



Reply to: info@LDEngland.org.uk

6th June 2023

Dear Members

The inquest into Sally Lewis' death

We have taken a few days to write to you as members because we wanted to spend some time talking and listening to each other on what we think and feel after hearing about Sally's life and death through the inquest.

We also contacted Sally's sister, Julie to share this letter with her and ask for her feedback to us as member reps.

As Jack said 'I can hardly think about how it must have been for Sally'

Another rep, Scott, said, 'I am fearful – what if I need support from a social care service one day? Will I be safe?'

As a group of people with learning disabilities, family carers and supporters, we are deeply saddened by the avoidable death of Sally Lewis and the extra trauma her family endured in trying to get openness on what happened. There are no words that can properly explain our sorrow and horror that Sally died of constipation and that it has taken so long to get to this point.

Our hearts go out to Sally's family.

Making sure people with learning disabilities have healthy good lives needs health and social care staff to have a full understanding of the health risks they face. Constipation is a big risk for people with learning disabilities - more people with learning disabilities are likely to experience constipation and it can be very serious when people do. By investing in training for all staff about the dangers, and likelihood, of different health conditions for people with learning disabilities, we can reduce the risk and help people live healthy good lives. Training is important but there is much more that needs to change alongside that.

Biggest of all is 'treat us as people like anyone else, not aliens'. (Scott Watkin)



Human respect and kindness must include people's families as well as people themselves.

There will be a meeting on 15th June at 2pm at which some people with learning disabilities and family reps will talk about how they feel and discuss any action that we might take together. If any members want to join us, please [click here](#) to find out more. The meeting will take place online.

When a loved one dies, it is one of the most difficult experiences you can go through. Care providers have a responsibility to be transparent with families from day one about the circumstances of any death. This openness can help families to understand what happened and to grieve. It can help families to make informed decisions and to know that it will not happen to others. It is the right thing to do.

It is wrong that families who have experienced the tragedy of losing a loved one must also fund legal support at the inquests.

Access to justice is a basic human right, yet the current system keeps an unfair power dynamic that favours corporations or governments over people and their families. Families should not have to go through complex legal proceedings and financial barriers while also grieving the loss of their loved one. It is time for a fair system that places the needs and rights of individuals and families first, and that makes sure that justice is open to all.

Representatives of support provider organisations are also members of Learning Disability England; we sit alongside people and families and agree with this statement wholeheartedly.

We invite our provider representative members to join us on 19th June at 3.30pm ([click here for more information](#)) to ask these questions:

"What really stops us admitting what we got wrong and saying sorry for it?"

"When things go wrong - as it did catastrophically here - how can we make sure people we support, and their families, have equal access to the legal support we as organisations benefit from?"

After all, legal advice for providers is paid for, ultimately by people and families.



We are talking with Dimensions too about how they talked with Julie's family and how that lives up to the shared values all members are asked to work to or show in action.

Learning Disability England exists because there is so much work to be done to make sure that people with learning disabilities have [good lives](#) and that their families are well supported. We will continue the work for justice and equality and welcome an opportunity to work with allies to explore ways to fund legal representation and some form of restorative justice for families when an inquest is needed.

As your elected member representatives, we want to hear what you think or what you are doing to build good lives. Please do email us or join us at one of the planned meetings, or at our Members and reps catch up in September.

[The Representative Body](#)