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-focused 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. Sometimes 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/carer's 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: