

## Learning Disability – Improving Lives Programme

**The Learning Disability – Improving Lives Programme is a cross government review of learning disability services sponsored by a number of Ministers. It looks at key services from a person centred point of view and across the life course. This paper seeks Cabinet approval of the review recommendations as part of the developing work on Prosperity for All and the Parliamentary Review.**

### Issues

### 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 project manager have been 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 difficulties<sup>1</sup>.

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 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:

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

- 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 lead 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 then 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 UNCRC.

## Delivery

23. Our vision for learning disability services in the future needs careful articulation as does change on the ground at service levels. Therefore, once recommendations are approved it is proposed that the programme moves directly to implementation stage using a co-production methodology and working closely with people with a learning disability and those who support them.

24. 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

## Finance Requirements and Governance Implications

25. The Learning Disability Improving Lives programme is cross-cutting in nature and has been developed by drawing together contributions across portfolios through the director level working group. All the recommendations have been agreed across portfolios.

26. There are a number of key funding streams identified above 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.
27. The recommendations outlined in Annex 2 in relation to Education, Skills and Employment can be met from existing resources within the Education MEG. The costs to support the ALNET Act will continue to be met from the Additional Learning Needs BEL (5115) of the Education MEG, which has a budget of £2.786m for 2017-18 and 2018-19 and the Raising School Standards BEL (5511) which has a budget of £0.5m in 2017-18 and £3.2m in 2018-19 (ALN element only). Funding for the Working Wales Programme will be met from the Employability & Skills BEL (4496).
28. As there are no issues of regularity or propriety, this submission does not need prior approval by the Corporate Governance Unit (CGU).
29. In clearing this advice Finance teams have considered the paragraphs above and their respective contributions and are content for the recommendations to be considered by Cabinet. Administrative costs of developing the recommendations are affordable within DRCs and given the overall approach for Prosperity for All, the specific learning disability posts will be considered as part of the prioritisation exercise currently underway.

This advice has been cleared by: the SHELL Operations Directorate No SHELL/CSE/198/17; the EPS Operations Team No EPS/HID/13/18; HSS Finance No JB 2018/6544; and Strategic Budgeting: clearance No SB0390/5.

### **Research and / or Statistics**

The research and statistics contained in the paper have been approved by Knowledge & Analytical services. This advice has been cleared KAS No 6/2018.

### **Communications and publication**

A written statement will be produced and the paper published in 6 weeks.

**Recommendation:**

**Cabinet is asked to approve the outcome-focussed recommendations and the co production process for implementation, as part of the developing work on Prosperity for All and the Parliamentary Review.**

**Joined up Working**

1. The Ministerial Learning Disability Advisory Group has considered the cross cutting issues around strengthening learning disability services. The group has met and bilateral meetings with individual Cabinet Secretaries and Ministers have taken place. Written contributions for each portfolio were also sought and received.
2. We propose the Learning Disability Advisory Group continues to meet to oversee the implementation of the Improving Lives Programme. 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.

Bilateral meetings have taken place with the following:

- Cabinet Secretary for Health and Social Services  
Cabinet Secretary for Education
- Minister for Children and Social Services
- Minister for Housing and Regeneration
- Minister for Welsh Language and Lifelong learning

As well as meeting key policy officials in:

- Department of Education and Public Services
- Department of Health and Social Services
- Department of Economy, Skills & Natural Resources

**Huw Irranca-Davies AM,  
Minister for Children and Social Care  
March 2018**

Drafted by Kath Palmer  
Approved by Andrew Goodall (Director General)