

Housing: Expectations and outcomes for young adults with learning disabilities

The issue

In England, spending on long-term social care (including housing) for adults with learning disabilities represents 69% of all long-term expenditures for social care on working age adults (NHS Digital 2021). However, very little is known about what models of housing provision are best and whether the age when people move matters. After the age of 18 years, when they transition from children to adult social care services, young adults with learning disabilities may move into various kinds of independent or supported living schemes, or into residential care settings. Many also remain in their family homes.

Commissioners told us they would like to know what is best for young adults aged 16-25 at this transition point and over the longer term. Social care practitioners wanted to know how to best support them and their families and what they expect from a move.

What we wanted to find out

What are the expectations of young adults with learning disabilities (aged 16-25 years) and their families in relation to housing? What outcomes matter to them and how can adult social care staff best support them in this?

Key messages

- Young adults with learning disabilities want to have choice and control over where and who they live with.
- Young adults and their families want to be supported through services that prioritise their goals and aspirations, through gradual preparation, and clear, honest, and timely information about the processes involved.
- There is a need for research that looks at longer-term outcomes such as wellbeing, health or cost, that may result from providing different kinds of housing for young adults with learning disabilities at around the time when they move between child and adult services.

What we did

We searched for systematic reviews published since 2010 but found none that were relevant or of high enough quality. We therefore searched for relevant individual studies. We extracted relevant findings from these and assessed their overall quality.

What we found

We found 12 studies and two rapid reviews that were neither published nor peer-reviewed (so-called 'grey' literature). These studies explored the experiences of young adults with learning disabilities aged 16-25 years and their parents or carers when considering housing options.

Four qualitative studies and one review focused on participants in the UK or Republic of Ireland; the others were conducted in Australia, Sweden, Mexico, and South Africa.

We also found research that suggests how social care staff can help support young adults and their families at this time.

What the evidence suggests

About the expectations of young adults with learning disabilities and their families:

Young adults say they would like to have *choice and control* over where to live and who to live with. This includes being able to *try out different housing options*, to find out what suits them, and to move as their circumstances change.

Young adults say they want to live in a place where they can grow their *social and community connections*, and to make and maintain the *family, friendship, romantic, or care-based relationships* that are important to them. They are sometimes *worried about feeling lonely or being isolated*. They would like to have more opportunities for *recreation, education, and employment*. They want to feel *safe and secure*.

Family members want to know that *risks to the young adult are well-managed* and that they and their finances are well-looked after. They also want their *aspirations and goals* to have been considered, wherever they live. They would like their young adults to experience *independence and autonomy*, in line with their capacities. Good access to *physical and mental healthcare* was considered important.

Family members wanted to improve their own *physical and mental health and wellbeing*. Parents may experience *feelings of loss, grief, guilt, and anxiety* during this period of change and want these to be recognised, along with the *contributions they have made and may continue to make* to support their young adult. They want to feel the young adult will be in good hands when parents are no longer able to make such contributions.

About the outcomes that matter to young adults and their families and how can social care staff can best support them:

Some things can make a positive difference when the young adult is considering a move to a new home, or making a move. Young adults and their families valued approaches tailored to individual needs and aspirations.

The provision of *good and timely information* was considered vital. Family members said they expected *honest communication from professionals* that would give them realistic expectations of the processes involved, the outcomes they could expect, and how long it all might take. Having *stable and trusted contacts* on hand throughout the process was valued. There is some evidence that gradual preparation may help young adults to feel more confident: for example, providing options of short-term trials of different housing options.

Family members said they often continue to advocate for and *support the young adult to manage finances and organise social and recreational opportunities* after they move. Family members may need *ongoing support* to do this and ensure their own wellbeing. Some found it helpful to *connect with others* in a similar situation.

The main external or structural factors hindering good outcomes was said to be the shortages of *appropriate housing options* and *appropriate and skilled support staff* in the local area. The limited availability of *suitable housemates* could also make finding shared housing problematic. Difficulties may also arise when housing is not considered or *integrated within other local transition pathways*, such as education, training, or employment.

Other factors have been found to lead to difficulties. These include disagreements *between professionals* and *between professionals and family members*. Delays and poor communication leave parents feeling frustrated, worried, and sometimes angry. *Anxieties about risk* and the vulnerability of the young adult can make parents unwilling to allow them to move. Increased *burden of care* can adversely affect parents' mental or physical health and wellbeing. Finally, when moves are an *opportunistic response to a crisis*, they may happen faster, but the outcomes may not always be what those involved want.

Relevance for practice and service users

The evidence supports the use of person-centred and strengths-based practice by adult social care practitioners for understanding the needs of young adults with learning disabilities around housing and supporting their aspirations. There is a need for clear communication between social care practitioners, young adults with learning disabilities and family members. This includes the timely and transparent provision of information to communicate process and decisions around housing provision and support.

The views of young adults with learning disabilities and their carers could usefully inform decisions around commissioning and recommissioning of accommodation.

Housing should be considered within and alongside other local transition pathways, such as education, training and employment and availability of care and support services.

Overall quality and completeness of the evidence

We assessed the sources we used as generally trustworthy, but most were small qualitative studies or used opportunistic samples and two were not peer-reviewed. It is difficult to be certain their findings reflect experiences or views of people in our area, or more widely. We found no studies looking at longer-term housing-related outcomes such as wellbeing, health, or cost, and only four studies conducted in the UK.

More information

The following resources consider how to best support people with learning disabilities and their families when they move between services, and how adult social care commissioners can make evidence-based decisions about different kinds of housing models for people with learning disabilities over the life-course.

Research in practice: Transitions: [Transitions – working with young people aged 16 to 25 years: Research Summary October 2021](#) | Research in Practice

Resources from 200 Lives project: Evaluating supported living and residential care for adults with learning disabilities. [Resources from 200 Lives project: Evaluating supported living and residential care for adults with learning disabilities - NDTi](#)

Contacts for further information

Kath Leman (North Somerset Council Evidence Champion): kath.leman@n-somerset.gov.uk

Karen Gray (North Somerset Council Researcher in Residence): Karen.gray@bristol.ac.uk

References

NHS Digital (2021). [Adult Social Care Activity and Finance Report, England – 2020-21](#). NHS Digital, Leeds. (Accessed 16/10/22).

Please ask for a full list of the included studies from the authors if you would like to read further.