

Tackling Inequalities webinar: Q&A responses

Thank you to all those who joined our webinar on Wed 19 March, “How can we make care more equal for people with learning disabilities and autistic people?”, held on Wednesday 19 March, as part of our [Tackling Inequalities project](#). We appreciate your participation and commitment to addressing inequalities in care.

If you were unable to attend, or want to share the webinar with any colleagues, [you can now find a recording on our website](#).

During the session, our expert panel - made up of members of the 'SCIE Fliers' co-production group, learning disability advocates and SCIE practice development consultants - discussed several key areas, including the inequalities faced by people with learning disabilities and autistic people, [points from our latest guidance on the topic](#) and the importance of engaging with people with lived experience.

It was great to have so many questions submitted during the session. As we couldn't respond to them all in the time allotted, please find a roundup of any missed questions with responses from our panel below.

Q: Where can we find the self-advocacy group map, please?

A (John Hersov and SCIE Fliers):

The Learning Disability England self-advocacy group map can be found here:
<https://selfadvocacygroups.co.uk/>

Q: It appears that the health and social care system requires a culture change to acknowledge invisible disabilities/conditions and the complexity and interconnected relationships in providing health and social care. Is Personalised Care the answer?

A (Dan Lacey, SCIE):

SCIE's Tackling Inequalities guidance promotes 4 key themes:

- Trauma-informed care
- Person-centred care
- Strength-based approaches
- Co-production

Each of these is focusing on recognising the unique experience of an individual drawing on health and social care, and tailoring support to meet their needs.

Furthermore, by embedding a culture and practice of meaningful co-production, organisations can better develop support services to meet the needs of individuals based on real experience not assumptions about what individuals go through.

We recognise that health and social care are in fact part of a wider system with community resources, third sector organisations and private providers. It is not enough for improvements to be made in pockets or isolation but need to be across the board. Treating people as individuals is a starting point.

Q: How can therapy be tailored for neurodivergent and people with learning disabilities who cannot leave their homes? Very often the emphasis is on them to attend appointments and when they don't, they are told that they did not engage!

A: (SCIE Fliers and John Hersov):

“Did not engage” often just means that a service didn’t try hard enough, or make reasonable adjustments to meet a particular persons individual needs. We can have therapy on phone, and online, so these services should be adapting to fit the needs of their clients.

Q: Was the data shared for individuals that had duality of a learning disability and being autistic only, or was there individuals who were autistic as standalone diagnosis? If so, what was the split in those of each cohort please?

A (Dan Lacey, SCIE):

Our guidance utilises data from multiple sources, the main one being the [LeDeR Annual Report Learning from Lives and Deaths: People with a Learning Disability and Autistic People \(2022\)](#). In the introduction, there is a preface explaining that in January 2022, LeDeR began collecting data on the deaths of autistic adults (aged 18 and over) who did not also have diagnosis of a learning disability. The data available for autistic adults only was small, with only 36 completed reviews.

As such, they took the following steps for their report:

- The data for autistic adults who do not also have a learning disability has been separated from the rest of the data and has been analysed in Chapter 7.
- As such, all other chapters do not use or review data that includes autistic adults, who do not also have a learning disability, for analysis.

According to the Foundation for People with Learning Disabilities, "[60-70% of people who have an autistic spectrum condition will also have a learning disability](#)".

In SCIE's Tackling Inequalities guidance, we made effort to highlight any distinctions between conditions, where the evidence and data allowed us to. An example of this being in our Mental Health Act 1983 section of the guidance.

SCIE recognises that autism is a lifelong neurodevelopmental condition and is not a learning disability, and we are conscious not to equate the two in our guidance.

Q: Thinking of the wider aspects of health e.g. BMI and how that impacts many health conditions, was this considered as part of the project?

A (Dan Lacey, SCIE):

We used the [LeDeR Annual Report Learning from Lives and Deaths: People with a Learning Disability and Autistic People \(2022\)](#) as the basis for our report as we were explicitly looking at the inequalities that people with learning disabilities and autistic people experienced during Covid-19.

The report breaks down various health conditions that contributed to the causes of death, and explores demographics such as age, sex, region, ethnicity, religion, and areas of derivation.

It states that as part of the research for the report that they explored *"sexuality and gender identity for adults with a learning disability including those who have a learning disability who are also autistic. Deaths of adults who identified as LGBTQIA+ were reported, but in small numbers, and as such cannot be detailed in the report for de-identification reasons."*

When writing our Tackling Inequalities guidance, we did not dive into the full extent of wider health impacts, in favour of reminding readers how best to support people with learning disabilities and autistic people using strengths-based and person-centred approaches.

As both of these approaches recognise and promote the individual, then adopting these positive approaches will lead to an improvement, regardless of a person's health circumstances.

Q: As a small community group we do not have access to specialists. How can we be more inclusive?

A (SCIE Fliers and John Hersov): To connect with health and social care specialists, contact one or two local professionals and engage them in your activities. You can take learnings from each person you speak to, make notes, and continuously build up knowledge so you are able to be more inclusive.

You may also be able to get some support and useful networking from linking in with your local Voluntary and Community Sector (VCS). They should be able to inform you of other activity taking place in your area and connect you with professionals in your local authority and NHS teams.

Q: I work in an adult community LD team as an Occupational Therapist- the team often decline referrals if they haven't been known to us or don't have formal diagnosis - how common is late diagnosis of a learning disability?

A (Dan Lacey & Jon Soros, SCIE):

Unfortunately, it is quite difficult to directly answer this question, as there is no readily accessible data to evidence patterns of diagnosis of learning disabilities and/or autism in relation to age at diagnosis, for adults.

Statistics from [Mencap](#) suggest that 2.5% of children have a learning disability and 2.16% of adults. So, it is reasonable to assume that most individuals are going to receive their diagnosis in childhood. However, this process is not 100% accurate. There are cracks within any system; so, children with atypical presentations, children not frequently in contact with health professionals, people coming to the UK later in life, and people in marginalised communities, may all find it harder to access the right support and receive diagnosis within childhood.

Formal diagnosis is used to determine service eligibility. This is a commonly accepted practice to make sure that services are ringfenced for the people they are intended for. However, this can create difficulties if there is a history of non-explicit diagnosis, due to delays or cost-implications experienced within the system.

At a place-based level, it is important health and social care organisations balance these two drivers: how can we meet informal or undiagnosed need within our communities, and how can we ensure that our resources are delivered to the right groups of people? This is a continuous balancing act for health and social care organisations which requires continual review, evaluation and strong intelligence and relationships with the community.

Q: Do we know why the 2024 LEDER report has not yet been released, does it mean the figures are worse?

A: Local integrated care boards (ICBs) are responsible for carrying out LeDeR reviews for their local areas, and King's College London were publishing the annual reports up until 2022. After this year, there has not been an annual report. However, ICB areas are still publishing local data on a yearly basis, and you can search for these online.