



# **United Response and Nicola's response to the House of Lords inquiry: Lifting the veil: Removing the invisibility of adult social care**

**May 2022**

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## **About us**

Since 1973 United Response has been supporting people with learning disabilities, mental health or physical support needs to live their life to the full. Our team of 3,400 people work across 330 locations in England and Wales to support around 2,000 people aged 16 to 65+. We campaign to ensure the people we support have equal access to the same rights and opportunities and challenge the negative attitudes and discrimination they face.

Nicola is supported by United Response to live independently in her own home, she studied health and community studies at university and works part-time at a local school.

## **Introduction**

1. United Response and Nicola welcome the opportunity to feed into The House of Lords Adult Social Care Committee inquiry: Lifting the veil: Removing the invisibility of adult social care.
2. We co-produced this submission of evidence. Direct quotes within our submission are from Nicola or otherwise are credited to United Response staff.
3. Our submission answers the following themes set by the inquiry:
  - a. The invisibility of adult social care and its consequences
  - b. Putting co-production at the heart of care.

## **Summary points**

- The invisibility of adult social care is a result of the complexity of the system, which we feel is contributing to the issue of unmet need.
- To make adult social care more visible, public perception needs to change to truly value how the system impacts people across all their life stages.
- The pandemic has further entrenched recruitment challenges, until there is a national workforce strategy to increase pay, recognition and respect this is unlikely to be addressed.
- For co-production to truly be at the heart of care, we need to have a system that is co-produced with the people who use it.
- We would like to see the annual review process reformed with standards co-produced with people accessing adult social care.
- People with profound and multiple disabilities are the most invisible within the system, their voice must be prioritised in co-production.

## The invisibility of adult social care and its consequences

4. The multifaceted nature of adult social care contributes to its invisibility. In contrast to the NHS, which operates under one banner, adult social care is a myriad of providers (private, public and voluntary) that support and care for people with wide and vastly differing needs.

*“Being a receiver of adult social care I think it is invisible. As a result, it means we don’t always get what we deserve.”*

5. Adult social care can be confusing for those who navigate the system – both as a person accessing services and for those who work in it.
6. Complex legislative frameworks, systems and pathways to support do little to create a clear and succinct narrative about what adult social care is.
7. Recent figures from ADASS found that the number of people waiting for social care is around half a million<sup>1</sup>. We believe that the invisibility of adult social care contributes to the growing issue of unmet need:

*“The hours that we receive aren’t enough. I receive 42 hours, which seems a lot, but not for my independence. It means I have to keep to a time limit. I’ve got a great life it’s fantastic but just that little bit of freedom would be even better. When I lived at home my parents looked after me and I only had 6 hours of support while they went to work. I was used to having fewer hours then but now I’m doing more in regards of going to work and setting up my own home I need more. But I feel like everything is questioned when it shouldn’t be. An able-bodied person can decide on the day if they want to go out for tea, but I don’t get that choice. The service I get from United Response is really good but they are only given the hours that they are told.”*

8. Public perception of the system does not always reflect the positive impact that adult social care can have on young and working aged disabled people, for whom, the purpose of social care is to expand their lives so they can have as independent a life as possible:

*“As a young person, adult social care has enabled me to have freedom and choice. I couldn’t cook before I moved into my own home. The staff that support me don’t stop until they help me achieve my goals. It’s given me more confidence to do things myself. I’m not really confident on the road on my own, but my next goal is to get around the town on my own”*

9. But that purpose isn’t always conveyed in the media which does little to help public perception:

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<sup>1</sup> <https://www.bbc.co.uk/news/uk-61413697>

*“It’s good that the media and TV shows are starting to introduce disabled people. Society is getting better but it feels like it’s just about adequate for disabled people. Society should be aiming for outstanding.”*

10. To understand and appreciate the diversity of the system there needs to be significant behaviour change so the general public can value people who access social care and respect how the system operates at different life stages.

*“Some of the general public need to change their behaviour, if you’re brought up around disabilities you’re less likely to be derogatory or disrespectful. If you don’t have to think about it, you don’t.”*

11. We believe that misinterpretation can also happen in Parliament, where the narrative around adult social care is often weighted towards older people or end-of-life care meaning the needs and aspirations of working aged disabled people get lost.
12. This was perhaps most starkly seen in the pandemic where adult social care guidance was often outdated, published late, or unclear.
13. By focusing on producing guidance for large care homes for older people, it felt as though the needs of people with disabilities were invisible within government.
14. And even now, despite the pandemic being over for the majority of society, people with learning disabilities and profound and multiple learning disabilities (PMLD) that are living in residential care homes are effectively being left in lockdown.
15. As a provider of both supporting living accommodation and residential care homes we see first-hand how the guidance around self-isolation negatively impacts people who have a learning disability that live in a registered care home<sup>2</sup>. An area manager from one of our accommodation services said:

*“We support T in one of our residential care homes along with four other residents. T is friends with A, who lives in one of our supported living services. Restrictions have been lifted for the majority of society but, for A and T, their lives couldn’t be more different now. If there is a positive case of Covid-19 in the residential care home where T lives everyone needs to self-isolate because the home is under CQC regulated care home activity. But our residents aren’t classed as clinically vulnerable so it feels like they are being punished for not being able to live independently. T can’t understand why she isn’t able to leave the home to see her friend. It’s affecting all of the resident’s mental health.”*

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<sup>2</sup> <https://www.gov.uk/government/publications/coronavirus-covid-19-admission-and-care-of-people-in-care-homes/coronavirus-covid-19-admission-and-care-of-people-in-care-homes>

16. The impact of the pandemic on the mental health of people accessing adult social care has been well documented.
17. HFT's research found that almost 50% of people with a learning disability surveyed felt the pandemic had increased their loneliness<sup>3</sup>.
18. Our own research with people we support in the Devon and Cornwall area had similar findings but we also found some positives.
19. 58% of people surveyed felt that they had closer bonds with people who supported them<sup>4</sup>. This reflects Nicola's experience:  
*"I felt very isolated but the staff were brilliant throughout the pandemic, everything they did was amazing. If I had a down day they would comfort me and tell me it would get better."*
20. But the sector is facing considerable workforce challenges which the pandemic has only exacerbated.
21. When staff members can have such a profoundly positive impact on the lives of people accessing adult social care, shouldn't the social care workforce be considered a higher priority?
22. We believe that until there is a desperate need for a national adult social care workforce strategy to create parity with the NHS in terms of pay banding, respect and recognition.
23. As a provider operating across England and Wales, we find that there is an inconsistent approach to social care contracting to allow for payment of the Real Living Wage.
24. If local service commissioning does not meet the rising cost of wage inflation, it causes significant challenges for a sector that already struggles to meet and exceed labour market demands.
25. With pay as a key driver for recruiting and retaining staff, any sector workforce strategy will need to be supported by adequate and sustainable funding for it to be a success.

### **Putting co-production at the heart of care**

*"They rely on our voices. This is what made me pick United Response. When I was moving out I was looking at lots of care providers and I just loved the ethos of*

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<sup>3</sup> <https://www.hft.org.uk/get-involved/campaigns/lockdown-on-loneliness/>

<sup>4</sup> <https://www.unitedresponse.org.uk/news-item/68-of-people-we-support-in-devon-and-cornwall-experienced-positives-during-covid-pandemic-including-learning-new-skills-and-feeling-supported/>



*United Response. They've lived up to my expectations. It's good that it's person-centred because it's giving people a chance at an independent life."*

26. As a person-centred organisation it is our aim at United Response that the people we support have an active voice in the care and support we deliver. We achieve this through person-centred planning, employing people we support to quality check our services, train our staff and lead on our stakeholder engagement.

*"I used the internet to find United Response. When I came round here to look at the house, there was a few staff and I got to talk to them, and I thought 'yes this is what I want for myself.' I'm a quality checker for United Response so I go and assess the different services the organisation has. I really enjoy doing it."*

27. But individual organisations can only achieve so much with co-production in a system that has not been co-designed with the people who use it.

*"Everyone deserves a life and independence but they're not actually giving us the time to be as independent as an able-bodied person. It really frustrates me. It's not the caregivers' fault it's the system."*

28. The annual review process can be a particularly distressing time. For co-production to be at the heart of care we would like to see the review process reformed so it can be truly person-centred, with standards of good practice co-produced with people who access adult social care so they have a consistent and quality assured experience.

*"I get really anxious every year when it comes around. The last review I had was done by a man over Zoom. He'd never met me before and he asked me how many times I go to the toilet. I laugh at it now, but who else gets asked that? There was no compassion there, it's exposing me. It's a very personal question. I need help to go to the toilet, that's all I'm asking for I shouldn't have to record everything. The lady who did my review meeting to get me into United Response was really nice, she didn't ask me that question but she was really thorough. I feel like I was spoilt with her. It was uncomfortable to have a male asking me personal questions like that. There should be standards of good practice so there is a consistent experience."*

29. A risk with any co-production is that you are only hearing from those who have the confidence and can share their views to have a voice.

30. People with profound and multiple learning disabilities are the most invisible within adult social care, their voice is largely absent within co-production activity or consultation.

31. Without robust support for self or family advocacy at a system level, people with PMLD will not have their voices heard and their needs risk being neglected.

*"We wouldn't have a life if our voices weren't heard. We'd suffer from depression."*

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## **Contact**

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