Reply to: info@LDEngland.org.uk

15th August 2023

Dear Members

**Stopping people dying younger: Update from member reps**

We wrote to you in June about our thoughts and feelings after hearing about Sally Lewis’ life and death through the inquest. [Read the letter here](https://www.learningdisabilityengland.org.uk/news/latest-news/treat-us-as-people/).

Thank you to everyone who came to the members meetings, shared their thoughts on what needs to change, or shared examples of their work. More than fifty members replied in just three weeks. [The notes from the meetings are here](https://www.learningdisabilityengland.org.uk/wp-content/uploads/2023/08/Stop-People-from-Dying-Too-Young.pdf).

We met in July and talked about everything we had heard and discussed what we wanted to do next as Learning Disability England members.

Learning Disability England exists to bring people and organisations together to make change happen so all people with learning disabilities can live a Good Life.

We continue to champion things which matter to people with learning disabilities and their families in everything we do. One clear message from members is that this is not the only time someone has been failed by a support provider. Nor is it the only time that their family have then had a long fight for justice and information. This fight can go on for years. There are concerns from everyone that this could happen again.

We know many other organisations, people and groups do important work. We believe that we are stronger together, so we will always connect people where possible rather than working on our own.

**The words services use about people**

Working on this together we were reminded of the importance of always using words and phrases which show respect for people and their lives.

The Mind Your Language campaign, led by self-advocates, clearly states why this matters. This [film](https://youtu.be/8YPUcw_ynng) explains what their campaign wants to see change in support providers. This [article](https://citizen-network.org/library/transform-your-language.html) by Mark Humble talks about how he thinks words show how support providers think and feel about the people they support.

We will keep raising this with members. We will challenge people when they use language that labels or separates people.

We will raise up the voices of people with learning disabilities and support campaigns on language which promote rights.

**The work members or partners are already doing**

We know that change is needed for people to live long good lives. There are many aspects of this change. In June we heard examples from you as members of what you are already doing both locally and nationally.

We will have a focus on promoting or sharing work on the following:

* stopping people dying younger (e.g. constipation or reasonable adjustments)
* changing systems to make them fairer (e.g. waiting lists)
* helping people know their rights (e.g. Do Not Resuscitate or treatment decisions)

If you are doing work which you think could help all of us make a difference, please let us know or join us at a reps meeting in September to talk about how Learning Disability England can help us all be stronger together.

**Learning to stop services failing**

We know that many people agree that the system for checking on what happens when someone dies is unfair to families who often have to fight the system for an inquest and then need to raise money to pay for legal fees.

We will speak to people who campaign for this to find out how Learning Disability England and their members can support those campaigns or make them bigger. There was an idea about service providers paying into a scheme for legal funds which families could apply for. We will keep sharing that idea and may have to get legal help to develop it further.

Most organisations have a framework system which looks at causes when something goes wrong, but the problems are found before someone is seriously hurt. It is often called a ‘never event’ or near miss. They look at the situation to learn from it and make changes to how they work. Some support provider members said that they would like the chance to share that learning with other members, so that they are able to get feedback from and share learning with people outside the situation.

Learning Disability England will set up a small project to create a challenging but safe place for members from all three voice groups to think about and help the learning when a service has failed so that other service providers can learn and improve.

We will also work with provider members to share how they look out for risks or problems in services and include what people with learning disabilities and family members think and feel in developing systems to spot problems early.

**Learning Disability Members shared work and policy**

Our work on this has made it clear that members agree on the importance of support from skilled staff with strong values who themselves are well trained and supported. Since 2019 we have heard from people that relationships matter in how services, support teams, people and their families work together.

We will carry on including this in our work on policy and ask all members to work on shared policy positions.

Some members want to see support workers covered by a registration scheme. We will give all members the chance to think about this or give us their feedback to decide if this is something we campaign for together.

Some reps met with Dimensions CEO, Rachael Dodgson, and talked about what they have changed since Sally died in their care, and how they work with people and their families. Rachael was open about Dimension’s failings and what they are now doing differently now. We think there is more to learn, and we shared our feedback as member reps.

**Building trust and being open**

When we were working on this, we talked a lot about social media and public statements. We looked at those made by both Dimensions and Learning Disability England.

We think all organisations should review how they respond to questions which they are asked publicly or on social media. We understand the need for personal privacy but to be open we think that organisations could better explain their reasons for not responding.

For example, an organisation could say how they are answering questions from people who they support and their families, or signpost who to get in touch with, or say that they are talking to all their staff at team meetings.

At Learning Disability England, we will include this in how we work. We will be clearer on how we work so that people understand why we might appear to be slow to talk about an issue in public or not on social media.

If we make a mistake, we will make any changes or updates to public information clear, along with our reasons for the change or update.

As your elected member representatives, we want to hear what you think or what you are doing to build good lives. If you would like to get in touch, please email us or join us at a members and reps catch up in September (there is a [self-advocate](https://www.eventbrite.co.uk/e/648047847557?aff=oddtdtcreator), [family and friends](https://www.eventbrite.co.uk/e/648046754287?aff=oddtdtcreator) and [paid supporter meeting](https://www.eventbrite.co.uk/e/648037265907?aff=oddtdtcreator)).

[The Representative Body](https://www.learningdisabilityengland.org.uk/welcome/about-us/representative-body/)