



Learning Disability England

Housing Choices July 2019 Update

1. Easy read summary



Learning Disability England

Learning Disability England has a priority on housing choices because members told us it is important.

This is an update on some of our work on that priority



In February the BBC released 2 programmes about supported living for people with learning disabilities.



The BBC asked **CQC** for information.



CQC is the Care Quality Commission.

They check health and social care services in England.

They make sure people are safe and are being treated well.



CQC told the BBC about:

- how many people die unexpectedly
- how many incidents were reported

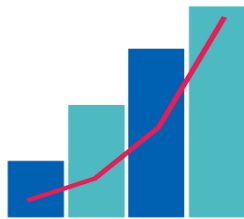


The numbers are about **supported living** and **domiciliary care** services which support people with learning disabilities.

Different types of **Supported living** and **domiciliary care** can look very different. Usually,

Supported living is when you live with share your home with other people. You would have staff that help with personal care.

Domiciliary care is when you live on your own and people visit to support you.



CQC's numbers say there has been more reports of incidents and deaths each year since 2010.

What did organisational members think?



We asked organisational members who run supported living what they think of the numbers

Most of the organisations who talked to us were **not** reporting more deaths and incidents

What do the numbers tell us?



We asked for help from the Learning Disability England Academics network.

We asked them to look at the numbers to help us understand them.

The numbers CQC gave us are hard to understand.

The information from CQC doesn't explain why the numbers are growing.

Trying to explain the numbers would mean making lots of guesses.





They don't think the other things we know match the explanations CQC have given us.

Examples of acting openly when things go wrong or are a worry



We asked members to tell us about what they do when things go wrong in the supported living that they run

L'Arche told us about what they have learnt and what they do differently now.



We will work more with organisation members on what they do to stop things going wrong or changing if something is not working.

What's important to self-advocates and their families



NDTi, Calderdale Self-Advocacy Network and Preston Learning Disability Forum shared research with us.



Its about what self-advocates and families think makes a good life.

It talks about what stops people from living a good life

It talks about housing issues



The most important points self-advocates and families said about home, housing and a good life were:



Having access to their rights and having choice and control over their own lives.



Feeling safe and secure in their home, relationships and not worrying about money.



Having personalised high quality support

What this leaves us asking or wanting to know more about



All this information has left us asking questions.

We are asking questions like:

How many people's housing and support is provided by the same organisation?

What do members think needs to happen to be confident people are safe and well supported?

What we are doing next



7 Ways to Get a House

We are working with Learning Disability England members to help create a housing resource.



The resource will help everyone understand what housing options are available locally.



Shelter



We are supporting Shelter's Social Housing Campaign.

They want to build more social housing



They want to have a new **regulator** to help make the housing better and help people renting the houses have a stronger voice.

A **regulator** is an organisation that makes sure people follow the rules that the government have set out.



Housing LIN



We are working in with Housing LIN to get up to date information on the barriers learning disabled people face when trying to get a house.

The work will focus on different ways Specialist Supported Housing is being developed and how it and social housing are part of people's housing choices.

Housing Choices

One of our member priorities for 2018-2020 is to support the development of housing choices for people with learning disabilities.

Engaging in work around safety in supported living is one area of work under this priority.

1. Supported Living: What we have done and why

BBC Programmes

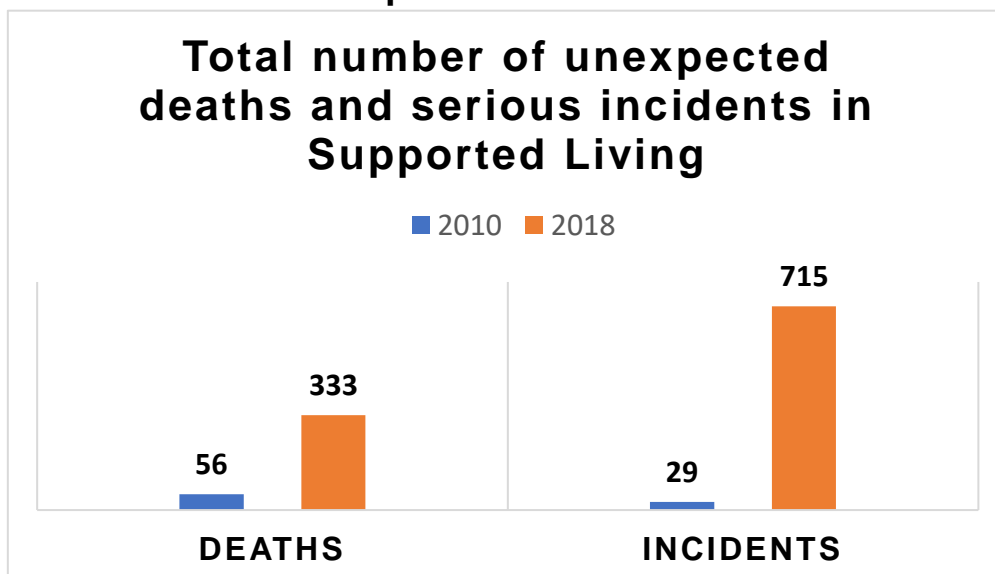
In February the BBC released 2 programmes about supported living for people with learning disabilities. They had asked CQC for information. CQC told the BBC about how many people were dying unexpectedly and how lots of incidents were being reported. The numbers were about domiciliary care and supported living. CQC's numbers say there has been more reports of incidents and deaths each year since 2010.

The BBC programmes asked if supported living was safe and secure for the people who lived there.

CQC Data

The numbers CQC collected say in supported living

- Total unexpected deaths
 - From in 2010 reports of 56 to 333 in 2018,
- Total serious injury
 - From 29 reports in 2010 to 715 in 2018



We sent a letter to CQC

Learning Disability England was very shocked and concerned by these numbers. We were also confused about them. We did not understand how CQC had found the numbers.

Our [Representative Body wrote to CQC](#) asking some questions about the numbers to try and help us understand better.

CQC wrote back to us. [You can read their full response here.](#)

Our questions and their responses are summarised below.

1. How are these figures collected?

CQC said registered providers must notify them when there is a death or serious injury of a person using their service.

2. Do CQC analyse them to check they are correct?

CQC looks at all the notifications from providers to look for outliers. Outliers are things that we wouldn't expect to see or that don't fit with other patterns and trends. The numbers are compared with other services that are similar in size and type. When outliers are found they are flagged to inspectors who can look at the service.

3. Has CQC looked at this information by area, provider or service type in more detail?

CQC don't look at the numbers by area. They look at numbers based on 'service type' (supported living service) and 'service user band' (people with a learning disability).

4. How does CQC use this information as part of its work on regulation and market shaping?

Inspectors can review the notifications when monitoring or planning inspections.

5. What do you think is happening that the numbers of incidents reported are going up and up?

- a. improved reporting, and therefore increased reporting
- b. an increase in the number of incidents
- c. an increase in the size of this type of sector
- d. the numbers of people being cared for in these care settings

6. How many more places or services were registered as being in Supported Living in this time?

In June 2011, there were 1267 supported living settings which increased to 1628 in June 2018. Between 2011 and 2018 that is a 28% increase.

7. Have other service types been reporting more serious incidents and deaths over this period?

CQC sent us lots of data about this but its not easy to understand. If you would like to see the spreadsheet, please get in touch.

Are organisational members of Learning Disability England reporting an increase?

We asked organisational members about the CQC data and if they felt it represented their organisations experiences around deaths and incidents in supported living.

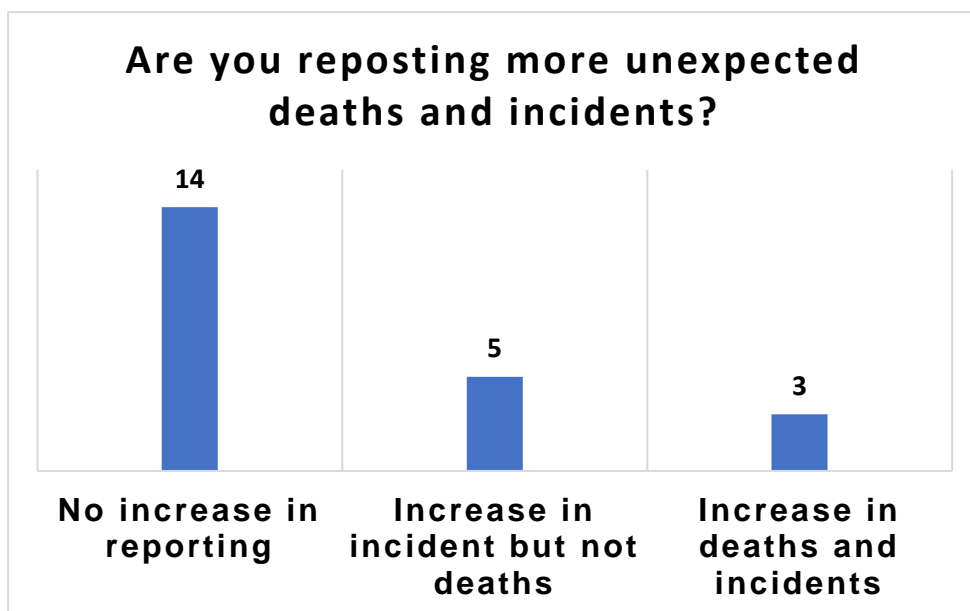
We ask our organisational members what they thought of the numbers. 22 organisations told us what they think. Those organisations support around 6000 people.

We asked if providers had been reporting more unexpected deaths and incidents.

14 of 22 providers said they had not reported an increase in deaths or incidents

5 of 22 providers have reported no changes to the number of deaths but an increase in the number of incidents.

3 of 22 providers reported an increase in reported number of deaths and incidents



This means most of our support organisations members who replied are not reporting more deaths and incidents.

CQC gave four reasons that they think contribute to the rise in reporting. These are:

1. Improved reporting, and therefore increased reporting
2. An increase in the number of incidents
3. An increase in the size of the sector
4. the numbers of people being supported in these settings

Members talked about the different reasons they thought there might be an increase in reporting. A member suggested the increase in the number of services could be significant,

“We have opened a number of new services in recent years, and often find a higher level of serious incidents occur in the settling in period. We have not reported a higher level of incidents in our steady state services.”

Members felt they were supporting more people, with a range of support needs.

“There are now more people with complex or very complex needs. This naturally leads to more safeguarding incidents. These incidents are therefore, not unexpected.”

Some members were worried about how notifications were made to CQC, they felt the form was badly designed and a poor tool for analysis.

“It does not seem appropriate for minor physical incidents between service users to be categorised under the same heading as incidents of staff assaulting service users.”

Staff also felt it was important to remember taking risks are part of learning to be independent and we shouldn't be overly cautious.

“Living in the community brings people more freedoms and they are supported to take more risks which lead to greater independence. In

taking risks, we do get incidents that are reported - but this is a journey towards independence that all young people take, and non-disabled young people have incidents too. People with learning disabilities should not have the right to being more independent taken away.”

What do the numbers really tell us?

CQC also sent us the information they had given the BBC. This was a spreadsheet of numbers about how many unexpected death and incidents there were, by providers and service type.

There was a lot of data which was difficult to understand. We asked the Learning Disability England Academics Network for help.

They said it is not possible to draw conclusions from the data about why reporting has increased. This means, at the moment, we don't have any evidence to explain why the numbers have gone up so much.

We would be making lots of guesses if we tried to talk about why.

Instead of guessing we want to talk about what matters and is already working. We want to keep collecting information to see what we can find out about what is happening.

Some of the questions we are asking are:

- **What all members think needs to happen to be confident people are safe and well supported**
- **What providers do to make sure they are learning from people dying and incidents and making changes based on what they learnt**

2. Examples of acting openly when things go wrong or are a worry

We asked some of our members who provide supported living to share with us the procedures they have put in place to make sure when things go wrong they are handled in the right way.

We think its important that when things go wrong we can talk openly about why it happened and what is being done to make sure it doesn't happen again.



Kevin Coogan, Registered Manager and a community Leader, L'Arche Manchester shared his experience with us.

Our learning was focused in our experience once we entered the health system. Joe had a fall (probably preventable but doing ordinary things in life that it would be pretty restrictive to stop him doing so as to keep him safe from the risk of a fall) but he went in to hospital and after 3 weeks he died. So, our learning is really around our interaction with the hospital.

The big learning point for us, and one we adopt now as a matter of course, is that when someone we support goes into hospital we immediately start a WhatsApp group for the people principally involved with supporting them in the hospital. On this we share which doctor came to see the person and when, what they said and how the person was about it. We also share our impressions of how the person is feeling or reacting to treatment. If, as in the case of Joe, the person can't express if they are hungry or in pain, the cumulative subjective opinion is really helpful to the friend/support worker standing in front of the specialist doctor who asks, 'And how are we today?'

[You can read a full account from L'Arche here.](#)

3. What is important to self-advocates and their families

This section talks about research carried out by NDTi and Calderdale Self-Advocacy Network. The research talks about what's self-advocates and their families think a good life looks like and what makes it hard. Preston Learning Disability Forum have also shared their report on housing with us. [You can read the full thing here.](#)

What does a good life look like?

For self-advocates and their families think a good life means...

- Having access to their rights and to have choice and control over their own lives.
- Feeling safe and secure in their home, financial situation and relationships.
- Being independent, taking risks, having purpose and being part of your community.
- Having personalised high quality support, that is responsive to the needs and wants of self-advocates.
- Having your own home which is accessible and somewhere you chose.

What are the barriers to a good life?

Self-advocates and families think these things can be barriers to living a good life.

- Some provision doesn't live up to its values, which makes it hard to find the type of service you want.
- People often don't know what their rights are as a tenant or where to find information.
- 'choice' and 'control' are often used as buzz words and are meaningless
- Worried about housing strategies that priorities purpose built individual flats
- Not having enough money to cover extras and leisure activities.
- Undervalued, untrained staff can stop you from getting good quality support.

Knowing what self-advocates, families and organisational members think has helped us think about what the big issues are.

4. What all of this leaves us asking or wanting to know more about:

After looking at all of the information we collected we started to think about these questions. These questions will inform some of our future work.

- What definitions of supported living are being used across the sector?
 - How can we make sure they really fit with the principles of supported living?
- What do members think needs to happen to be confident people are safe and well supported?
- What definitions are organisations using when reporting incidents?
 - Are the categories being used consistently across the sector?
- What do providers do to make sure they are learning from people dying and incidents and change what they do as a service?
- How widespread is the issue of people living in supported living where both the housing and support is provided by the same organisation?
 - What impacts is this having?
- There appears to be an increase in the commissioning of purpose-built individual flats for people with learning disabilities. This appears to be moving people into towns but segregating them from the community. The growth of this model might suggest reduced housing choices. Is that happening?

5. What work we are doing now in the short term

7 Ways To Get A House

We are working with Learning Disability England members to create an easy to use resource. It is to be used locally, to explain and link to all the local housing options

Housing LIN: My Life, My Home



Housing LIN

We know that in many places people with learning disabilities have very limited housing options.

In partnership with Housing LIN, Learning Disability England will do a small programme of work around issues and barriers that people with learning disabilities face around housing.

We will do this work in partnership with representatives from all parts of Learning Disability England's membership.

The work will focus on different ways Specialist Supported Housing is being developed and how it and social housing are part of people's housing choices.

Shelter: A vision for social housing

Shelter have proposed a vision for social housing campaigning in response to the housing crisis.

The vision includes a two-pronged approach.



Firstly, 3.1 million more social houses to be built. Offering people security and the opportunity to get onto the housing ladder by allowing them to save for their future.

Secondly, renting reform including introducing a new regulator to improve standards. They also want to see social renters have a stronger voice both locally and nationally.

[You can read more about the campaign here](#)

Learning Disability England have discussed if we will publicly & actively support their vision for social housing campaign.

We heard feedback from some housing and support members organisations about this.

Generally, feedback was very supportive of LDE working with Shelter. Members felt that building more, good quality, safe social housing would enable many people to live more fulfilling lives. They also felt being involved in mainstream campaigns was important.

Some members have noted their hesitations around the call for a new regulator. They felt this would bring confusion to the sector, regulator and service users. While they support the motivation for this proposal, to increase consumer regulation, they felt this would be better achieved through extending the role of the current regulator.

Learning Disability England will support the campaign and ask its members to actively contribute too to influence the outcome and make sure people with Learning Disabilities benefit from any impact.