



## Do we need to re-think our approach to choice, and giving people with learning disabilities the choices that are spoken of?

There are two points that my Housing LIN viewpoint wishes to highlight: firstly, is there real choice if the housing solution promoted for people with learning disabilities is limited by supply? And secondly, is there real choice if we only offer one solution and thereby make an assumption about what the demand should be?

Written for the Housing Learning and Improvement Network by **Dr Theresia Baumker**, deputy for her brother with profound physical and learning disabilities and Director and Founder of Mannawell

October 2017

As highlighted in an article in The Guardian newspaper<sup>1</sup>, a recent statement by the Office of the United Nations High Commissioner for Human Rights reveals a number of problems with institutional care that interfere with people's human right to decide for themselves where they want to live and what they want to do when they need support in daily living. As such, models where housing and care are separately contracted (such as Supported Living) have found favour in the current UK health and social policy world. They incorporate aspects of choice and control that are not found in residential care models. Yet, real choice is limited because of too little supply: too little housing exists for people with learning disabilities to allow them to make the choice to move away from living at home with aging parents into settings other than traditional residential care (which then often occurs at a time of crisis) or to move out of their current residential care setting.

According to the National Development Team for Inclusion, 'it appears that we are currently seeing a shift away from options that offer choice and control, towards more traditional residential care – with these developments being implemented on the rationale that residential care is lower cost'.<sup>2</sup> One of the most concerning issues raised by individuals, families and local authorities is the lack of available housing for people with a learning disability – something that is a major barrier to independent living. Too many people with a learning disability remain on waiting lists for long periods of time, housed miles away from family or living in housing arrangements that need improving.<sup>3</sup>

This was the motivation for the recent roundtable event/discussion day<sup>4</sup> hosted by the Housing LIN and HACT. The event brought together parties interested in increasing the supply of housing for people with learning disabilities and how to make this happen practically, on the ground. I was delighted to be given the opportunity to speak on behalf of families with a loved one with a learning disability at the event.

As summarised at the end of the *Transforming Care Partnerships – Housing Choices, Housing Cares* day, 'we are not speaking of a provider solution, but about people's homes'. There was a clear message throughout the day that it is not only about talking and sharing, but also about 'doing'. We need to 'do' in terms of increasing the supply of housing options for people. The day was about exploring and sharing best practice that can *lead* to service improvement and transformation – to redesigning housing and care pathways on the ground.

In this context, there is ever more a sense of urgency to listen to the voices of the people. The UN document mentioned above<sup>5</sup> states that 'countries should include the voice of persons with disabilities in their plans for independent and community living'. This was wonderfully put into practice at the beginning of the event, which began with a video of Hayley Burwood's personal account of her own circumstances.<sup>6</sup> At the heart of all that should be done for the future of housing choices, should be what the industry has termed 'experts by experience' – people with learning disabilities, their carers and families, and parents with children living at home. Their voices must remain at the centre of the debate, when decisions are made about future provision of housing.

---

<sup>1</sup> <https://www.theguardian.com/social-care-network/2017/jun/29/councils-pushing-residential-care-stripping-rights-save-money?CMP=ema-1696&CMP>

<sup>2</sup> <https://www.ndti.org.uk/resources/publications/housing-choices-discussion-papers>

<sup>3</sup> [https://www.mencap.org.uk/sites/default/files/2016-08/2012.108-Housing-report\\_V7.pdf](https://www.mencap.org.uk/sites/default/files/2016-08/2012.108-Housing-report_V7.pdf)

<sup>4</sup> <https://www.housinglin.org.uk/Events/Transforming-Care-Partnerships/>

<sup>5</sup> <http://www.ohchr.org/EN/HRBodies/CRPD/Pages/DGCArticle19.aspx>

<sup>6</sup> <https://www.housinglin.org.uk/Topics/type/Listening-to-me-Video-address-by-Hayley-Burwood-Volunteer-Chair/>

In 2014, the NHS England commissioned Sir Stephen Bubb to produce a report on how to accelerate the transformation of care for people with learning disabilities, in which he rightly stated; “*People with learning disabilities and/or autism and their families have an array of rights in law or Government policy - through human rights law, the Equalities Act, the NHS constitution, the Mental Health Act, the Care Act, the Mental Capacity Act, the UN Convention on the Rights of Persons with Disabilities, and so on... [but] the **lived experience** of people with learning disabilities and/or autism and their families **is too often very different. Too often they feel powerless, their rights unclear, misunderstood or ignored***” (*Transform Care NX, Winterbourne View, pg. 10*).

By urging policy-makers, commissioners and providers to listen to the voices of the people, raises the second point this article wishes to highlight: let us not offer only one solution, but let us maximise choices. Let decision-makers listen, even to the most marginalised groups.

The policy agenda is about separation of housing and care, and rightly so, as this affords not only choice and control to people with learning disabilities but also protection from being removed from their homes if they or their families complain about the care [see my Housing LIN guest blog, *Home is where the heart is*]. But often families just want a *solution*, especially older parents of people with a learning disability. If they find the right care, but need to struggle to navigate the pathways into housing, then either someone has to walk this difficult path together with them step-by-step, or there should be sufficient housing so that finding an appropriate home is not a difficulty.

For most people with learning disabilities, their support and housing needs to be planned together. However, this pathway is not easy to navigate and can appear daunting and fragmented to individuals and their families who take the initiative. Most people approach social services, but others will approach specialist providers and others will go to the housing department. Difficulties can arise in coordinating social services and housing, in understanding the complexities of the benefit system, various regulations and funding streams.<sup>8</sup> We should be cautious that regulation of supported living, which emphasises separation of housing and care, does not prevent organisations from walking the path with people to help them find a solution for *both* housing and support. It cannot be left to committed, persistent and long-suffering families to draw these two elements together on their own – which is often the case in the success stories.

There are some marginalised groups for whom there are greater barriers to housing than others. For them, even more needs to be done to improve choices and increase housing provision. These are people with profound and multiple learning disabilities, people with a learning disability who live with older parents and people with behaviour that challenges. Seventy-six per cent of local authorities report that they have had difficulty arranging housing for adults with profound and multiple learning disabilities, compared with 29% for people with a mild learning disability.<sup>9</sup>

This draws me to a personal observation: shared supported living and living in intentional communities is not emphasised in the policy and regulation agenda of independent living. But not everyone wishes to live alone: people search for community and building relationships. People with learning disabilities also search for community and building relationships.

---

<sup>7</sup> <https://www.housinglin.org.uk/blogs/Home-is-where-the-heart-is/>

<sup>8</sup> [https://www.ndti.org.uk/uploads/files/Feeling\\_Settled\\_Final\\_Report\\_February\\_2011.pdf](https://www.ndti.org.uk/uploads/files/Feeling_Settled_Final_Report_February_2011.pdf)

<sup>9</sup> [https://www.mencap.org.uk/sites/default/files/2016-08/2012.108-Housing-report\\_V7.pdf](https://www.mencap.org.uk/sites/default/files/2016-08/2012.108-Housing-report_V7.pdf)

Therefore, living arrangements focussed on community and living together with others should still be open to them, especially for people with profound learning disabilities who cannot access the local community so easily.

From an economic perspective, support costs can also be shared in sharing living arrangements and staff wellbeing improved by not working alone. People with complex needs require high levels of support from staff with the appropriate skills. Alongside a suitable housing arrangement, the right support is therefore critical. A report by Mencap tells of occasions when families were advised by their local authority that certain housing types would never be an option, given the person's high support needs and thus costs.<sup>10</sup> There are success stories of people with profound and multiple learning disabilities achieving the lives they desire when funding and skilled support are in place. However, often the path to achieving these has been long and difficult for them and their families.

Yet, there are many success stories that need to be celebrated, shared and built upon. The hope for the future is that such stories will be easier to achieve. The great encouragement for the future is that key stakeholders are aware of the lack of availability of housing that limits people with learning disabilities exercising real choice, that dialogue is happening such as the roundtable event, and that positive action is planned. Let us keep compassion and care for people with learning disabilities and their families at the heart of all that is done to provide homes for them, and keep listening to them and each other.

## **Note**

The views expressed in this paper are those of the author and not necessarily those of the Housing Learning and Improvement Network.

## **About Theresia Baumker, Mannawell**

Theresia Baumker, PhD, is Director and Founder of Mannawell. Mannawell is a Supported Living provider, registered with the Care Quality Commission (CQC). Mannawell's purpose is to provide compassionate care to people with profound physical and learning disabilities in shared supported living homes of 2 to 4 people. The vision is to support the integration of people in communities of all abilities, and to serve them in line with the Christian principle of loving your neighbour. In so doing, Mannawell aims to be the visible ambassador for both the individuals with disabilities and their families, to support them and to give them a voice. Mannawell was established in 2017 in response to the need to provide a housing and care solution to people traditionally placed in residential care models, where they have limited control and choice over their own lives. See [www.mannawell.uk](http://www.mannawell.uk) for more information.

---

<sup>10</sup> [https://www.mencap.org.uk/sites/default/files/2016-08/2012\\_108-Housing-report\\_V7.pdf](https://www.mencap.org.uk/sites/default/files/2016-08/2012_108-Housing-report_V7.pdf)

## About the Housing LIN

The Housing LIN is a sophisticated network bringing together over 40,000 housing, health and social care professionals in England and Wales to exemplify innovative housing solutions for an ageing population.

Recognised by government and industry as a leading 'knowledge hub' on specialist housing, our online and regional networked activities:

- connect people, ideas and resources to inform and improve the range of housing choices that enable older and disabled people to live independently
- provide intelligence on latest funding, research, policy and practice developments, and
- raise the profile of specialist housing with developers, commissioners and providers to plan, design and deliver aspirational housing for an ageing population

For more information about our housing and learning disability resources, visit the Housing LIN's dedicated pages at:

[www.housinglin.org.uk/Topics/browse/HousingLearningDisabilities/](http://www.housinglin.org.uk/Topics/browse/HousingLearningDisabilities/)

## Published by

Housing Learning & Improvement Network  
c/o EAC, 3rd Floor,  
89 Albert Embankment  
London SE1 7TP

Tel: 020 7820 8077

Email: [info@housinglin.org.uk](mailto:info@housinglin.org.uk)

Web: [www.housinglin.org.uk](http://www.housinglin.org.uk)

Twitter: @HousingLIN & @HousingLINews