, outside the person's 'Trust of Origin' geographical boundary.

- An Individual's **Care Plan** will include a review of home and/or accommodation needs and will be discussed with them on an **annual basis**.
- HSC Trusts will **periodically review availability of placements** at a population level to ensure sufficient supply of accommodation-based and floating support services. This data will be shared with the NI Housing Executive to enable strategic needs assessment.
- DoH and HSC agencies will continue to **work collaboratively** across government departments, agencies and independent sector to enable access to a greater choice of housing options.
- Individuals can access placements to meet their individualised needs. This may involve engagement with agencies to adapt the environment and/or provide bespoke accommodation for those with more complex needs. This may include the availability of larger spaces, therapeutic and sensory provision, assistive technology and staff facilities.
- Services and placements will be **connected and located** within wider community services, including access to day activity, transport links, and general public amenities. Services will be **integrated and coordinated** to ensure need is considered holistically and to support continuity of care.

2.5.3 Actions for SPPG and Trusts

- HSC Trusts will develop and maintain regionally consistent registers of children and adults with a diagnosed learning disability, including demographic information, health and care needs, and living arrangements. This should be

used to enable long term planning and facilitate inter-agency working with non-HSC agencies, e.g., the Northern Ireland Housing Executive.

- In collaboration with the independent sector, HSC Trusts will ensure the availability of a wide range of services that enable an individual to live independently in their home, including floating support, accommodation based services and access to allied health professionals. Services will be connected to wider HSC and community services.
- HSC Trusts will monitor and review the usage and cost of bespoke accommodation placements.
- HSC Trusts will ensure availability of crisis support services to be delivered in a home or homely setting, as part of a wider continuum of supports to support people with mental health needs and/or behaviours of distress or concern.

2.5.4 Relevant Guidelines and Standards

Learning Disability and Behaviour that Challenges: service design and delivery, NICE Guideline, March 2018. [Learning disabilities and behaviour that challenges: service design and delivery \(nice.org.uk\)](#) - [Recommendations | Learning disabilities and behaviour that challenges: service design and delivery | Guidance | NICE](#)

[Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges \(nice.org.uk\)](#)

[Housing with support - SCIE](#)

2.6 Key Ambition 6 – Mental Ill Health and Behaviours of Distress or Concern

Key Ambition Statement 6: People with learning disabilities will achieve better mental health outcomes through integrated community and specialist hospital services that meet their needs.

2.6.1 Introduction

People with learning disability have significantly higher rates of mental illness and behaviours of distress or concern than the general population. This is due to a range of complex biological, psychological and social factors. The mental health needs of individuals with learning disability can at times be difficult to identify, as symptoms can be mistaken and misattributed to their learning disability. This can result in an individual's mental health needs being undiagnosed and untreated.

Behaviours of distress or concern displayed by individuals with learning disability can include behaviours directed towards oneself, for example self-injurious behaviour; behaviour directed towards others, such as physical aggression; and behaviours directed towards property, for example destruction of furniture. Individuals may also at times display offending behaviours which will bring the person into contact with the Criminal Justice System. Behaviours of distress or concern may be considered as communication of an unmet need.

Support for individuals with mental health needs and/or behaviours of distress or concern should be provided in accordance with a stepped care model. This model provides a framework for the organisation and delivery of services with the aim of ensuring that individuals receive the level of required support and/or intervention appropriate to their need.

Stepped Care Model



The rationale for this model is to ensure that the best intervention is delivered in the right place, at the right time, by the right person to meet the person’s assessed needs. Within the stepped care model preventative and early intervention; and interventions for mild difficulties are delivered at Step 1 and Step 2.

Information regarding these interventions is outlined in the Health and Wellbeing Section.

For individuals with more significant or severe mental health and/or behavioural needs, interventions are delivered at Steps 3 to 5 of the Model.

Step 3 interventions are evidenced based approaches which treat mental health difficulties and/or behaviours of distress or concern.

This can include the provision of individual or group-based psychological therapy and behavioural interventions. For example, Positive Behaviour Support (PBS) is a person-centred, evidence-based approach designed to understand and address the reasons behind behaviours of concern, and to improve the individual’s quality of life. PBS, and other therapies, can be provided in a community setting and be enhanced through the engagement of the individual’s support network (e.g. family and staff members).

Step 4 interventions offer more specialist and highly intensive support. Interventions can be provided in the community, for example through Intensive Support Behaviour Services; specialist Psychological Services (for example the Promote Team, Northern

Trust); or Specialist Forensic Services (for example the Community Assessment Rehabilitation Service, Southern Trust). Step 4 Services can also be provided on an accommodation basis.

Step 5 Services are delivered in inpatient hospital settings. These services are required when an individual has an unstable mental health condition and requires assessment and treatment which cannot be provided safely or effectively in the community.

Services for individuals with learning disability and mental health needs can be delivered by Mental Health services; by Learning Disability services; or by a combination of both Services. The Bamford Review of Learning Disability recommended that services for individuals with mild learning disability and mental health needs, should be provided by Mental Health Services; and that the needs of individuals with moderate to profound learning disability should be met by specialist Learning Disability services. The Model supports this position and advocates that Mental Health and Learning Disability services should work together to achieve a culture of shared responsibility and robust partnership working. This will ensure greater collaboration if an individual requires services across both programmes of care; and facilitates the sharing of expertise across both services.

A key aim of this model is to improve coordination between adult mental health services and specialist learning disability services through greater **co-location**. By this, we mean more than just physical proximity. Co-location will include shared governance arrangements, joint leadership, pooled staffing where appropriate, and a culture of collaborative working.

While adult mental health and specialist learning disability services remain distinct in their clinical focus and professional expertise, there are individuals who may need support from both. Improved integration between the two will help avoid gaps, duplication, and service delays.

The current separation between mental health and learning disability services can result in fragmented care, repeated assessments, and missed opportunities for early intervention. Co-located services will allow multidisciplinary teams to work together more effectively — improving decision-making, strengthening clinical governance, and ensuring that individuals with complex needs receive timely, coordinated and person-centred support. This approach will also support better transitions between community and inpatient care and help to build sustainable specialist capacity across the region.

2.6.2 Outcome Measures – What Success Looks Like

- Individuals will be supported to optimise their mental health and wellbeing through provision of a range of integrated and specialist services, in keeping with the Stepped Care Model of service delivery.
 - Individuals will receive a review of their **comprehensive assessment** of their strengths and needs; risk; and their capacity to make decisions and express preferences. This assessment will be coordinated by a professional with expertise in mental health problems and/or behavioural concerns for people with learning disabilities, and an understanding of how those needs can be met. The comprehensive assessment may be completed by Community or Specialist services.
 - Individuals will receive an individually tailored, evidence based **therapeutic care plan**. This will outline details of an up-to-date physical health assessment, a review of existing social supports; and details of behavioural, psychological and pharmacological interventions as required.
 - Services will be delivered by those with expertise to meet the assessed needs of the person supported. This may involve engagement with **Mental Health services** (for those with mild learning disability); engagement with **Specialist Learning Disability services** (for those with moderate to profound learning disability) or a **collaborative system**

of care with mainstream Mental Health services and Specialist Learning Disability services. It is important to stress that care will be provided by the right person, in the right place, at the right time.

- There will be a clear plan for each individual regarding the appropriate care pathway to meet their needs.
- Individuals will access evidence-based interventions in line with the stepped care model. This may include **communication and activity-based interventions**; **psychological and/or behavioural interventions** (such as Positive Behaviour Support; Cognitive Behaviour Therapy; Art Therapy; etc.) and **pharmacological interventions**, as required.
- Individuals who require more intensive support (Step 4) will receive intervention from **integrated, community-based, specialist multidisciplinary HSC services**. This may include input from mainstream Mental Health services, Specialist Learning Disability services, or a combination of both services.
- Individuals who have come/are at risk of coming into contact with the Criminal Justice System as a result of their mental health or behaviour will have access to **Community Mental Health or Learning Disability Forensic services**, who have established links with criminal justice agencies.
- Some individuals may require intervention from **Specialist Mental Health services**, for example **Substance Misuse services**, **Personality Disorder services**; **Perinatal services**; **Dementia services**; etc. Individuals with mild learning disability may access these services directly. Community Learning Disability services may also engage with these **Specialist services** in order to access consultation

and expert guidance with regard to addressing these needs for individuals with moderate to profound learning disability.

- Individuals experiencing a crisis can access **intensive 24/7 multidisciplinary HSC assessment, intervention and support** at home or in a homely setting, including in a Community Assessment and Treatment. This support will be delivered by highly skilled and experienced multidisciplinary teams with specialist knowledge in understanding and meeting the mental health and complex behavioural needs of people with learning disability.
- People who present an immediate risk to themselves and/or others due to their mental health or behaviour, may require admission to **inpatient services**. People with learning disabilities should be assessed and treated in mainstream mental health services where this is the most appropriate option. Consideration of physical and health care needs will be facilitated when people are in inpatient settings.
- Each individual's **named worker** from Community Services will remain engaged with the patient while under the care of hospital staff and/or Forensic Services and will have an active role in discharge planning.
- Planning for discharge will start from the point of admission. A **community-based, specialist multidisciplinary health and social care team** will coordinate the discharge from inpatient care to another setting.

2.6.3 Key actions for Trusts and SPPG

- HSC Trusts will ensure that supports for people with learning disabilities are structured through a stepped model of care and are aligned to mainstream mental health services and CAMHS. SPPG will develop a regional

commissioning plan to ensure this shift in service delivery is facilitated in a standardised way.

- Mental Health, Behaviour Support and Forensic services for people with moderate to profound learning disabilities will be provided by specialist learning disability teams. These services will be distinct and separate from, but closely linked to, mainstream Adult Mental Health and Community Learning Disability services. These services will comprise of staff from psychiatry, psychology, nursing, social work, AHP, behaviour support and other specialist practitioners.
- HSC Trusts will ensure the availability of specialist integrated multidisciplinary health and social care support in the community for people with a learning disability.
- HSC Trusts will ensure the availability of specialist inpatient services on a localised basis for people with learning disabilities. SPPG in collaboration will establish a clinical oversight panel to monitor and expedite inpatient admissions and discharges.
- In collaboration with the independent sector, HSC Trusts will ensure the availability of crisis prevention and crisis response services, including Home Treatment services, to maintain people's health and placement stability in the community.
- HSC Trusts will ensure all people with learning disabilities who have complex mental health and/or behavioural concerns, will have a named worker. The named worker will coordinate all aspects of care. This will include ensuring that the individual's physical and mental health care needs are being met; helping services to communicate with the person supported and their family and carers; and monitoring the implementation of the individual's care plan.
- HSC Trusts will collaborate to ensure a regional approach to the implementation of a Positive Behaviour Support Framework.

2.6.4 Relevant Guidance and Standards

Department of Health, Forensic Managed Care Network NI (2022) Strategic Plan 2022-2025

NICE. Care and Support of People Growing Older with Learning Disabilities. (2018). [Care and support of people growing older with learning disabilities \(nice.org.uk\)](https://www.nice.org.uk/guidance/CG125)

NICE. Challenging Behaviour and Learning Disabilities: Prevention and Interventions for People with Learning Disabilities. (2015). [Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges \(nice.org.uk\)](https://www.nice.org.uk/guidance/CG125)

NICE. Mental Health Problems in People with Learning Disabilities: Prevention, Assessment and Management. (2016). [Mental health problems in people with learning disabilities: prevention, assessment and management \(nice.org.uk\)](https://www.nice.org.uk/guidance/CG125)

Learning Disability and Behaviour that Challenges: service design and delivery, NICE Guideline, March 2018. [Learning disabilities and behaviour that challenges: service design and delivery \(nice.org.uk\)](https://www.nice.org.uk/guidance/CG125)

3 How The Model Will Be Taken Forward - Strategic Delivery Plan (SDP)

The Model sets out the vision for the future of learning disability services in Northern Ireland. Publication is only the beginning of the process. There are a number of key mechanisms that now need to be put in place to ensure it is implemented. We call this the Strategic Delivery Plan (SDP).

The SDP will be a live document and sets out key outcome measures and key actions as described in the Model, as well as how we report progress, defines lead responsibility, identifies resource implications and set timeframes. A phased approach to delivery is described and will be closely monitored and reviewed to reflect strategic priorities and available resource.

The key outcomes in the SDP recognise the importance of 'Quality of Life' and 'Health and Wellbeing', and in particular, to enable individuals with learning disabilities to live safe, active and valued lives.

In order to progress the key actions as described within the Model, each HSC Trust will be required to develop Local Action Plans. These plans should be developed by 'multi-agency multi-spread' representatives, and have individuals living with learning disability, their families and their carers at the heart of the decision-making process.

3.1 Reporting Infrastructure

All Government Departments share responsibility for the development and delivery of services to support individuals with learning disability. The current Model outlines the key actions which will be completed by DoH and HSC services. The Model emphasises that collaboration and partnership working across all Government Departments will be essential to achieve healthier and happier lives for individuals with learning disability.

DoH will establish a Learning Disability Collaborative Leadership Board to ensure HSC oversight of the Model against the Key Ambitions, Outcome Measures and Key Actions set out in the SDP. This Board will comprise of DoH policy and strategic

planning and performance group professional leads, HSC Trust Directors, clinical leads, voluntary sector representation, and individuals with lived experience/ carers.

This group will convene a number of thematic work streams based around the Key Ambition Statements and other associated priorities, to take forward the SDP.

3.2 Outcomes Based Reporting

Outcomes Framework

The delivery of services across Northern Ireland is underpinned by a focus upon outcomes. An Outcomes Based Accountability approach (OBA) has been translated into a Strategic Outcomes Framework and associated key indicators. These key outcomes are intended to be viewed as a collective approach to improving the health and wellbeing of the whole population.



The Model will also implement an OBA approach. This focus upon:

- How much did we do?
- How well did we do it?
- Is anyone better off?

A number of OBA scorecards will be developed to collate data regarding key indicators. This will ensure monitoring of achievement of our Key Ambitions and provide assurances that improvements are being implemented and sustained.

Examples of key performance indicators may include:

- % of young people with a Transition Handover plans in place
- % of adults moved from day care to community-based programs
- adults offered annual health checks.

Learning Disability Service Model Consultation – Privacy Notice

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Address: Castle Buildings, Stormont, Belfast, BT4 3SG

Email: ldsm@health-ni.gov.uk

Telephone: 02890520570

Data Protection Officer Name: Charlene Maher

Telephone: 02890522353

Email: DPO@health-ni.gov.uk

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Glossary of Terms

Adult Learning Disability Services: Services provided by Health and Social Care Trusts to support adults with a learning disability, including social care, nursing, psychology, day opportunities, supported living, respite and care coordination.

Behaviour(s) of Distress or Concern: Behaviours that may challenge services or indicate that a person is experiencing distress, unmet needs, or difficulty communicating. These are sometimes called “behaviours that challenge” but this Model uses more person-centred language.

Care and Treatment Review (CTR): A multi-agency review process used (particularly in England) to ensure that people with learning disabilities or autism are not in hospital unnecessarily and receive the right support in the community. This Model includes plans for similar clinical oversight mechanisms.

Carer: A person (often a family member or close friend) who provides unpaid support to someone with a learning disability.

Co-location: A model where adult mental health and learning disability services work more closely together through shared buildings, leadership, staffing, governance, and day-to-day working. It supports more joined-up care for people with complex needs.

Co-production: A way of working where people with lived experience, families, carers, and professionals work together as equal partners to design and improve services.

Cross-Departmental Working: Collaboration between government departments (such as Health, Education, Communities, and Justice) to improve outcomes for people with learning disabilities whose lives and needs span different public services.

Delivery Plan: The supporting document to this Model, setting out the actions, timescales, responsibilities, and measures that will be used to implement the Model over the next three years.

Health and Social Care (HSC): The integrated health and social care system in Northern Ireland, delivered through five regional Trusts and overseen by the Department of Health.

Hospital Passport: A document that includes important information about a person with a learning disability — including communication preferences, health needs, and reasonable adjustments — to help hospital staff provide safe and person-centred care.

Learning Disability: A significant, lifelong condition that affects how a person understands information, learns new skills, and communicates. People with a learning disability may need support with everyday activities. This Model does not include learning difficulties such as dyslexia.

Named Worker: A designated professional responsible for coordinating a person's care and support across services. Also referred to as a keyworker in some contexts.

Outcome-Based Accountability (OBA): A performance approach focused on outcomes (what difference is made) rather than just activity (what is done). This Model uses OBA to frame its six ambitions and associated actions.

Out-of-Area Placement: When a person with a learning disability is placed in accommodation or hospital services outside their home Trust area — often far from family and community — due to a lack of suitable local provision.

Personalised Support / Person-Centred Planning: Support that is tailored to the individual's needs, preferences, aspirations, and rights. Involves listening to the person and their support network and co-producing a plan that reflects their goals.

Positive Behaviour Support (PBS): An evidence-based approach that seeks to understand the reasons for behaviours of distress and develop proactive, person-centred strategies to improve quality of life and reduce restrictive interventions.

Respite / Short Breaks: Support that gives families and carers a break from their caring role, while providing meaningful support or activities for the person with a learning disability.

Self-Directed Support: An approach that enables people to have more choice and control over the support they receive, including options for managing a personal budget.

Transition: The planned process of moving from children's to adult services, or from one stage of life or service to another. Effective transitions are key to preventing breakdowns in care and promoting continuity.

Abbreviations

ADHD - Attention Deficit Hyperactivity Disorder
AHP - Allied Health Professionals
BHSCT - Belfast Health and Social Care Trust
CAMHS - Child and Adolescent Mental Health Services
CATU - Community Assessment and Treatment Unit
CLDT - Community Learning Disability Team
DBT - Dialectical Behaviour Therapy
DE - Department of Education
DES - Data Encryption Standard
DfC - Department of Communities
DfE - Department for the Economy
DoH - Department of Health
GAIN - Guidance Audit Implementation Network
GDPR - General Data Protection Regulation
GP - General Practitioner
HAP - Housing Assistance Payment
HFMA - Healthcare Financial Management Association
HSC - Health and Social Care
HSCB - Health and Social Care Board
HSE - Health Service Executive
IMPACT - Improving Adult Care Together
KPI - Key Performance Indicator
NHS - National Health Service
NHSCT - Northern Health and Social Care Trust
NI - Northern Ireland
NIHE - Northern Ireland Housing Executive
NICE - National Institute for Health and Care Excellence
NISAT - Northern Ireland Single Assessment Tool
OBA - Outcomes Based Accountability
OSS - Office of Social Services

PBS – Positive Behaviour Support
PfG - Programme for Government
PHA - Public Health Agency
PQC - Promoting Quality Care
QA - Quality Assurance
RQIA - Regulation and Quality Improvement Authority
RNLD - Registered Nurse – Learning Disability
SAAT - Self Assessment of Autistic Traits
SCCF - Social Care Collaborative Forum
SCIE - Social Care institute for Excellence
SDP - Strategic Delivery Plan
SDS - Self-Directed Support
SEHSCT - South Eastern Health and Social Care Trust
SHSCT - Southern Health and Social Care Trust
SPPG - Strategic Planning and Performance Group
UNOCINI - Understanding the Needs of Children in Northern Ireland
WHO - World Health Organisation
WHSCT - Western Health and Social Care Trust

References & Bibliography

- Alborz, A.; McNally, R.; & Glendinning, C. (2005) Access to Healthcare for People with Learning Disabilities: Mapping the Issues and Reviewing the Evidence. *J Health Serv Res Policy*, 10 (3): pp. 173-182.
- Alzheimer's Society website. (Accessed 9/9/23). Learning disabilities and dementia | Alzheimer's Society (alzheimers.org.uk)
- American Psychiatric Association (2022) Diagnostic and Statistical manual of Mental Disorders (DSM-V)
- Amir, J.; Nakata, V.; & Micheal, D. (2019) Diagnostic Overshadowing in Learning Disability: Think Beyond the Disability. *Progress in Neurology and Psychiatry*, Vol. 23, Issue. 2
- ARC Scotland (2017) *Principles of Good Transitions 3: Scottish Transitions Forum*
- Baxter, K., Glendinning, C. and Clarke, S. (2008) Making informed choices in social care: the importance of accessible information, *Health and Social Care in the Community*.
- [Beyer](#), S.; [Brown](#), T.; [Akandi](#), R.; & [Rapley](#), M. (2010) A Comparison of Quality of Life Outcomes for People with Intellectual Disabilities in Supported Employment, Day Services and Employment Enterprises. *Journal of Applied Research in Intellectual Disabilities*, pp. 290-295.
- Bigby, C. & Anderson, S. (2021) Creating Opportunities for Convivial Encounters for People with Intellectual Disabilities: "It Looks Like an Accident", *Journal of Intellectual and Developmental Disability*, Vol. 46, Issue 1, pp. 45-57.
- Boardman, J. (2011) Social Exclusion and Mental Health: How People with Mental Health Problems are Disadvantaged. *Mental Health and Social Exclusion*, Vol. 15, No. 3, pp. 112-121.
- Boyle, F. & Palmer, J. (2017) The Hospital Resettlement Programme In Northern Ireland After The Bamford Review Part 2: The Experience Of Learning Disabled People Resettled From Long Stay Hospitals
- Brown, M.; Chouliara, Z.; MacArthur, J.; Truesdale, M. & Higgins, A. (2020) *Transition from Child to Adult Health Services for People with Complex Learning Disabilities: Learning from Families and Nurses*
- Brown, F. & Dalrymple, J. (2021) *A New Way Home (Scottish Edition)*
- Carers NI, (2022) *State of Caring: A Snapshot of Unpaid Caring in Northern Ireland*
- Department of Health (1992) *Mental Health Order (NI) Code of Practice (1992)*
- Department of Health (2005) *Review of Mental Health and Learning Disability (Northern Ireland): Equal Lives report: Review of Policy and Services for People with a Learning Disability in Northern Ireland*
- Department of Health (2010) *Circular HSC (ECCU) 1/2020 Care Management, provision of Services and Charging Guidance*
- *Department of Health (2014) Positive and Proactive Care: reducing the need for Restrictive Interventions*

- *Department of Health (2014) A positive and proactive workforce*
- Department of Health (2016) The Mental Capacity Act (Northern Ireland)
- Department of Health (2016) Systems, not structures: Changing Health and Social Care; Expert Panel Report
- Department of Health (2021); Mental Health Strategy 2021-2031
- Department of Health (2021) *Mental Health Services for Children and Young People with an Intellectual Disability in Northern Ireland: Recommendations to the Mental Health Strategy Advisory Panel 2021-2023.*
- Department of Health (2022) Prevalence of Autism in School Aged children in Northern Ireland. Annual Report 2022
- Department of Health, Forensic Managed Care Network NI (2022) Strategic Plan 2022-2025
- Department of Health (2023) *Autism Strategy 2023-28, To Respect, To Listen, To Involve*
- Department of Health (2023) *Autism Strategy 2023-28, Delivery Plan 2023-2025*
- Department of Health (2023) Adult Learning Disability – Data Overview, Learning Disability Strategic Plan Task and Finish Group
- Department of Health (2023) Learning Disability Service Model - Draft
- Department of Health (2023) Review of Learning Disability Service Model
- Department of Health (2023) Adult Learning Disability: Baseline Position – Population, Service Provision & Workforce, SPPG, Adult Social Care
- Department of Health (2023) *Regional Policy on the use of Restrictive Practices in Health and Social Care settings- and regional operational procedures for the use of seclusion*
- Department of Health (2024) Children’s Services Overview Report – Children with a Disability – M Leeson, SPPG
- Department of Health (2024) *Regional Transition Protocol for Children and Young People with a Learning Disability, including Children and Young People with a Learning Disability and Co-occurring Autism. A Multi Agency Approach – draft*
- Department of Health, Learning Disability Unit (2024) Meaningful Lives and Citizenship Thematic Review
- Department of Health, Learning Disability Unit (2024) Transitions Thematic Review
- Department of Health, Learning Disability Unit (2024) Home Thematic Review
- Department of Health, Learning Disability Unit (2024) Health and Wellbeing Thematic Review
- Department of Health, Learning Disability Unit (2024) Carers and Families Thematic Review
- Department of Health, Learning Disability Unit (2024) Mental Health Thematic Review
- Department of Health England (2009) *Valuing People Now: Summary Report*
- DHSSPS. (2005). A Strategic Framework for Adult Mental Health Services. *The Bamford Review of Mental Health and Learning Disability (Northern Ireland)*. DHSSPS, Belfast
- Diffley Partnership (2023) *Literature Review: Transitions to Adulthood for Disabled Young People*

- Dusseljee JC, Rijken PM, Cardol M, Curfs LM; & Groenewegen PP. (2022) Participation in Daytime Activities among People with Mild or Moderate Intellectual Disability. *Journal of Intellectual Disability Research*, pp. 4-18.
- Emerson, E. (2015) the determinants of health inequities experienced by children with learning disabilities. Public Health England
- Emerson, E.; Baines, S.; Allerton, L.; & Welch, V. (2012) *Health Inequalities & People with Learning Disabilities in the UK*,
- Emerson, E. & Hatton, C. (2007) Mental health of children and adolescents with intellectual disabilities in Britain. *British Journal of Psychiatry*. 191:493–99
- Equality Commission for Northern Ireland (2013) Review of the Formal Investigation into the Accessibility of Health Information for People with a Learning Disability in Northern Ireland.
- Haigh, A.; Lee, D.; Shaw, C.; Hawthorne, M.; Chamberlain, S.; Newman, D.W.; Clarke, Z.; & Beail, N. (2013) What Things make People with a Learning Disability Happy and Satisfied with their Lives: An Inclusive Research Project. *Journal of Applied Research in Intellectual Disabilities*, pp- 26-33.
- [Hartnett, E.](#); [Gallagher, P.](#); [Kiernan G.](#); [Poulsen, C.](#); [Gilligan E.](#); & [Reynolds, M.](#) (2008) Day Service Programmes for People with a Severe Intellectual Disability and Quality of Life: Parent and Staff Perspectives. *Journal of Intellectual Disabilities*, pp- 153-172.
- Hawthorne, R.; (2021) what are the Barriers and Facilitators to Participation in Active Recreation for People with Learning Disabilities? *British Journal of Learning Disabilities*, Vol. 50, Issue 3, pp. 350-363.
- HCA Affordable Homes Programme 2015-18 Housing for Vulnerable and Older People- Supplementary information
- Heslop, P.; Blair, P.; Fleming, P.; Hoghton, M.; Marriott, A.; & Russ, L. (2013) *Confidential Inquiry into Premature Deaths of people with Learning Disabilities (CIPOLD)* Executive Summary
- Hithersay, R.; Startin, C.; Hamburg, S.; Mok, K.; Hardy, J.; Fisher, E.; Tybulewicz, V.; Nizetic, D. & Strydom, A. (2019) Association of Dementia with Mortality Among Adults with Down Syndrome Older than 35 Years, *JAMA Neurol*, Vol. 76, No. 2, pp. 152-160.
- Homes & Communities (2015) Agency Rent Standard Guidance https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/419271/Rent_Standard_Guidance_2015.pdf
- Kaehne, A. (2012) *Transition for young People with Learning Disabilities: Learning from Research*. Report from Cardiff University
- Kelly, A.; Donnelly, J P.; Donnelly, L.; Humphrey, S.; Reilly, S.; Macpherson, H.; Hall, E.; and Power, A. (2022) Researching Belonging with People with Learning Disabilities: Self-building Active Community Lives in the Context of Personalisation. *British Journal of Learning Disabilities*, Vol 50, Issue 3, pp. 307-320
- Kelly, B. (2013). *Don't Box Me In: Disability, Identity and Transitions to Young Adult Life*. Barnardo's NI & QUB. P. 26. http://www.barnardos.org.uk/don_t_box_me_in_-_final_report.pdf
- Kelly, B.; McShane, T.; Davidson, G.; Pinkerton, J.; Gilligan, E. & Webb, P. (2016) *You Only Leave Once? Transitions and Outcomes for Care Leavers with Mental Health and/or Intellectual Disabilities*, Belfast QUB

- Joint Commissioning Panel for Mental Health (2013) *Guidance for commissioners of Mental Health Services for People with Learning Disabilities*.
- Kouroupa, A; Hassiotis, A; Hamza, L.; Courtenay, K; Hall, I.; Langdon, PE; Taggart, L; Crossey, V; Lloyd-Evans, B & Morant, N (2023) Stakeholder perspectives on intensive support teams for adults with intellectual disabilities who display behaviour that challenges in England. *J Appl Res Intellect Disabil*. Sep; 36(5):1101-1112.
- LeDeR Annual Report (2021): *Learning from Lives and Deaths- People with a Learning Disability and Autistic People*. (Kings College: London).
- Lunskey, Y.; Jahoda, A.; Navas, P.; Campanella, S. & Havercamp, S. (2022) the Mental Health and Well-being of Adults with Intellectual Disability during the COVID-19 Pandemic: A Narrative Overview. *Journal of Policy and Practice in Intellectual Disabilities*, Vol. 19, No. 1, pp. 35-47.
- McGibbon, M.; Spratt, T. & Davidson, G. (2018) [Young Carers in Northern Ireland: Perceptions of and Responses to Illness and Disability within the Family](#)
- McNally, P. (2022) *A Framework for the Implementation of Trauma Informed Care in Residential and Supported Living Services for Adults with a Learning Disability*.
- McNally, P., Taggart, L., & Shevlin, M. The development of a trauma informed care framework for residential services for adults with an intellectual disability: Implications for policy and practice. *Journal of Policy and Practice in Intellectual Disabilities*, (2023): pp. 1–17.
- McVeigh, M. (2017) Learning disability in Northern Ireland: Where are we now? [Learning disability in Northern Ireland: Where are we now? - Research Matters \(assemblyresearchmatters.org\)](#) (Accessed 6/6/23)
- Mansell, J. (2007) Services for people with learning disabilities and challenging behaviour or mental health needs. London, Department of Health
- Mencap website. (Accessed 8/9/23). [Learning Disability and Mental Health - Mental Health Research | Mencap](#)
- MENCAP NI Briefing Paper No.3. (2019) *Treat Me Well: Equal Access to Healthcare for People with a Learning Disability*.
- MENCAP website. [Learning Disability - Health Inequalities Research | Mencap](#) (Accessed 2.6.23)
- Muckamore Abbey Hospital Review Team (2020) A review of Leadership and Governance at Muckamore Abbey Hospital
- National Institute for Clinical Excellence (NICE) (2015) *Challenging Behaviour and Learning Disabilities: Prevention and Interventions for People with Learning Disabilities*.
- National Institute for Clinical Excellence (NICE) (2016) *Transition from Children's to adults Services for Young People Using Health or Social Care Services*
- National Institute for Clinical Excellence (NICE) (2016) *Mental Health Problems in People with Learning Disabilities*
- National Institute for Health and Care Excellence. (2018) *Care and Support of People Growing Older with Learning Disabilities*
- National Institute for Clinical Excellence (NICE) (2018) *Learning disability and behaviour that challenges: service design and delivery*

- National Institute for Clinical Excellence (NICE) (2020) - Supporting adult carers
- National Institute for Clinical Excellence (NICE) (2021) *Autism: recognition, referral, diagnosis and management of adults on the autism spectrum*. Clinical Guideline 142, London
- National Learning Disability Professional Senate (2023) – CLDT Guidance: Delivering Effective Specialist Community Learning Disabilities Health Teams/Services for adults with learning disabilities and their families and carers
- National Institute for Health and Care Excellence (2021) *How our Work Affects People with a Learning Disability*
- National Institute for Health and Care Excellence (NICE) Website. [NICE impact people with a learning disability | Reviewing the impact of our guidance | Measuring the use of NICE guidance | Into practice | What we do | About | NICE](#) (Accessed 5/6.23)
- NCEPOD (2023) *The Inbetweeners- A Review of Barriers and facilitators in the Process of the Transition of Children and Young People with Complex Chronic Health conditions into Adult Care Services*
- NHS England: Bristol, North Somerset and South Gloucester Clinical Commissioning Group. *Learning Disabilities Mortality Review (LeDeR) Annual Report 2021/2022*, p. 3.
- NHS England website. [NHS England » Improving health](#) (Accessed 2.6.23)
- NHS Website. [Learning disabilities - Annual health checks - NHS \(www.nhs.uk\)](#) (Accessed 2.6.23)
- NHS England (2018): STOMP: Stopping the Over Medication of People with a Learning Disability, Autism or Both. [STOMP everyone working together to stop the overuse of psychotropic medicines and to improve people's quality of life \(england.nhs.uk\)](#) p.3.
- NHS – Skills for Health, Health Education England (2019) Core Capabilities Framework for Supporting Autistic People
- NHS – Skills for Health, Health Education England (2019) Core Capabilities Framework for Supporting People with a learning disability
- NHS – Health Education England (2023) Oliver McGowan - Mandatory Training on Learning Disability and Autism
- NHS England – the NHS Long Term Plan (2019)
- Northern Ireland Assembly: [report-on-tyc-and-learning-disability.pdf \(niassembly.gov.uk\)](#)
- Northern Ireland Executive (2024) Our Plan: Doing what matters most – Programme for Government 2024-2027
- Northern Ireland Practice and Education Council & Department of Health (2024) Equity of Access and Outcome – The future role of RNLDs in supporting people with learning disabilities to achieve the best health possible
- Palmer, J.; Boyle, F.; & Wood, A. (2014). The Hospital Resettlement Programme in Northern Ireland after the Bamford Review. Part 1: Statistics, Perceptions And The Role Of The Supporting People Programme
- Perez, S.; Tao Ma, Mufson, E.; Ginsberg, S. & Ledreux, A. (2022) *Down Syndrome, Neurodegeneration and Dementia*.
- Pinals, D.; Hovermale, L.; Mauch, D.; & Anacker, L. (2022) Persons with Intellectual and Developmental Disabilities in the Mental Health System: Part 1. Clinical Considerations. *Psychiatric Services*, Vol. 73, Issue 3, pp. 245-363.

- Robertson, J.; Beyer, S.; Emerson, E.; Baines, S.; & Hatton, C. (2019) The Association Between Employment and the Health of People with Intellectual Disabilities: A Systematic Review, *Journal of Applied Research in Intellectual Disabilities*, Vol. 32, Issue 6, pp. 1335-134
- Royal College of Psychiatrists (2012) *Enabling People with Mild Intellectual Disability and Mental Health Problems to Access Healthcare Services*
- Scottish Commission for Learning Disability (2020). *Consultation Response: Response to the Proposed Disabled Children and Young People (Transitions) (Scotland) Bill*.
- Singh, S. & Tuomainen, H. (2015) *Transition from Child to Adult Mental Health Services: Needs, Barriers, Experiences and New Models of Care*. *World Psychiatry*, Vol. 14, Issue 3
- Social Care Institute for Excellence; *Having a Good Day? A Study of Community-based Day Activities for People with Learning Disabilities*. (2007)
- Social Care Institute for Excellence (Website) [Community-based day activities and supports for people with learning disabilities - Messages from 'Having a good day' \(scie.org.uk\)](https://www.scie.org.uk) (Accessed 28/6/23)
- Swan, A. (2016) Building The Right Home - Guidance for commissioners of health and care services for children, young people and adults with learning disabilities and/or autism who display behaviour that challenges
- Taggart, L. & Hanna-Trainor L, (2015-2016) *Providing Supports to People with a Learning Disability Transitioning into Older Age*, KESS
- Taggart L. & Hanna-Trainor, L. (2017) Supporting older adults with a learning disability and their ageing family carers: A family and community support model
- Taggart, L.; Marriott, A.; Cooper, M.; Atkinson, D.; Griffiths, L.; Ward, C. & Mullhall, P. (2021) Developing Curricular-content and Systems-related Impact Indicators for Intellectual Disability Awareness Training for Acute Hospital Settings. *Journal of Advanced Nursing*.
- Taggart, L.; McConkey, R.; Ryan, A. & Truesdale-Kennedy, M. (2012) Examining the support needs of ageing family carers in developing plans for a relative with an intellectual disability
- Taggart, L.; Truesdale-Kennedy, M. & Slevin, E. (2012) Issues in caregiving for older people with intellectual disabilities and their ageing family carers: a review and commentary
- Taggart, L. (2024) Why do we continue to exclude the most vulnerable in our society in diabetes research and education? Addressing the challenges presented by people with intellectual disability. *Practical Diabetes*, Vol 41; Issue 2
- University of Ulster (2011) *Supporting People with Intellectual Disability – A Rapid Review of Evidence*
- Watchman, K (2023): *Stand by Me - Perspectives of older couples with a learning disability when one partner has dementia: identifying support needs of carer dyads*
- Welsh Government. *Learning Disability Strategic Action Plan 2022-2026: Our Plan for Developing and Implementing Learning Disability Policy from 2022 to 2026*
- Western HSC Trust <https://sharedlivesplus.org.uk/scheme/western-trust-adult-placement-scheme/https://www.keyring.org/>

- Winchcombe M (2012) 'a life more ordinary: Findings from the long-term neurological conditions research initiative'.
- World Health Organisation (2022) International Classification of Diseases (ICD-11)