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Ymateb gan: | Response from: Mencap Cymru



Mencap Cymru's response to the Health & Social Care Committee's Mental Health Inequalities Inquiry.

About Us

Mencap Cymru is a learning disability campaigning organisation and service provider in Wales. Our vision is for the UK to be the best place for people with a learning disability

We welcome the opportunity to present our views and those of our membership on mental health inequalities in Wales, and ideas to address them.

Background

People with a learning disability have long been the subject of mental health inequalities. This historical injustice was born from the mass hospitalisation of people with a learning disability and mental ill-health in the early, twentieth century. Those not hospitalised for decades were also hidden from view, unable to take part in society.

The legacy of this period in our history is a society that is catching up to the needs of the individuals and their family/carers. People with a learning disability have less autonomy, are more dependent on others, and are more reliant on services provided for them, and therefore more affected by changes to policy and Government funding decisions.

Because of this dependency, people with a learning disability are more likely to be affected by 'negative life events'. This can include staff changes, physical health issues, a lack of agency over their lives, housing issues, being ill-equipped to deal with bereavement etc.

(Bond et al. 2004) Found a link between negative life events caused by the above and people's mental health "It is likely that people with intellectual disabilities are exposed to more life events than the general population and this may be due to different living conditions, dependency on others and having less autonomy. In addition, negative life events are found to be predictive of later psychological trauma in people with intellectual disabilities (Wigham et al. 2013).

Some studies suggest the rate of mental health problems in people with a learning disability is double that of the general population (Cooper, 2007; Emerson & Hatton, 2007; NICE, 2016). The estimated prevalence of mental health disorders ranges from 15-52%, depending on the diagnostic criteria used (Cooper et al., 2007; Emerson & Hatton, 2007; Hatton et al. 2017; McCarron et al. 2017).

Other people's attitudes also have a massive impact on people's mental health. Stigma and discrimination can become internalised, which can result in psychological distress (Ali et al., 2015; Pelleboer-Gunnink et al., 2019)

Drivers of mental health inequality for people with a learning disability

Mental health inequality is not just about a direct pathological link between learning disability and mental health problems, or poor access to treatment and support, it's a symptom of wider inequalities in society, and of trauma.

We must view mental health problems as a social problem. The social determinants of health (<https://www.gov.uk/government/publications/health-profile-for-england/chapter-6-social-determinants-of-health>) are areas where people with a learning disability have been at a historical disadvantage. If the circumstances of a person's birth, where and how they live, their education and work opportunities, meaningful connection with friends and social networks, and finances all contribute to a person's health it can come as no surprise that these play an important part in the mental health of the people we support.

People with a learning disability begin post-pandemic life at an even greater disadvantage than before. A reduction in face-to-face primary care, annual health checks, access to social workers, and opportunities to socialise will compound people's mental health issues. But it is not just a person's environment that will impact, people with a learning disability often have limited control and agency to bring about change in their lives. We need to devolve power to people with a learning disability and their family/carers.

In England only 6% of people with a learning disability known to services have a paid job. With 17% of all adults with a learning disability in paid work (Emerson and Hatton 2008). We suspect this number to be similar for Wales. Only around 4% of people with a learning disability are living as part of a couple, some are unable to choose who they live with, or have the autonomy to decide when and where they socialise.

Access to support

The key to erasing mental health inequalities is to address the underlying causes of mental ill-health. We feel that for most people with a learning disability, mental health problems are not the result of an internal problem, but a result of the external.

However, people will likely need access to some mental health support.

We know that people with a learning disability often struggle to receive the right mental health support. For so long the discussion has been which is an individual's 'primary diagnosis', after which a determination is made around whether people should receive specialist mental health, or learning disability support. It is often a choice between one or the other.

We feel this approach is outdated and rooted in the period of institutionalisation. An increasing, but still small number of people with a learning disability are given a dual diagnosis of learning disability and mental health. Whilst a diagnosis of learning disability is helpful for several reasons, we feel that it should be seen primarily as a social condition, not medical. We 'treat' mental ill-health, we do not treat learning disabilities. They should not be a binary choice.

A better approach is to treat people with a learning disability with specialist mental health support, rather than passing people between teams depending on

circumstances. We also need to recognise that trauma could include the chronic denial of choice or control, in addition to a catastrophic incident. This will require social care staff who are trauma-informed, which is an approach that recognises the importance of recognising relationships, understanding power dynamics and creating connections. (<https://www.bild.org.uk/wp-content/uploads/2021/02/Trauma-Informed-Care-Toolkit-pdf-SABP.pdf>)

Mencap Cymru runs the Wales Learning Disability Helpline, funded by Welsh Government. We have fielded several calls from social workers who have moved into taking on learning disability casework seeking more information about learning disabilities. We feel it is important that Social Workers are well-prepared to support people with a learning disability, something that needs to begin during their training. It is an already over-stretched and depleted workforce, we must do better to prepare people who hold incredible importance and power in many people's lives.

We are also concerned about diagnostic overshadowing. We know from the death of Paul Ridd that it can have a profound impact on physical health. But we remain concerned that it also impacts the diagnosis of mental health issues. We know of people in our services experiencing a profound mental health crisis, whose staff are told by health colleagues that their crisis is likely their learning disability, not their mental ill-health.

Annual Health Checks

Mental health questions form part of the Annual Health Check in Wales, which is to be commended. However, we hear time and time again, through our helpline and carers network that the quality of annual health checks vary, with many people not asked the right questions by GPs around mental health.

Mencap Cymru has funded a PhD study at the University of South Wales (Dawn Cavanagh) on annual health checks "Annual health checks for people with learning disabilities: an exploration of experiences, follow up and self-management of health conditions" it found that *"Not all participants were asked about mental health at the AHC, despite people with learning disabilities being less likely to voice mental health issues (Thorpe, Davidson and Janicki, 2000) and having a greater propensity for developing mental health problems compared with the general population (Foundation for People with Learning Disabilities, 2019).*

Many participants described ongoing issues with their mental health in the months following the AHC. A few participants reported struggling to get support from their GP."

Some GPs won't do the checks, forcing people to either not have one, or travel to a practitioner they are unfamiliar with. People value seeing a named person they are familiar with when addressing health issues.

Annual Health Checks are a vital tool to allow health professionals to pick up on the early signs of mental ill-health, we must ensure GPs are asking the right questions, do not diagnostically overshadow (seeing the learning disability as the cause, not the mental ill-health), and are trauma-informed.

Restrictive Practises

There has to be clear data to which the extent of restrictive practices are used in social care settings. There has long been a misconception around the causes of behaviours that challenge. They are rarely caused simply by the presence of a learning disability. Behaviours are more often than not caused by our environment, the people around us and importantly trauma. By having a trauma-informed workforce we can work to reduce the use of restrictive practices.

There are some residential colleges in Wales leading the way around the development of trauma-informed Positive Behavioural Support plans which has seen a large reduction in the use of restrictive practices. We would welcome research into this approach and how it can be applied in settings across Wales.

Loneliness, isolation and social connection

A lack of social support and reduced coping skills are associated with depression and anxiety in people with a learning disability (Austin et al., 2018; Bond et al., 2019). This can increase the stress and burden felt by people with a learning disability when they are exposed to negative life events (Bond et al., 2019).

Research shows that children and teenagers with a learning disability partake in fewer activities and participate less frequently than their peers without a learning disability. They also tend to have fewer friends (Solish et al., 2010; Taheri et al., 2016). Many parents who have children in mainstream school have shared with us their experiences of their non-learning-disabled children being invited to parties of peers where their learning-disabled child is not invited. This form of discrimination and exclusion will have an impact on the mental health and wellbeing of young people with a learning disability.

There is a direct connection between lower levels of anxiety and depression and having more social connections. But this is an area of everyday life people with a learning disability find is often put behind barriers. Direct support services are not designed to facilitate socialising outside of office hours. Successive policies, programmes and projects focus on the activities people do, not the connections they have.

The move towards one-to-one support in place of day services fails to recognise the importance of friendships and relationships on well-being.

Being physically present in a community does not necessarily mean people with a learning disability feel integrated within the community or accepted by their peers. Social inclusion involves making meaningful connections and participation in fulfilling activities (Cummins and Lau 2003; Overmars-Marx et al., 2013). Research suggests that 1 in 3 young people with a learning disability spend less than 1 hour outside their home on a typical Saturday (Mencap, 2019).

To address mental health inequalities, we must also tackle the inequalities that lead to poor mental health. Some of the people we support are telling us that they would rather not return to their day centre, preferring the more personalised approach

necessitated by COVID through direct payments. However, they also report missing the community afforded them by building-based activities. So for many, the answer is neither building based activities, nor direct payment. Instead, new spaces need to be co-created, using the principles of co-production. We would be keen to share with you the progress made around our co-produced day service being piloted in Rhondda Cynon Taff.

When the long-stay hospitals closed, people were resettled to their local communities with no regard paid to the friendships and relationships that developed over many decades. This undoubtedly had an impact on individuals' well-being, as we found during our 'Hidden Now Heard' oral history project. This mistake cannot be repeated as day services are re-shaped. More one-to-one support must not simply be about taking someone to sit in a community, they must be supported to maintain their old friendships, and develop new ones. To be part of a community.

Whilst many local authorities are reviewing building-based day services, we feel they are doing so to save money, not to improve the well-being of the people who attend.

Assessment & Treatment Units

It has now been eleven years since the Winterbourne View Scandal (<https://www.itv.com/news/wales/2021-06-01/i-hate-my-life-how-one-patient-feels-living-in-a-hospital-hundreds-of-miles-away-from-home>). Winterbourne highlighted serious failings in the inspection regime of Assessment and Treatment Units (ATUs) in England, where today approximately 31 Welsh people live (National Care Review of Learning Disabilities Hospital Inpatient Provision 2020). There are many more living out of county but within Wales.

These units have become home for too many people with a learning disability who are far from their family, where they feel most safe. The same review stated that the average stay at an ATU is over 5 years, meaning 155 years of people with a learning disability's lives have been spent living a long way from their loved ones in England. With a further 87 people residing in units or hospitals within Wales (Psychiatric Census, NHS Wales Informatics Service, 2019).

We can be rightly proud in Wales, that we as a nation has led the way in the development of services for people with a learning disability with the 1983 All Wales Strategy, born from lessons learned from the 1969 Ely Hospital scandal. The strategy provided a platform that developed services and supported living for the estimated 15,000 people with a learning disability currently known to statutory agencies living in Wales. But we risk losing ground.

We risk not learning the lessons of long-stay hospitalisation where thousands of people were taken to live, geographically isolated from their loved ones. Places that were home in name only, and with as much potential for abuse as the ATUs. These individuals are denied the opportunity to belong to a community and to form long-lasting connections.

Mencap Cymru played an integral role in the closure of the long-stay hospitals in Wales through the “Longest Waiting List” campaign that culminated in the last hospital in Wales closing in 2006.

In the ten years since Winterbourne further cases of abuse were uncovered at Mendip House in Somerset, and Whorlton Hall in County Durham, this is not an issue limited to ATUs. Thankfully in Wales, we have avoided such scandals to date because the Welsh Government engaged with the Learning Disability Advisory Group, and the updated Private and Voluntary Care Regulations 2009, which limits the number of beds in a long-term setting to 10. But 31 people remain outside of these regulations in settings in England.

As long as there are people with a learning disability being placed out-of-county and out-of-Wales, we are failing to uphold the promise that Winterbourne would never happen again, and could never happen in Wales.

COVID

The impact of COVID will have had a profound effect on pre-existing inequalities. The Welsh Government's Locked Out Report (2021) found that “Evidence presented in this report demonstrates the disproportionately negative effect of the pandemic on disabled people’s mental health and well-being.”

The pandemic has acted to amplify the mental health inequalities experienced by people with a learning disability. During the pandemic people with a learning disability have become invisible. When restrictions were lifted for most of society, they remained in day centres and residential homes, leaving them even more isolated than the general population. So recovery is going to require additional support on top of the support that was required.

The Locked Out report also found that “people reported more frequently than non-disabled people that the pandemic is affecting their wellbeing because it makes their mental health worse (41% for disabled people and 20% for non-disabled people);”

Family/Carers

Your enquiry must be holistic, considering the needs of family/carers, and not just people with a learning disability.

We must not forget the impact on family/carers' mental health. Family/carers will be at the forefront of facing and fighting mental health inequalities. The pandemic has left many feeling burnt out, but determined to carry on. If family/carers are in distress and left depleted this will further impact the mental health inequalities experienced by their learning-disabled family members.

Many family/carers we have engaged with feel unable to complain to local authorities or other providers about the problems they face, for fear of losing the support they already have. This causes additional stress and impacts their well-being.

One of the parents we regularly engage with on our parent's forum is currently feeling the impact of mental health inequalities on their daughter and themselves. Since 2019 they have been funding a music therapist to come to their home themselves. Their daughter has increased in confidence and all of their wellbeing has improved markedly. However, since a continuing healthcare package was agreed upon in 2021, they have learned that the therapy must now take place outside their home and county, with their daughter travelling to the venue to see their current therapist.

Such a journey would negatively impact their daughter's well-being. Currently, significant effort is put into preparing their daughter emotionally for the session which includes long walks beforehand. The family feel strongly that being forced to attend a new venue could erase any benefit of the sessions themselves. If the family had greater power and had truly been able to co-produce this service they would not be facing such a difficult situation.

In addition to services like this being out of county, the family/carers of those in assessment and treatment units face additional mental health pressures from being separated from their loved ones either out of county or out of Wales.

Conclusion

The mental health inequalities experienced by people with a learning disability are a result of a long history of failure by government to address the wider inequalities people face. Whilst we recognize that having a learning disability means you are more likely to experience mental ill-health, it is often because of society's inequalities, not anything inherently pathological.

A move to centralise annual health checks in local hubs risks leaving people with a learning disability less likely to engage with primary care. This will result in fewer mental health issues being identified earlier. This means more crisis intervention is required, increasing pressure on health and social care.

A misplaced focus on activities over connections has impacted the well-being and mental health of people with a learning disability and their family/carers. Isolation and loneliness have a big impact on people's mental health and we must not repeat the mistakes of the past.

COVID is an opportunity to rethink how we support mental health, but only if it includes the views and experiences of people with a learning disability and their family/carers. It must not be driven by the needs of local authorities and the Government to save money, but by a desire to undertake a devolution revolution in social care.