

Learning Disability Wales' response to Welsh Government's draft Learning Disability Action Plan

Learning Disability Wales welcomes this opportunity to give feedback on the draft Welsh Government Learning Disability Action Plan 2021-2026. As part of the listening exercise undertaken by Welsh Government, we shared the plan with our members and stakeholders and invited feedback. We received 8 responses from organisations, 3 from individuals, and 1 from the Covid Research Study. Additionally, 3 separate responses were received from groups of people with a learning disability. A collated response is provided as an appendix as well as copies of all the full responses.

We suggested that the responses could be structured around the 4 questions for consideration that were included in Andrew Stevenson's email of 20 January 2022. However, most of the respondents, within a very short timescale, provided detailed comments about sections and actions important to them. We are aware that the Welsh Government is committed to publishing the Learning Disability Action Plan before the end of the current financial year and hope that the responses from Learning Disability Wales and its stakeholders will assist with production of the final version.

The response from Learning Disability Wales below is structured around the 4 set questions.

Are the areas identified in the plan the ones you think Welsh Government should be focussing on?

The plan appears to be comprehensive and highlights the important issues in the lives of people with learning disabilities, their families, and paid carers. The plan is very aspirational but lacks detail on implementation.

We understand that a more detailed implementation plan that sets out specific actions within each area to help deliver the main themes of the action plan will be produced and we look forward to reading this. However, we are concerned about how each part of the plan will be monitored and how any progress, or otherwise, will be measured and shared with stakeholders including people with a learning disability and their families/carers. While it is positive that outcomes are noted in the action plan, during the evaluation phase consideration needs to be given to whether the outcomes are being met, what has happened to enable this and if they are not being met, why this is.

Learning Disability Wales welcomes the strategic priority area 1.2 'Continued commitment to an inclusive and fully accessible Learning Disability Ministerial Advisory Group for people with a learning disability'. However, some of our members, including organisations and groups for people with a learning disability, have said that they do not know who sits on the group or what their

roles and remit are. If membership was widely known, stakeholders could then work with members of LD MAG to highlight items for the agenda. The outcomes of discussions are also not publicly available outside of the group, which again excludes stakeholders who do not have a representative on the group.

Some of the outcomes require funding eg 3.1 Outcome 1: 'reduce admissions through crisis prevention'; Outcome 2: 'ensure access to high quality, safe and effective specialised care as close to home as possible' and Outcome 3: 'support individuals to return home/ close to home as possible'. Without a substantial funding commitment these important outcomes will not be achieved. Other outcomes are rather vague eg 3.7 'reduce health inequalities and avoidable deaths through improved service provision' and require further clarification of how they will be achieved. Strategic priority area 2 – 'Covid Recovery and Well-being' needs to include reference to the recommendations from the ['Locked Out: liberating disabled people's lives and rights in Wales post Covid-19' report](#) and the findings from the [Covid Research Study](#) that looked out how Covid-19 affected the lives of adults with a learning disability in Wales.

Learning Disability Wales believes that section 5 is very thin on detail and ambition. We have received some excellent feedback from stakeholders on this section and recommend that Welsh Government review these responses carefully. With regards to the action under 5.1 'Children and Young People's Learning Disability Services': 'Welsh Government to work with stakeholders and service providers to improve collaborative working [...] including transition services across health, social care and education', Learning Disability Wales would like to draw your attention to several reports around transition to adulthood for young people with a learning disability that have previously been published. It is very important that these are highlighted and the recommendations contained within them addressed. If they are not, we are in danger of reinventing the wheel and it will also be an injustice to the young people involved in the research. The report we would like to highlight is: ['DON'T HOLD BACK' - Children's Commissioner for Wales](#) - Transitions to adulthood for young people with a learning disability report. Learning Disability Wales feel that the Action Plan should include a specific action on improving transition arrangements. Real Opportunities was a pioneering project in Wales that supported young people with additional needs to transition to employment. The learning and [resources from the Real Opportunities project](#) and the current [Engage to Change supported employment project](#) should be referenced within the Action Plan and/or implementation plan.

We welcome that the issue of loneliness and isolation is included in 3.8. The action here is to explore the prevalence and causes of loneliness and isolation for people with a learning disability. However, consideration needs

to be given to how to address these issues rather than simply identifying them.

We also note that some areas such as transport have only one action. Accessing public transport is very important to people with a learning disability and many groups across Wales have carried out a lot of work in this area including developing a travel app. As part of this action, travel training for people with a learning disability must be developed to ensure they are able to use transport independently. Public transport was also raised as an issue by the group of people with learning disabilities supported by the North Wales peer advocates. Issues highlighted included accessibility and the fact that some people have different transport needs that require them to use taxis, especially as support workers are not allowed to provide transport for individuals in their cars.

Some of the actions can be linked together, for example Point 3:1 'Implement recommendations from the 2020 review of Adult Specialised Services' Outcome 2: 'Ensure access to high quality, safe and effective specialised care as close to home as possible' and Outcome 3: 'Support individuals to return home/close to home as soon as possible' should be linked to Point 7.3: 'Housing and accommodation - Improve choice and control for people with learning disabilities including where they live and who they live with, within community housing, supported living and private tenancies'. Learning Disability Wales would like to support the point made by one of our members that if you do not have the right placements available, placements are likely to break down and the person will inevitably result in having to be placed miles from home. Bespoke local provision is needed that minimises the risk of placement breakdown and the person having to be placed elsewhere (for example, in secure provision such as an ATU or secure residential setting).

Is Welsh Government doing enough in these overarching areas to meet the needs of people with a learning disability?

The plan is comprehensive but as mentioned above some areas could be firmed up, such as transport and advocacy. We support the comment made by the North Wales focus group of people with a learning disability who note that *"Self-advocacy has an important role to play if future Learning Disability Strategies are not repeating themselves. Self-advocacy is the only way to get co-production and improve people's choices."*

We wait to see how the plan transfers into making a positive difference to the lives of people with learning disabilities and their families so that they can live the life they choose to live. This must be the main aim. However, Welsh Government could do more by ensuring that a mechanism is put in place to ensure the outcomes are monitored and evaluated. Without this, the plan is likely to remain purely aspirational.

Welsh Government must also ensure that all local authorities and health boards understand their obligations within the Action Plan. We support the comments from one of our members that “A mechanism should be in place to measure specific commissioner related outcomes to avoid a disjointed approach from health and local authorities who don't work together or have a shared vision.”

We also support the comment from another member whose response to the action under 1.6 'Joint working, co-production and collaboration' that states 'gather views from people with learning disabilities, families and carers on what Wales should look like for them in 2033, if the programme is to be a success' was “*Joint working, co-production and collaboration cannot be achieved by gathering views. A new relationship is needed where different forms of knowledge and expertise are recognised and contribute to co-designing an understanding of the problem and then possible ways forward. The policy focus needs to shift back to people's lives (as in the 1983 strategy vision) and away from focusing on services (a shift in focusing increasingly evidence since 1994)*”.

Do you think these proposals will be achievable in the years ahead or will they put too much pressure on services during the ongoing health crisis?

Learning Disability Wales accepts that the public health crisis has put a huge strain on services already and this will continue as we come emerge from the pandemic. However, being a partner in the Covid Research Study has highlighted the massive impact that the pandemic has had on the lives of people with a learning disability and their families. We found that many existing support structures were removed or reduced dramatically because of the COVID-19 pandemic, which resulted in challenging and complex caring situations being exacerbated. As well as thinking about recovery and a 'return to normal', thought also needs to be given to considering the likely longer-term impact of living and caring through the pandemic. Well-being outcomes must be met and people with a learning disability and their families must be enabled to exercise voice and control. We note that strategic priority 3.12 is 'review of the Social Services and Well-being Wales Act 2014' and welcome the outcome to 'ensure the aims and objectives of the Social Services and Wellbeing (Wales) Act 2014 meet the needs of people with learning disabilities and their parents and carers'. It is also essential that discussions and plans for improving health and social care services for people with learning disabilities include plans to better support carers in the longer term.

People with a learning disability have found that contact with statutory services such as social workers has been reduced since the pandemic began. Support packages had also been reduced and some services have still not been reopened or are running at a reduced level. This has left people being unclear about what support services they should be getting. The

reduction or removal of social and health care support remains a major concern for people with learning disabilities and their families. Therefore, although the proposals may put pressure on services, we strongly believe that it is vital that these proposals are put into effect.

Are there other areas that should be included as a priority?

Learning Disability Wales is very concerned that the plan makes no reference to learning disability liaison nurses. We understand that the funding to continue the provision of liaison nurses for the next 3 years is being made available. However, we believe it must be mentioned as a key priority area and action in the plan to ensure health boards remember that this valuable service must be provided.

There is also no mention of health action planning in the document. We are pleased to see that 'Increase access to Health Checks for people with a learning disability' is noted as a strategic priority area at 3.5. To achieve this, it is vital that the learning disability register and the GP flagging system is improved to ensure that anyone who would benefit from the annual health check (AHC) receives one. However, the AHC is a process. As one of our members noted, annual health checks are *"more than just the consultation and if the issues identified at the health check are to be followed up and addressed health action planning is key"*. People with a learning disability can often present late with health issues so it is even more important people with learning disabilities can access investigations, treatment etc at a time when the NHS is under such severe pressure. Health action planning is also key to ensuring that people with a learning disability are supported to self-manage their health in between health checks. We are also concerned that the annual health check easy read resources that were produced nearly 3 years ago have still not been made fully available to the public. It is essential that these are available not only to primary care professionals but also to people with a learning disability and their families/carers to improve the accessibility and efficacy of the annual health check process.

We are concerned that in 3.7 one of the actions is to 'review use of the flagging system and use of the care bundle'. This needs to be strengthened so that as well as bring reviewed, the practical tools available are relaunched to ensure more mainstream NHS professionals know about them, and can identify and respond to the needs of an individual with a learning disability.

Another omission is that there is no mention in the plan of secondary health care or Care Inspectorate Wales. Stakeholders have told us that they have concerns around the latter organisation and their lack of engagement with people with a learning disability and their families. We also recommend that people with a learning disability and family carers receive training to be lay inspectors alongside Care Inspectorate Wales inspectors.

Learning Disability Wales supports that action 3.10 is looking at the interface between Direct Payments and CHCs. However, we recommend that the action should not simply 'explore' this interface but resolve the current situation where someone receiving Continuing Health Care cannot have a Direct Payment. We also recommend that as well as allowing social care to be provided under a Direct Payment, health care can also be provided. Details can be provided of how a child received healthcare as well as social care as part of a Direct Payments package. This included health staff training personal assistants to do PEG feeding etc and being covered by health insurance.

Learning Disability Wales was invited to do a focus group with a group of people with a learning disability who live in supported living provided by one of our member organisations Mirus. They provided some feedback to the different sections of the plan but they all wanted to point out an omission. This was the fact that they wanted to be in control of their own money. More information about the discussion is contained in their full response (attached as an appendix). Learning Disability Wales realises that this point may not be appropriate to include in such an overarching plan but we felt that it should be highlighted as the members of the focus group felt so strongly about this issue.

The North Wales self-advocacy group of people with a learning disability support the inclusion of BAME people with learning disability in the action plan. However, they express disappointment that the same pledge is not given to people from the LGBTQ+ community. The group also felt that respecting the right for people with a learning disability to choose relationships including friendships and sexual relationships should be included.

Finally, Learning Disability Wales would like to support the call by the Paul Ridd Foundation for the Learning Disability Education Framework for healthcare staff to be named in Paul Ridd's name as the training was established following his death and many years of campaigning by his family to ensure no one else with a learning disability received an inadequate level of health care.

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