CB-NSG November 2025 – Supporting adults with learning disabilities and their family carers as they grow older: what is needed and how can it be achieved?

Summary of workshop discussion and agreed actions

Discussion

> *"It's a terrifying prospect and concern for families and their relatives with a learning disability, that the quality of life of the person will be worse and the transition traumatic."*

Why does planning for the future need to begin as early as possible?

Attendees all discussed the importance of looking ahead as early as possible. Across the country, there are likely to be thousands of families who slip under the radar, supporting a loved one with complex needs without major input from their local authority. However, as families age and their capacity to support loved ones inevitably decreases, there is often no safety net.

This can put many families into crisis, risking a breakdown in care and support for their loved one.

> *"[There is] a young man whose mother did everything for him and unfortunately on the way back from [social club], she died in the car with him … he was left in the car from 9:00 until 6:00 in the morning before police found him … I try to support him, but our local authority are very slow to give him support. They don't understand how much that mother did for her boy and that's what frustrates me greatly."*

Many attendees expressed frustration that local authorities often hugely underestimate the extent to which families are the ones 'keeping everything together'. Even when there is strong external support, or a loved one's situation is currently stable, family carers carry the heavy burden of knowing this could change in an instant.

> *"My sister is not at risk of care or breakdown or an admission to hospital, but that could change if my mum falls and breaks a hip because she's extremely frail and has osteoporosis or my dad suffers a heart attack tomorrow."*

This constant worry significantly affects family carers' quality of life. Attendees highlighted that the need to be able to care for their relative, and the lack of a contingency plan for if they became suddenly unable to care, leads to family carers turning down employment opportunities, putting off essential healthcare e.g., operations, or avoiding activities which could result in injury e.g., not running when it is frosty.

Attendees also raised the trauma caused by navigating unsupportive systems; for example, having to repeat their relative's story multiple times to each new professional. They highlighted that having all of the key information in one place, which can then be shared easily, can help address this issue.

> *"It can be very difficult to let go and imagine a world in which you are not able to care for your loved one."*

Finally, attendees discussed the importance of viewing planning for the future as a continuously evolving process. Many highlighted the importance of regularly looking at and updating the plan. A suggestion was to schedule monthly email reminders to update the plan, so that they and others could be assured that the plan was always up-to-date and accurate.

What role do, or should, professionals play in planning for the future?

1. Being proactive

Local authorities should be planning for the future and engaging with people with learning disabilities and their families to do this[1]. Doing this proactively helps reduce the likelihood of crisis situations occurring. However, in the experiences of attendees, this rarely occurs. For example, one family carer stated that this had never been mentioned to them, while another attendee said that the extent of their 'planning for the future' support was being told – when their child was age six – that the sooner they moved their relative into residential care, the better.

Attendees also highlighted that while guidance states that there should be a single point of contact for people with learning disabilities and their families, and that services should work together to provide support for people with learning disabilities and their families as they age, families are often required to "join the dots" between services which do not speak to each other. This reliance on families to plug the gap both impacts

---

[1] See NICE Guideline NG96: Care and support of people growing older with learning disabilities

family carers and puts people with learning disabilities who do not have families to advocate for them at a disadvantage. Having someone who could bring together the different services that support someone with a learning disability and their family would both improve the quality of support and would reduce the impact on family carers.

Attendees also felt that support from a local authority only kicks in when families reach crisis, rather than proactively.

> *"Basically, if you're coping, you don't get any support. So therefore, the only time that you are going to get some support is when you cease to cope or cease to be here, which just seems so ridiculous."*

Attendees shared examples of families struggling to get their local authority to record key information about their relative. This failure to record key information could result in unsuitable support and/or issues being missed. Attendees also highlighted the inconsistency in data records; some GP surgeries proactively add digital 'red flags' to records to identify people with learning disabilities and carers, which was seen as a helpful step, but others do not.

> *"[We need] to flag to you that we exist and somebody might need to know about it in the very near future"*

While the focus of this discussion was on people with learning disabilities and family carers who are growing older, attendees pointed out that many of the key principles and solutions discussed would be applicable at all stages of life. For example, contingency plans for if a family carer becomes unable to provide support due to sudden illness or injury are equally important for younger people with learning disabilities whose behaviour challenges, as this could occur at any time.

2. Communication

For families to feel able to begin the emotionally difficult process of planning for the future, there needs to be a level of trust that professionals involved will continue to support a family member's relative with the same care as their loved ones have. However, attendees highlighted that this trust frequently does not exist. The issue of "systems-generated trauma", where trauma is caused to families as a result of navigating complex systems, was raised by attendees, alongside the need to communicate proactively with families.

> *"We're dealing with a care manager at the moment who hasn't replied to me in 8 weeks."*

3. Data Collection

A major barrier to a more proactive approach from local authorities is the fact that the numbers of families at risk of support break down in the near or distant future is not known. Local areas should know how many people there are who are being cared for by family members with little external support, but, as discussed above, these families are often invisible to services until crisis point. Without this knowledge, it is not possible to adequately and proactively plan services and support, and the likelihood of crisis is increased.

On the other hand, attendees did highlight that changes in technology, e.g., forms that can be filled out online, can make it easier for family carers. For example, if there are any changes needed to someone's information, it is now possible to change only that one piece of information on an online document without having to fill out the entire form again.

What other factors are overlooked in planning for the future?

1. Physical Health Needs

The support available for people with a severe learning disability is already very limited, and sadly it is often not able to adapt to meet emerging physical health needs as people grow older. Adults with a severe learning disability and behaviour that may challenge are not immune to the same physical effects of ageing that people without a learning disability face, yet there seems to be very little provision that caters for changing physical health needs.

> *"I've been [to] around 65 different providers so far and the barrier in almost all [of them], interestingly, has not been the [challenging] behaviour … it's actually been the level of physical disability … no rooms on the ground floor, or if there are, you can't get up to the main living area."*

2. Siblings

Attendees highlighted the impact on siblings – in particular, that there is an assumption that they are able and willing to drop or dramatically alter their lives to take over providing support for their relative. Attendees also highlighted that while there are rightly concerns about parents providing support into older age (and the impact that this has on e.g., health), siblings would also be ageing alongside their relative and so some of the same issues could arise.

> *"I certainly have got a very full life and the facing the prospect that I might have to completely upend all of that to go and become a full-time carer for my ageing sister as an ageing woman myself doesn't feel like a practical solution."*

On the other hand, some siblings report wanting to be more involved, but feeling dismissed by professionals as not 'knowledgeable' enough. This lack of recognition from the system for the role that siblings play, and a related lack of support, creates barriers to siblings who both provide support currently and may be providing a greater level of support in future.

3. Finances and Digital Access

Attendees highlighted several issues with finances, particularly related to the benefits system. For example, attendees raised that family carers stop being eligible for Carer's Allowance when they reach pension age, regardless of whether they are continuing to provide support (which many family carers of people with learning disabilities whose behaviour challenges do).

Attendees also discussed issues with the benefits system, particularly when a family carer is responsible for navigating the benefits system on their relative's behalf. The need to provide support and advice to family carers who engage with the benefits system on behalf of their relative was emphasised by attendees. Issues with the benefits system raised in this workshop included lack of clarity around entitlements under Universal Credit (for example, does being on Universal Credit entitle someone with a learning disability to free prescriptions?), and logistical issues around technology (e.g., phone number verification, one-time passcodes over text).

Working together to improve support for older people with learning disabilities and family carers – actions

Existing information and support for family carers

Attendees identified circles of support as an existing process which can support people with learning disabilities and their families as they grow older. Peer support from other families was also identified as helpful, with specific peer support for siblings identified as something that should be expanded. Attendees also identified the Jointly app (Carers UK) as a helpful tool. Sibs was highlighted as an organisation that provides support specifically to siblings.

Key systemic issue(s) that need to be tackled by the CB-NSG and other partners

Attendees identified the need to:

a) **Expand peer support** for family carers to support them with planning for the future
b) **Promote wider awareness** of the issues facing older people with learning disabilities whose behaviour challenges and their families
c) **Campaign to change Carer's Allowance** so that it does not automatically stop at pension age – a suggestion was to link up with Carers UK to do this
d) Embedding proactive planning for the future within the **Dynamic Support Register**

Practical solutions which could be implemented in the short-term to make a difference

Attendees suggested:

a) Asking family carers in attendees' networks whether they have started planning for the future, and signposting them to the support identified above
b) Filling out, or supporting someone to fill out, the Planning for the Future template

Thank you very much to Jenny Steeples (Family Carer) and Marie Lovell (Skills for Care) for facilitating this workshop, and for all attendees for their contributions.