



Llywodraeth Cymru
Welsh Government

Learning Disability Improving Lives Programme

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Mae'r ddogfen yma hefyd ar gael yn Gymraeg.
This document is also available in Welsh.

Learning Disability – Improving Lives Programme

Background

1. Prosperity for All is a single cross-cutting strategy to inform all decision-making and to provide a framework for improved cross-governmental working and to improve the quality of people's lives. The learning disability transformation programme called Improving Lives supports Prosperity for All and provides valuable evidence to develop the five priority areas and integrated working across portfolios and sectors to improve the lives of its citizens and address inequalities where they exist.
2. The review was set up by the Cabinet Secretary for Health and Social Care, the former Cabinet Secretary for Children and Communities and the Minister for Social Care to examine how services for people with a learning disability could be strengthened.
3. In 2007, a statement of policy and practice for people with learning disability was published. This describes the key principles, aims, responses and outcomes that the Welsh Assembly Government believes are desirable. This is Welsh Government's latest guidance and is still relevant today.
4. Key Legislation underpinning this review is the Social Services and Wellbeing (Wales) Act 2014, the Wellbeing of Future Generations Act, the Equality Act 2010 and the Health and Social Care Act 2008 where health and social care organisations have to make "reasonable adjustments" in how services are provided in order to reduce preventable inequalities in health by people with a learning disability.
5. The UK Equality Act 2010 defines disability using the medical model – disabled people are defined as people with certain conditions or limitations on their ability to carry out normal day to day activities. However, the requirements for employers and service providers to make "reasonable adjustments" to their policies and practices follow the social model. This review uses the term "learning disability" as this is recognised and currently widely used.
6. Whilst the principles in the 2007 Statement remain, relevant anecdotal evidence is that in recent years there has been a gradual fragmentation of services with the retirement of learning disability specialised staff, cost pressures of supported living, social services being asked to focus on other areas and the pro rata spend on learning disability services being high proportionally per person, resulting in cuts to non-statutory services, e.g., day services, in order to reduce overall budgets.

The Review

7. This review began in February 2017. It reflects the voice of people with a learning disability as well as professional services and Welsh Government policy leads. A Senior Civil Servant and a programme manager were seconded to undertake this work. A desk top review of information was undertaken and then meetings were held with over 2,000 people. The team engaged with people with a learning disability, parents and carers and with existing groups, e.g., regional partnership boards, health boards, local authorities, communities of practice as well as the third and private sector groups and Commissioners in Wales.

Evidence

8. Data on people with a learning disability are recognised as being poor in Wales. A learning disability affects the way a person learns new things, how they understand information and communicate. It is estimated around 1.5 million people have a learning disability in the UK (source: People with Learning Disabilities in England 2011), some have a mild, moderate or severe learning disability and this remains throughout life.
9. Whilst approximately 15,000 adults with a learning disability are known to social services in Wales there are potentially at least 60,000 people in Wales not known to social services (based upon the People with Learning Disabilities in England 2011 data). The definition of a learning disability can be confused with a learning difficulty and in education children with a learning disability are included in the additional learning needs wider definition.
10. The additional learning needs (previously “special educational needs”) will capture children with, e.g., a short term, learning difficulty as well as children with a lifelong learning disability. Recent data (January 2017 Pupil Level Annual School Census) detail 92,975 children with special educational needs in maintained schools without a statement and 12,602 SEN children in maintained schools with a statement. Therefore 105,577 (22.6%) of children have a special educational need out of 466,508 children. 4,727 children with SEN, with or without a statement, are in special schools.
11. Changing demographics show that people with a learning disability are living longer than before and as a result have more complex needs, e.g., 1 in 3 people with Down’s Syndrome will go on to develop dementia in their 50s. Additionally, with advances in neonatal care, many premature and very low birth weight babies are now surviving but with physical and learning difficulties¹.
12. Funding for a person with a learning disability is often long-term and over their lifespan. Once a funding package has been agreed it can be difficult to change it. The cost of funding people with a learning disability varies, with the most specialised complex care costing up to £500K a year per individual in exceptional cases. High costs can be paid for out-of-country placements if there are not the

¹ M Kessenich (2018) Developmental Outcomes of Premature, Low Birth Weight, and Medically Fragile Infants (accessed from: https://www.medscape.com/viewarticle/461571_3)

placements for such specialised care in Wales. Many local authorities have focused on their learning disability services to try and reduce costs through re-commissioning of services for example.

Key Findings from the Review

13. There is a passionate, committed and enthusiastic learning disability community and the constituent organisations, people, staff and officials all want to do the right thing. There are also lots of good practice documents, reviews and policies across the UK which can continue to strengthen our policies for people with a learning disability.
14. Joining up and integrating services is a challenge, for example, when people leave school or college support may vanish. Parts of learning disability services are, for instance, in health, social services, children and communities, housing, education and economy and there is no overall policy lead for learning disabilities in Welsh Government.
15. The overriding response from parents and carers regarding their lived experience was that it was a “fight” and a “battle” to get the right services and the right support. Services were generally not seen by parents and carers as person centred and flexible to adapt to people’s needs. **Appendix A** details the experiences that people with a learning disability, families, carers and professionals found throughout the life course.
16. There are also commonalities in the life course experience of people with disability learning needs and other groups of people whose life circumstances need additional support. This demonstrates that a whole government approach and the integration of services is something that should be universal, for instance, where people with a learning disability, autism or dementia who have common needs can experience some level of equality when accessing services, outside of needing specialist support.
17. Key issues have been collated into the five themes of early years, housing, social care, health, education & employment as detailed below:
 - Early intervention and prevention is essential for the long-term quality of life, reducing adverse childhood experiences, improving the ability of parents with a learning disability to keep their children, ensuring we are supporting parents and carers to access employment and therefore stay out of poverty, and by reducing inappropriate use of medication and restraint through alternative therapies.
 - The ability to have access to a decent home should be everyone’s right as it is a key part of having a good quality of life. The impact of vacancy led placements through commissioning can led to a negative impact on the individual and may result in the breakdown of the placement. People can be living in NHS assessment and treatment centres for over a year and be in effect homeless. There are still people being placed out of country due to a lack of accommodation and services in Wales.
 - There is therefore a need to increase supported housing options including those for more complex health needs. This will reduce the burden on

hospital settings as well as providing people with more appropriate, sustainable housing and personal choice.

- More integrated health, social care and housing is an aim and whilst this is challenging, it could improve life chances and services and allow funding to be used more effectively. The impact of social care and health working together through commissioning, funding and services will not only improve people's quality of life but also provide better value for money. Welsh Government funding rules on Continuing Health Care, for instance, mean that if an individual is eligible for it, a joint package of care cannot be provided. The recommendations look to reduce the unintended consequences of these policies.
- One of the most disturbing parts of the expert evidence gathered was concerning health services and the negative impacts of getting it wrong which at worst could mean a number of avoidable and premature deaths. To reduce the health inequalities, reasonable adjustments have to be made to all services for people with a learning disability and resource must still be put into specialised learning disability services. The lack of consistency of treatment and screening across Wales is concerning and must be addressed to reduce the negative impacts.
- Wellbeing is a key outcome for the whole population and community engagement is an essential part of increasing wellbeing for people with a learning disability. They should have a right to career paths, employment opportunities and access to education. The impact of a more integrated and joined up education system with social services and health is key and again could improve life chances.

18. Challenges were also identified which will enable services to be strengthened. These were in particular to:

- Have the information/data required to be able to plan services both accurately and appropriately, and thereby meet the needs of people with a learning disability. This also includes ensuring that information is presented in easy read formats and the terminology used reflects stakeholder choice.
- Ensure the voices of people with a learning disability and their families and carers are listened to and acted upon across public services.
- Ensure when standards are set in services and outcomes monitored and evaluated, the needs of people with a learning disability are considered.
- Strengthen transport services so they are designed to meet the needs of people with a learning disability wherever possible.

Outcome-Focussed Recommendations

19. To address the key review findings, a series of outcome-focused recommendations have been made. These were formed from the views of people with a learning disability and their families and carers and have been agreed by the Welsh Government Directors Steering Group and the Learning Disability Advisory Group who represent our key stakeholders. They have been formed in collaboration with key partners including All Wales People First who represent people with a learning disability.

20. The detailed recommendations are included in **Appendix B** and the three key priorities of the recommendations are:

- To reduce health inequalities – through reasonable adjustments to mainstream services and access to specialist services when needed.
- To improve community integration, including increasing housing options closer to home, integrated social care, health and education, and increased employment and skills opportunities.
- To enable improved strategic and operational planning and access to services through streamlined funding, better data collection, partnership working and more training and awareness.

21. The recommendations strengthen existing policies and services as opposed to creating new policies and programmes where ever possible, for example, with the ACEs work, ALN and Working Wales plan.

22. They link to the Prosperity for All actions as follows:

- Prosperous and secure – linking to the new employability plan, free education and childcare, and making Wales a fair work nation.
- Healthy and active – integrating health and social care, in communities away from hospital, community health and care centres; pooling budgets and joint commissioning; promoting good health and well being; tackling health in equalities; housing health and social care capital programmes and community connectors.
- Ambitious and learning – supporting young people to make the most of their potential, providing targeted careers advice to help young people to access jobs, reforming our approach to additional learning provision, reviewing all existing skills and work based learning programmes.
- United and connected - building capacity of communities as places in which to support better health and wellbeing, e.g., social prescribing, countering the threat of extremism and hate crime, accessing Welsh language.

They also accord with the recently published Parliamentary Review of Health and Social Care and look to address inequalities faced by people with a learning disability and their families and carers to enable them to have a good quality of life. They are supported by the Equality and Human Rights Act and the United Nations Convention of the Rights of the Child.

Delivery

23. Prosperity for All and the Parliamentary Review present clear opportunities to take forward the recommendations and the **key deliverables** of the Improving Lives programme are:

- To reduce health inequalities – through reasonable adjustments to mainstream services and access to specialist services when needed.

- To conduct research and data on people with learning disabilities especially on population needs, looked after children, childcare and homelessness (in its widest sense)
- To make better use of existing funding through
 - direct payments, looking at how they are used, e.g., for short breaks, to support parents of children with a learning disability and to increase wellbeing options.
 - reallocating health and social care funding to enable swift packages of care to be agreed combined with joint commissioning of services
- To increase housing options – developing new models of supported housing and integrated housing health and social care solutions.
- To support partnership working particularly linking up education, social care and health and creating employment opportunities
- To support training and awareness raising – through easy read communications, using evidenced based therapies and interventions like positive behavioural support.

24. We propose a strengthened Learning Disability Advisory Group continues to meet to oversee the implementation of the Improving Lives Programme and provide direct advice to Ministers. Cross-Government working will also be required to ensure the leadership and implementation of the programme recommendations. Operational delivery would need to involve Regional Partnership Boards, Public Service Boards, Health boards, Local Authorities, and the third and private sector.

Finance Requirements and Governance Implications

25. There are a number of key funding streams identified that support people with learning disabilities – this is estimated to be at least £500M a year. It is recognised that a number of these funding streams are under pressure as a result of ongoing UK Government austerity which is a risk to the delivery of the recommendations but also adds to the case for managing resources across funding streams more effectively. The recommendations contain no new or unfunded items instead they seek to refocus our approach to learning disability services and to align and refocus existing funding streams accordingly. All activity will be managed from within existing budget plans. Some of these actions are scoping or pilot activities and future activity may be recommended in light of the evaluation of these pilots. Funding for this would be sought through normal budgetary processes. Any significant actions arising will be subject to the usual assessment of financial implications including the opportunity cost, and based on realistic and sensible planning assumptions of the future financial outlook.

The Lived Experience of Learning Disability Services, across the Life Course

1. Context

1.1 Welsh Government is committed to improve the lives of its citizens and address inequalities where they exist. This cross government review of learning disability policy, services and funding has looked to identify areas where action could be taken to build on existing good practice in Wales. It is underpinned by Welsh Government's Strategy: Prosperity for All.

1.2 The review which began in February 2017 has taken a lifespan point of view (from pregnancy to end of life) and has considered all main services areas. This document looks at the experiences of people with a learning disability, their families and carers and the professional staff who support them. A desk top review of information was undertaken followed by meetings with over 2,000 people to understand the lived experience of learning disability services.

1.3 In order to address the issues that have been identified a series of outcome-focussed recommendations have been made. The approach has been to develop recommendations that strengthen our existing policies and services as opposed to creating new, wherever possible. The recommendations are focused on the Prosperity for All five cross cutting themes:

- Early Years,
- Housing,
- Social Care,
- Health and Wellbeing
- Education, Employment and Skills

1.4 The findings from the experts by experience are that there are pockets of good practice and strong services, however, too many have to fight for support to enable them to have an ordinary life. The three key priorities of the recommendations are therefore:

1. To reduce health inequalities – through reasonable adjustments to mainstream services and access to specialist services when needed.
2. To improve community integration, including increasing housing options closer to home, integrated social care, health and education, and increased employment and skills opportunities.
3. To enable improved strategic and operational planning and access to services through streamlined funding, better data collection, partnership working and more training and awareness.

2. Background

- 2.1 A key turning point in the Welsh history of learning disabilities was the 1983 All Wales Mental Handicap Strategy. This had global significance and was a pioneering document. It provided dedicated funding for community care as the staged process of closing hospitals began. It had three key principles which were that people with a learning disability had a right to:
- have an ordinary pattern of life within the community
 - be treated as an individual
 - have additional help and support in developing their maximum potential
- 2.2 It supported advocacy of people with learning disabilities. The leadership of learning disabilities moved to local authorities and social services departments; previously there had been a health/medical and psychiatric emphasis in hospital settings. New guidance ensured that there had to be a detailed planning process involving key stakeholders – statutory and non statutory. Funding was only provided on the production of a suitable plan. It created a workforce of learning disability specialist staff – in health, social care and the third sector. Funding was also provided for dedicated learning disability training.
- 2.3 In 2004 section 7 Guidance was produced by the Welsh Government in response to “Fulfilling the Promises”. This promoted person centred planning, information provision, advocacy, joint working, transition planning, community living, employment, further education and day activities, general health needs, complex health needs and those with challenging behaviours. In 2007, a statement of policy and practice for people with learning disability was published. This describes the key principles, aims; responses and outcomes that the Welsh Assembly Government believes are desirable. This is Welsh Government’s latest guidance and is still relevant today.
- 2.4 The abuse of people with a learning disability in Winterbourne View private hospital in 2012 raised the profile of this vulnerable client group. Whilst Winterbourne View was in England it took sometime for the Welsh Government to be informed that three Welsh people had previously been accommodated there. This raised the issue of out of county and out of country placements amongst other issues of overall safeguarding. It also raised the issues of needing to have data on where people with a learning disability are, how monitoring of out of county and out of country happens and whether lay people, e.g., families and carers, should be part of the inspection regimes.
- 2.5 England’s response was to implement the Transforming Care programme (2013 – 2019), which is aimed at reducing hospital stays/placements and improving the quality of lives of people with a Learning Disability. Wales passed the Social Services and Wellbeing (Wales) Act 2014 which focused on keeping people as independent as possible, reducing or preventing the requirement for targeted services and in particular keeping people out of long term and institutional care. This aimed to improve the outcomes for individuals and ensure long term sustainability of social services in Wales. In addition, a number of cross cutting

inspections on Learning Disability services was conducted by HIW and CSSIW. These have highlighted some of the issues contained below.

- 2.6 Other key Welsh legislation includes the Wellbeing of Future Generations Act, the Equality Act 2010 and the Health and Social Care Act 2008 where health and social care organisations have to make “reasonable adjustments” in how services are provided in order to reduce preventable inequalities in health by people with a learning disability.
- 2.7 Whilst the principles in the 2004 guidance and the 2007 statement remain, relevant anecdotal evidence is that in recent years there has been a gradual fragmentation of services with the retirement of learning disability specialised staff, cost pressures of supported living, social services being asked to focus on other areas and the pro rata spend on learning disability services being high proportionally per person resulting in cuts to non statutory services, e.g., day services, in order to reduce overall budgets.
- 2.8 The needs of people with a learning disability are increasing as people live longer and more neonatal babies survive. This is one of the most vulnerable groups in our society which can be evidenced from recent and past high profile cases of for instance, sexual abuse, and slavery. Safeguarding these very vulnerable people is the responsibility of public services and society as a whole and sometimes the focus on people with a learning disability can be lost next to higher profile mental health or autism services. In addition people with a learning disability are often unlikely or unable to complain about the services they receive, as a consequence their needs are often not being met and services are not adapting appropriately.

It is against this background the review findings sit.

3. Life Course Experiences

- 3.1 In this review the approach taken was to look at services from maternity through to end of life. After many conversations with over 2,000 people including the Learning Disability Advisory Group, visits to establishments and a review of data it is evident that there is a passionate, committed and enthusiastic learning disability community and the constituent organisations, people, staff and officials all want to do the right thing. There are also lots of good practice documents, reviews and policies across the UK which can continue to strengthen our policies for people with a learning disability.
The following provides examples of experiences particularly from people with a learning disability, parents and carers.

3.2 Pre Birth - Early Years - 14 Years

- 3.2.1 Maternity – health professionals are normally the first contact an expectant parent will have when a baby is assessed as having a learning disability. In the past this may have been a negative experience with some health professionals telling the soon to be parents, for example, their child will not have a fulfilling and worthwhile life. This negative attitude potentially effects the rest of the person’s and family’s’ life

- 3.2.2 The assessment and diagnosis process for a child with a learning disability normally occurs by the age of 3.5 years old. However, diagnosis is not always clear cut especially for mild learning disability needs. Quite often there is no clear pathway to follow particularly with health, education and social services. Many parents also discussed feeling very isolated following diagnosis with a lack of professional and peer support. Even the support of school gate friendships are not available to parents as children often use local authority transport due to their nursery / school often being located at a considerable distance from their home.
- 3.2.3 With the mainstreaming of services, specialist services can be lost or discounted. A child with a learning disability may need more specialist support, ,, this is not always available and close to home. In schools, mainstream or specialist there is not a consistent use of evidenced based behavioural therapies such as Positive Behavioural Support (PBS) to help cope with challenging behaviour and reduce overuse of medications and restraint.
- 3.2.4 Children with a learning disability will often have greater health needs and there is concern that there is a lack of a learning disability nurses in specialist schools and lack of access to them in mainstream schools. Annual health checks start at 16 years old in Wales and 14 years old in England.
- 3.2.5 The positive views were that a child with a learning disability can access a combined health, education and social care package. However, every parent interviewed said it is after a “battle” and not just one “fight”. Some parents said that they had found some community learning disability teams had stopped taking on children with a learning disability. Others had experienced children with complex care needs being placed out of county/country and away from family support.
- 3.2.6 Often an individual’s needs are clearly not just their learning disability as they may have other conditions, such as mental health or a physical disability. This can lead to confusion as to which health team will support the child.

3.3 Adolescence 14yrs – 25yrs

- 3.3.1 Someone with a learning disability may have a number of transitions throughout their life, however, a key one highlighted time and time again is moving from children to adult’s services. The aspirations of a young person with a learning disability entering adulthood are often very low and the changes to services and loss of education support results in there often being a battle between social services and health. Employment, community engagement, quality of life chances and opportunities are often an after thought.
- 3.3.2 Housing needs can change especially if coming out of residential education establishments. People felt there is no clear pathway for young people to transition to adulthood. It was also found that whilst some Local Authorities were good at identifying children from 14 years old and planning for their future housing and support needs, involving housing associations and support providers at an early stage, this was not consistent across Wales. The lack of clear data on people with a learning disability and what their future needs might be, for example, was an identified issue which hindered long term planning.

3.4 Early Adulthood 19yrs+

- 3.4.1 Moving into adult life often means an end to education and the choice for the person seems to a stark one of either being assessed under health or social services depending upon needs and qualifying definitions. Funding seemed to be one of the main drivers of service delivery.
- 3.4.2 Adults funded under Continuing Health Care funding have some advantages and disadvantages as do those who are funded under social services, local authority funding. This results in there being differences in services. An adult receiving Continuing Health Care funding, for example, cannot access Direct Payments and therefore, may lose their personal assistant and access to some day services. One local authority said they had continued to fund a personal assistant for someone who had a limited life expectancy even though this went against the Continuing Health Care funding guidance. There are some examples of joint funding packages, however, these appeared to be inconsistent, patchy and not necessarily formalised.
- 3.4.3 Another aspect of adulthood is people with learning disabilities becoming parents. The chances of having a child taken from you if you are a parent with a learning disability is six times more likely, resulting in more looked after children. The assessment process to see if you are a “good parent” has been commented on as not appropriate and it was felt that parents with a learning disability need more tailored support to enable them to keep their children where possible. Fear of having your children taken away also drove some people to hide their disability and not seek the additional support they needed.
- 3.4.4 Many people with a learning disability especially from 24 years expressed an ambition to work and had the potential to work but found the opportunities very limited and often short term. The evidence that only 6% of people with a learning disability are in employment supports this

3.5 Mid Life – 30 Years+

- 3.5.1 Some people found that their health needs were changing but it was not as clear cut as needing just health care or social care. There were some who had an annual health check and found this useful, however, there were others who had never had a health check or did not see the importance of them. Some GPs refused to provide an annual health check and others did not use easy read material to invite people for the annual health check. Experiences in secondary care varied between good “reasonable adjustments” being made, especially when there was a learning disability liaison nurse in a hospital, to exceptionally avoidable deaths occurring.
- 3.5.2 A common concern was about having nothing meaningful to do in the day and a lack of employment opportunities. Sometime there were issues with housing support and particularly the challenge of living with others in more traditional forms of supported accommodation. An aspiration for having your own front door, living as independently as possible and being able to access flexible, targeted support came over as a strong desire for many adults with a learning disability.

3.6 Later Life - 50 Years+

- 3.6.1 UK statistics show that people with a learning disability are living longer. However, when some reach 50 years plus then there is a higher chance of them getting dementia and other illnesses. This was a particular a concern of local authorities. People with a learning disability over 50 can be placed into care homes for the elderly and be labelled as “elderly” and therefore, become unknown to public services for their learning disability resulting in appropriate adjustments to meet their needs were not necessarily being made.
- 3.6.2 Some people with a learning disability have been living with their parents all their life. As their parents become more elderly they may suffer poor health and end of life. This can result in a person not being able to stay in their own home and needing to move into residential care or supported housing. This can be a traumatic experience and whilst there are good examples of public services working together there is inconsistent treatment and solutions across Wales.
- 3.6.3 Palliative and end of life care planning is often not put into place for people with a learning disability despite the higher probability of an expected death. Whilst research is being undertaken on adults for end of life there is no research on children.

4. Learning Disability Life Course

- 4.1 The key issues raised by stakeholders have been mapped across the life course looking at risk factors and protective factors and have helped to identify the key recommendations of this review:



4.2 Early years (pre birth – 7 years)

Risk factors

- Assessment and diagnosis
- Parents not able to cope
- Parental unemployment

Protective factors

- Prenatal, perinatal and postnatal support
- Family support and parenting – includes childcare options, short break services and looked after children
- Positive behavioural to reduce the risk of challenging behaviour
- Wider strategies to reduce ACEs

4.3 Adolescence (14 – 25 years)

Risk factors

- Limited housing and education choices often out of area
- Potentially challenging behaviour
- Wanting independence and opportunities
- Risk of bullying and abuse
- Lack of education regarding personal and sexual relationships

Protective factors

- Advocacy, rights, choice and empowerment
- Signposting and service navigation – including joining up health, social care and education
- Annual health & wellbeing checks to start at 14 years old
- Employment opportunities – supported traineeships

4.4 **Early adulthood (19 years onwards)**

Risk factors

- Loss of children services at 18 years
- Loss of education at 19 years and may not meet the threshold for adult services
- Diverse adult services
- Want own front door with support

Protective factors

- Awareness raising and education
- Health promotion and education – including secondary care reasonable adjustments
- Opportunities for day time activities/work
- Supported living options

4.5 **Mid life (30 years plus)**

Risk factors

- Changing health needs
- Nothing to do in the day
- Changing housing needs

Protective factors

- Accessing healthcare
- Meaningful occupation/activity
- Integrated housing/health/social care models

4.6 **Later life (50 years plus)**

Risk factors

- Risk of earlier onset of frailty and premature death
- Family and carers aging/dying
- Placed in residential care homes as no other options
- Lack of end of life planning

Protective factors

- Changing support care – integrated health and social care services
- Housing options
- Palliative care, end of life care and bereavement

4.7 **Across the lifespan need:**

- Definitions and Data needs to be met
- Communication and team working
- Well trained and motivated workforce
- Awareness raising and education
- Accessing health and social care
- More flexible funding

- Improvements in commissioning
- Safeguarding through enabling people to protect themselves, standards monitoring, assurance, regulation and inspection
- Ability to access services and opportunities – transport

5. Key Life Course Issues and Challenges

5.1 These experiences have been captured and summarised below:

- The importance of positive attitudes of professionals and the workforce throughout the lifespan, and especially from health professionals from first point of contact with someone with a learning disability and their family.
- The need for a clear integrated pathway following assessment and diagnosis for people with a learning disability and their family/carers.
- The importance of mainstreaming services and reasonable adjustments being made whilst not losing specialist services when needed.
- The need for detailed population data and monitoring systems to ensure the needs of people with a learning disability is addressed.
- Education (mainstream or specialist schools) to embrace evidenced based interventions such as positive behavioural support (PBS) consistently to reduce restraint and avoidable medication.
- Difficult transitions between Local Authorities and Health – especially concerning funding streams and moving from children to adult services.
- Housing provision and when needed secure services, for children and adults being available closer to home rather than out of county or country.
- The need for consistency of service provision to ensure equality, e.g., how to support people to live independently rather than go into residential care.
- More focus on employment, community engagement, quality of life chances and opportunities particularly from 14 years on.
- Greater clarity and quantity of housing options throughout the lifespan, this should include the NHS considering their current role as landlord for some supported living arrangements.
- The need for streamlined funding solutions which are person centred and equitable.
- A lack of reasonable adjustments being made in primary and secondary health care, for example, using easy read communications for annual health checks and increasing the number of learning disability liaison nurses in hospital.
- More support for parents with a learning disability.
- The need for sustainable employment opportunities and targeted support for the employed (for example, induction training being geared to individual needs)
- The need for more palliative care and end of life planning for children and adults

5.2 There were also other challenges identified, some outside of the powers of Welsh government, these include:

- Living wage – overnight cost (sleep-in allowance) increases and impacts on providers and service users.
- Welfare benefit changes – supported housing and Universal Credit.
- Local Authorities frequently re-commissioning services to reduce costs resulting in a lack of certainty of provider and recruitment and retention issues of support staff.

- The ability to achieve value for money in the context of budget constraints and increasing health and social care cost predictions.
- Perverse incentives and unintended consequences, e.g., funding streams which prevent joint packages of care or increase delayed transfers of care.
- A lack of day services, respite and childcare solutions.
- The persons and families/ carers voice not being heard in regulating and inspecting regimes.
- The importance of transport – especially in rural areas and a lack of reasonable adjustments, e.g., on buses and taxis
- Preventing custodial sentences and prison services

6. Stakeholder Engagement

6.1 The diagram below illustrates a snapshot of the stakeholders met during the course of the review and the feedback they provided:

Learning Disability Improving Lives Programme

Stakeholder Engagement



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Early Years/Children

Desired Outcome	Recommendation
<p>To improve people’s life chances, through building on the team around the family approach, with the aim of reducing the number and impact of Adverse childhood Experiences (ACEs) experienced by children, including those with a learning disability.</p>	<p>Through the ongoing work of the ACE hub ensure professionals working with families with a learning disability are ACE aware and use this understanding to build on the team around the family approach.</p>
<p><u>Looked after children</u> – to improve the outcomes of parents with a LD and their children to ensure a good quality of life.</p>	<p>To understand the reasons behind children being taken into care through the current research underway. The adoption of appropriate alternative solutions to increase the support of families through e.g. shared lives and parenting groups.</p>
<p>To ensure there is adequate <u>childcare and short break</u> solutions for children with a learning disability to enable families to live an ordinary life including going to work where possible.</p>	<p>To increase the range of options for short break support through e.g. local authorities agreeing creative uses of direct payments . To evaluate the early implementation of the childcare offer, including the possible impact on the demand for, and availability of, childcare for children with additional learning needs.</p>
<p>To reduce inappropriate use of medication and restraint through increasing the use of a range of evidence based interventions for example <u>Positive Behavioural Support and active support</u> to ensure early intervention of challenging behaviour and prevention where possible.</p>	<p>Implementation of evidence based interventions e.g. PBS and active support training programmes and awareness sessions across services and the lifespan. Starting with guidance for children and parents and carers and linking to the ACE awareness training and learning from the English STOMP (STop Over Medicating People) programme.</p>

Housing

Desired Outcome	Recommendation
<p>To ensure there is choice of appropriate housing solutions integrated in communities for young people as well adults to ensure everyone has access to a decent, sustainable home, wherever possible.</p>	<p>To increase <u>new supported housing options</u> in the community across the lifespan through the targeted 20,000 homes agenda, working with LAs and RSLs.</p>
<p>To provide accessible and integrated social care, health and housing options and services for vulnerable people especially those with a learning disability.</p>	<p>To develop <u>integrated housing, health, social care models & guidance</u> learning from previous examples that provide accessible services for vulnerable people especially those with a learning disability. Utilising part of the potentially expanded Integrated capital and revenue care fund.</p>
<p>Build capacity within local services and preventative approaches to ensure people are housed in their community and to progress the repatriation agenda for those with complex needs.</p>	<p><u>Increasing accommodation options closer to home, in one place</u>, through working collaboratively with health boards, LAs, housing providers and Third sector social care providers.</p>
<p>To ensure housing funding solutions to sustain <u>housing tenancy support</u> and to reduce the number of <u>homeless people</u> with a learning disability through the prevention agenda to ensure a good quality of life.</p>	<p>Commission research on homelessness and learning disability and then take appropriate actions including housing options for those people who are living in assessment and treatment centres, in the criminal justice system and other inappropriate housing settings.</p>

Social Care

Desired Outcome	Recommendation
To ensure value for money, consistency and streamlined services through <u>integrating health and social care processes</u> , funding and systems for people with a learning disability.	To enable a person centred approach through developing models of funding to enable joint packages of care through social care funding and health care funding to prevent delayed transfers of care and inappropriate placements/ accommodation.
To ensure a person centred flexible approach to commissioning housing and support services that meets individual needs, prevents stigma and provides value for money outcomes.	To make <u>improvements to commissioning</u> moving from a contractual procurement model to a more innovative flexible person centred approach. Including potentials for a regional model for eg forensic services and more strategic planning, monitoring and evaluation.
A sufficient, high-quality, valued and skilled social care and health workforce to ensure excellent standards of care.	To work with Social Care Wales and Health Education Improvement Wales (when established in April 18) to ensure social care and health strategic workforce plans that include career pathways, progression and learning.
To ensure appropriate levels of services and support in residential care settings to enhance quality of life and progression where possible.	To ensure everyone has a care and support plan with agreed periodic reviews and follow up action, to ensure close monitoring to ensure progressive care is delivered.

Health and Wellbeing

Desired Outcome	Recommendation
<p>To reduce health inequalities for people with a learning disability and reduce avoidable and premature deaths through early intervention, prevention & accessible services.</p>	<p><u>Primary care</u> – Improve the take up and quality of annual health checks to monitor & identify health needs. To ensure traffic light systems/ health passports are put in place and the health equalities framework. To work towards one GP register that captures population health needs.</p>
<p>To improve secondary care services and diagnostic overshadowing to reduce health inequalities, premature and avoidable deaths.</p>	<p><u>Secondary care</u> – To ensure reasonable adjustments are made for people with a learning disability through using care bundles, having LD champions, system flagging and increasing the number of learning disability liaison nurses across Wales.</p>
<p>To increase wellbeing, community engagement and quality of life for people with a learning disability.</p>	<p>Local authorities, health boards and the third sector to collaborate to build upon wellbeing assessments and social prescribing models which more systematically signpost people to a range of non clinical wellbeing support to enable access to leisure, sport and culture for instance.</p>
<p>Meeting specialist health care needs throughout the lifespan to ensure a good quality of life.</p>	<p>To ensure that people with complex needs have timely and easy access to LD specialist services through maintaining multi disciplinary teams, reviewing health’s bed placed provision and developing appropriate care services, eg trauma informed care, PBS, mental health and out of hours access .</p>

Education, Skills and Employment

Desired Outcome	Recommendation
<p>To join up services between education, social services and health to enable person centred support</p>	<p>Ensure there is a <u>champion</u> for the rights of children and young people with ALN and Learning Disability in schools and health through the ALN Code’s guidance on the role of the ALN Coordinator and DECLO, including their roles in supporting effective <u>multi-agency working</u>. Implement the specialist and mainstream school nursing framework.</p>
<p>To plan and provide opportunities for young people with a learning disability to ensure they have a good quality of life</p>	<p>Provide guidance on effective multi-agency planning to support a smooth <u>transition from 14 -25 years old</u> through the ALN code. To provide operational and joined up solutions to reduce the trauma of transition including offering employment, skills and housing.</p>
<p>Ensure there is adequate specialist support provided across Wales to meet more complex needs in education, skills and employment</p>	<p>Put <u>learners at the centre of services</u> through regional planning for specialist support e.g. hearing and sensory loss services</p>
<p>Increase planning and opportunities for people with a LD through strengthening of <u>career pathways</u>.</p>	<p>Explore options for individuals with a learning disability to access employability support, including through the new <u>Working Wales Programme</u>.</p> <p>Explore possibility of introducing <u>supported paid work placements</u> into Wales and disseminate good practice.</p>

Key Enabler Recommendations

Desired Outcome	Recommendation
<p>To have the information needed to be able to plan services to accurately and appropriately to meet the needs of people with a learning disability.</p>	<p>Definition/Data - need to consider options of a data observatory for Learning Disability services - learning from England and Scotland</p>
<p>The voice and needs of people with a learning disability and their families and carers is listened to and acted upon across public services.</p>	<p>Regulation/Inspection/assurance - need to work with the regulators to strengthen the voice and empowerment of people with a LD and families and carers</p>
<p>To ensure when standards are set in services and outcomes monitored and evaluated, the needs of people with a learning disability are considered.</p>	<p>Standards, monitoring and evaluation – need to ensure appropriate standards and monitoring are in place.</p>
<p>Transport services are designed to meet the needs of people with a learning disability wherever possible.</p>	<p>Transport – ensure action through the transport panel for vulnerable people to enable accessible services appropriate to the needs of people with a learning disability</p>