

Statement from Inclusion North on lived experience and system learning

Inclusion North has been reflecting on recent changes to LeDeR arrangements and the wider implications for lived experience involvement in system learning.

While these changes are taking place within North East and North Cumbria, they raise broader questions about how lived experience is understood, valued and embedded within health and care systems.

For many years, lived experience has played a central role in shaping learning from deaths, challenging systems and ensuring that insights translate into meaningful change. This has not been an additional layer.

It has been a critical part of how systems understand risk, inequality and the realities of people's lives.

The loss of established lived experience structures risks removing a critical source of insight, challenge and accountability from the system. It also risks systems becoming further removed from the experiences of people most affected by inequality, reducing opportunities for people with lived experience and family carers to directly influence strategic decision making and highlight emerging concerns early.

There is a risk that, as systems evolve and structures change, lived experience becomes positioned primarily at place level. While local engagement is essential, it is not sufficient on its own. Strategic decisions about commissioning, service design and system priorities require direct insight from people with lived experience at a system level.

Without this, there is a real risk that learning becomes fragmented, diluted or disconnected from the realities it is intended to reflect.

There is also an opportunity to consider how LeDeR continues to evolve.

A future model should move beyond retrospective review alone and towards a more preventative approach, drawing on lived experience, people's experiences of services and real time system insight to identify risks earlier and prevent harm.

While learning from deaths remains essential, there are limits to what can be achieved through retrospective review alone. People's deaths cannot be undone. The challenge for systems is not only to learn after harm has occurred, but to identify patterns, inequalities and risks early enough to prevent avoidable harm happening in the first place.

This requires:

- clear and resourced mechanisms for lived experience to influence strategy and decision making
- strong links between lived experience, clinical insight and commissioning
- independent spaces where people with a learning disability, autistic people and family carers can share insight and challenge the system
- a continued focus on translating learning into measurable improvement

Inclusion North remains committed to working in partnership with Integrated Care Boards and system partners to strengthen how lived experience informs learning, improves services and reduces inequalities.

We believe there is an opportunity not only to preserve what has already been achieved, but to build a stronger and more preventative approach to system learning where lived experience remains central to both learning and action.

All the best,

Inclusion North