

# *Stolen* lives

## MANIFESTO

### **Stolen Lives Campaign Group: who are we?**

STOLEN LIVES is a campaign group of families who have loved ones with a learning disability or who are autistic, and who are living or have lived in inappropriate mainstream mental health or specialist learning disability hospital provision.

We are joined by allies from different organisations who support us. These include self-advocacy organisations, user-led organisations of disabled people, researchers, and activists.

There are five main actions that we want the Welsh Government to address. We also want health and social care commissioners to act decisively at a local level. We would love it if more people in general knew about this scandalous injustice and spoke up and out.

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**W**E NEED you to find out and tell us how many children, young people, and adults with learning disabilities and autistic people from Wales are away from home in inappropriate hospital and so-called assessment and treatment units?

*We need you to tell us how you are going to bring our family members back closer to home and into provision that meets their needs.*

We need you to recognise and understand what families like ours experience daily, to hear our voices, and to act on our concerns.

*We think that sectioning people is not a solution, just because social services, health boards, and service providers are failing to meet the needs of people with learning disabilities and autistic people.*

We need you to work together with organisations representing people with learning disabilities and autistic people, as well as family members, to produce better support.

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## We need you to find out and tell us how many children, young people and adults with learning disabilities and/or autism are away from home in inappropriate hospital and so-called assessment and treatment units?

IN GENERAL THERE is a lack of high quality and differentiated data about the lives of people with learning disabilities and autistic people in Wales as referenced in the Equality and Human Rights Commission (2023) report, *Is Wales Fairer?* which says:

“There are difficulties in understanding the inequalities faced by specific groups of disabled people. The differences in the gaps and rates between groups are not always clear, due to the lack of available evidence, issues of aggregation or sample and population sizes in the data. The issues faced by people with a learning disability, for example, may be concealed by the aggregation or conflation with learning difficulties into a single category in data sets.”

It adds:

“Data on people with a learning disability are recognised as being poor in Wales.” (*Learning disability – Improving Lives Programme, 2018*). The fact that there were people from Wales in Winterbourne View, ‘...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.”

We call for a National Learning Disability Observatory for Wales and keenly await the outcome of, “a feasibility study to identify costs/benefits of establishing a Learning Disability Observatory for Wales – by April 2024.” *Learning disability delivery and implementation plan 2022 to 2026* (2023)

The overall number of people living ‘stolen lives’ must be known. Even if numbers are small, the issues require urgent action. Individual families have been told that this is a ‘niche issue’ for too long. An Observatory may help drive evidenced-based policy including in relation to the on-going scandal of the premature deaths of people with learning disabilities (*Can you spot the difference? We Can’t*, 2023).

There is no data that we can find on the premature deaths of people with learning disabilities in Wales.

*Improving Care, Improving Lives* (NHS Wales, 2020) is a descriptive, snapshot of relevant data (with a raft of largely unactioned recommendations with untraceable threads of actual outcome/accountability). Data presentation works on the assumption that there is a static group of people in inpatient units. While there are an awful lot of people stuck in places for years and years, there are also people going into and coming out of hospitals, sometimes repeatedly, that snapshots at one point in time do not reveal. It’s important to get information that captures this – one simple one would be:

### How many different people over the course of a year have spent some time in an inpatient unit?

We are also aware of people with learning disabilities who have entered hospital for genuine medical issues (mental and physical health problems) and have not been resettled back into the community. We know of one man who is still in such a situation after sixty-six years! We also know that a lot of people with learning disabilities and autistic people are spending time (sometimes short periods of time) in ‘mainstream’ mental health inpatient services that do not show up in other datasets and can be ignored in policy terms. It is important that people in these circumstances are visible and built into policy, because even if ‘specialist’ inpatient units close it might mean that people instead end up spending time in mainstream mental health inpatient wards. We are not aware of work to see how these services work or not for people with learning disabilities and autistic people.

## We need you to tell us how you are going to bring our children and young people back closer to home and out of these places.

WE SEE NO urgency, no leadership, no policy or strategy that is going to resolve this. In England, endless reviews and promises to reduce the numbers of people with ‘stolen lives’ have all failed entirely. Barbara Keeley MP writes:

“The Government’s answers to my Parliamentary Questions tell you everything you need to know about the ... *appalling lack of action* to end the

detention of autistic people and people with learning disabilities in inappropriate inpatient settings.”

We find no specific, actionable goals in relation to people with stolen lives. *Improving Lives 2020* is a descriptive account with no significant recommendations for Welsh government. Section 3.1 of the *Learning disability strategic action plan 2022-26* (2022) states:

- 3.1 Implement recommendations from the 2020 review of Adult Specialised Services “Improving Care, Improving Lives, National Collaborative Commissioning Unit.”
1. Reduced admissions through increased community-based crisis prevention/early intervention support
2. Access to high quality, safe and effective specialised care as close to home as possible.
3. Individuals supported to return home /close to home as soon as possible.

**But how exactly?** When? By whom? Who is ultimately accountable to ensure these things happen? The absence of specificity has been noted by *Learning Disability Wales*:

“While we believe that this plan has the potential to make a significant difference to people with a learning disability in Wales, we are looking forward to seeing more detailed information in the delivery plan that clarifies how Welsh Government is planning to achieve its goals. We also hope to see some of the goals clarified and be more ambitious in their aims so that they will make a more substantial difference to people with a learning disability in Wales.”

Learning Disability Wales raised a question in 2021 which sadly remains just as pertinent today - *Is there a ‘Winterbourne in Wales?’* So we look to the Learning Disability Ministerial Advisory Group for more detailed information and updates on progress but find that the last minutes are of a meeting in December 2019. The speed of progress – or at least being able to find information in the public domain about progress is discouraging, including:

- The *Learning Disability Strategic Action Plan 2022 to 2026*. Last updated: 24 May 2022
- *Patients and Mental Health Hospitals and Units in Wales Data*. Last updated: 2019

It maybe that numbers are such that it is possible to independently review the situation of every single person away from home in an unsuitable ‘placement.’ (Who lives in or calls a ‘placement’ home?) We mention this possibility will a great deal of caution. Baroness Hollins’ review of the care and treatment of 191 people who were detained in long-term segregation in England (*My heart breaks - solitary confinement in hospital has no therapeutic benefit for people with a learning disability and autistic people*) between November 2019 and March 2023 was able to look at every case which will have included people from Wales. Sadly, there is general disappointment at the **UK government’s lack of useful response** and we worry that reviews delay things and can be a proxy for inaction; we need to have complete trust in any review process and the person/people doing that work.

### How much public money is being spent (badly?) on putting people into inpatient units and keeping them there that could be better invested in supporting people at home?

## We need you to understand what this has been like for our families. We need our voices to be heard and treated seriously.

VERY OFTEN WHEN we go to meetings, or speak to people in ‘high places’, we don’t even say all the terrible things that have happened to us because it makes us sound a mix of unbelievable and ‘mad.’ We worry people will be even quicker to dismiss us. In our small group alone we’ve been told more than once that we are combinations of racist, alcoholic, sexually inappropriate, controlling, difficult. We could go on and on. The parent and carer blaming is so rife we are almost accustomed to it. And that’s before we even start to say what the actual thing – the important thing – has been like for us: the emotional and mental distress of the stolen lives of our children. Sometimes we wonder why the people who keep closing doors in our faces and writing us letters telling us a version of, ‘we are doing everything we can’ can’t imagine just for a moment, what it’s been like for our children and our families. It’s deeply traumatic – and we use the word very deliberately.

Blaming families is not new and in fact evidenced in *research in England*. There is no reason to assume (and it is our experience that)

things are not different in Wales:

“National and local social care policies in England create a default position for those assessing disabled children, that assumes parental failings. This approach locates the problems associated with a child’s impairment in the family – a phenomenon referred to in this report as ‘institutionalising parent carer blame.’”

We should look for and learn from all available good practice including, for example:

- *Dynamic support registers and Care (Education) and Treatment Review code of practice (2023)*
- *STOMP – Stopping over medication of people with a learning disability, autism or both (2018)*
- *Reducing long term segregation and restrictive practice*

**We think that sectioning is not a solution, just because social services, health boards, and service providers are failing to meet the needs of people with learning disabilities and/or autism.**

IT SHOULD BE a matter of clear understanding underlying all legislation, codes of practice and subsequent actions relying on that legal framework that sectioning is not a solution or an alternative to accommodating people’s needs. There need to be tighter processes to ensure that all procedures have been correctly followed and clear ways to make challenges when they have not been. We think that institutions and organisation which fail to follow guidelines should be held publicly accountable for their actions. Our families have experiences of our loved ones being sectioned without anybody even telling us.

“People with a learning disability and autistic people can currently be sectioned under the Mental Health Act even if they don’t have a mental health condition. This is wrong as people can end up detained in a mental health hospital just because there is a lack of the right support in the community, not because they need inpatient mental health care.”

*No Freedom, No Dignity, No Life* (Mencap)

**We need you to work together with organisations of people with learning difficulties and/or autism as well as family members to produce better support.**

WE ARE NOT alone in wanting things to change. We do not represent everybody affected in the ‘Stolen Lives’ group. We do not seek to ‘talk over’ people with learning disabilities/autism even though as family members we are allowed to have a voice. Self-advocacy groups and disabled people’s organisations can all offer help and wisdom in finding better ways to do things. Please reach out and take up this expertise as inclusively as you can. A good place to start is the *All Wales People First Position Statement on ‘Mental health and learning disability in-patient services’* which amongst other things says:

“In our experience, where our needs are met in an accessible way and close to home, it could avoid us reaching crisis in the first place.”

Perhaps a brave new look at this is needed which requires a huge jolt to the idea that things are as good as they can be or that somehow the grind of bureaucratic nothingness will lead to better days. A point First Minister Mark Drakeford made powerfully about the way in which the Ely Hospital scandal was uncovered by a whistle-blower:

“It requires an outsider, someone who hasn’t just become used to seeing things – who comes in from the outside and says, ‘Well, however is that allowed to go on?’”

**What services and supports people are getting outside of inpatient units – from community teams, planned crisis prevention plans for people etc, so that being put in an inpatient service does not come into anyone’s head as an option? If the policy is saying that’s what should be happening, then show it!**

## The Stolen Lives manifesto is endorsed by these organisations

