

## Stop People from Dying Too Young: Learning Disability England Members Meetings



In response to Sally Lewis' inquest that happened between the 24<sup>th</sup> and 30<sup>th</sup> May 2023 the Learning Disability England reps wanted to meet with members.



Sally Lewis died on 27 October 2017 at age 55 of a large bowel obstruction as a result of faecal impaction.

This followed Sally having suffered with constipation for many years.



Sally was under the care of Dimensions and it has since been found that there was some serious problems with her care before her death.



Reps wanted to meet with members to talk about action to stop preventable deaths for people with learning disabilities and autistic people.



On the 15<sup>th</sup> June, 30 self-advocate and family members met to talk about this.



They also wanted to speak about how people's families are supported and how providers respond when services failed.



On the 19<sup>th</sup> June 15 people who work in paid supporter organisation members met to talk about this.



**Here are the main messages that came from members who attended on the 15<sup>th</sup>:**



People with learning disabilities need to be listened to, respected and valued.



Families need to be listened to and not seen as a nuisance. They are an important part of prevention.



People and families desperately want and need reliable and robust social care.

People are scared and angry about what happened to Sally Lewis.

These incidents make people distrustful of care providers and worry what will happen to their loved ones when they aren't around anymore.



There are lots of people and organisations taking action on trying to stop people from dying younger and challenging health inequalities.

Some people feel listened to locally but we aren't seeing change nationally.



Does the learning from people's deaths or the campaigning and best practice we see get seen and understood by support workers on the ground or does it just sit at a strategic level?

This isn't an issue with one provider but a system-wide issue. Responsibility doesn't just lie with social care but other agencies too.



We know there are examples of people delivering brilliant and creative support.

How do we make sure this happens for everyone rather than it being one great organisation or support worker?



Part of the answer is a better funded social care system that ensures support workers get opportunities to train, supervisions, progress in their career, are well paid and valued.

However, paying people more won't alone solve this issue. Values-based recruitment and a growing workforce are needed, to ensure people have a real choice over who supports them.



Relationships are so important to people's lives. Both with support staff but also the unpaid people in people's lives.

Do people have good friends and circles of support? Being known is important to stop things going wrong



We need to ensure that we respect people's rights, privacy and dignity in how we tackle these issues. Toilet logging books aren't the answer.



We need to question if it is possible to do some management roles, in their current forms, well.

Some managers are currently responsible for multiple services when historically they would have had one.



Need values driven people in support roles, who care about the person they support rather than just for them.



The cavendish review, exploring the role of support workers was 10 years ago. Is this something we want to be refreshed?



**Here are the main messages that came from members who attended on the 19<sup>th</sup>:**



Organisations often apologise but when how and by whom might not be 'right' often enough.

Does that apology get lost in the process of establishing the facts, learning from failure or mistakes and if a legal or formal process starts?



How do organisations keep the human-facing side of how they respond when something goes wrong?

Could there be a set of principles on keeping human in how organisations work through failings or near misses?



Legal advice does not have to mean not staying human – how do organisations influence legal firms and insurers to understand they want human principles?



Families need to be listened to and alongside people with learning disabilities need to be partners in keeping safe and stopping failings – they are an important part of prevention.



Can organisations share learning from near misses – linked to local or regional networks?



Can LDE host some 'safe space' reflective sessions on near misses that share learning and debate action across the 3 voice groups



Some organisations have ‘wobbly lists or checklists for situations that mean a service could be riskier (e.g., Manager absent) – can we do more to share those to inform them and make them stronger (include the 3 voices)



How can we help create a legal fund to stop families having to face legal fees?

Do we ask Access Social Care if they have ideas?



Organisations should do it right from the start in terms of ensuring people are seen as humans with equal rights.

Challenge use of language such as placements, services.

Don't accept assessments / information that leaves out what's really important to the person.



Please be in contact if you are a member of Learning Disability England and you think there is anything important that has been missed.

You can email on [info@ldengland.org.uk](mailto:info@ldengland.org.uk)



Or you can call 0300 1110444