

CB-NSG November 2025 – Using Public Money Better: Reforms to Support Independent Living

Summary of workshop discussion and agreed actions

Please see the [workshop outline](#) and [presentation](#) for further information about the background to this discussion and the proposal being responded to. Alongside this summary of key factors preventing/enabling access to community support, recommendations and ideas from this workshop have been used to update/expand on the draft proposal.

Discussion

What factors either facilitate or are barriers to independent living for people with learning disabilities whose behaviour challenges?

1. Integrated/pooled budgets

The lack of pooled budgets within the current system is a barrier to achieving independent living. Both family carers and attendees working in services highlighted that currently, significant time and money is spent in disputes over which body is responsible for paying, this is not person-centred and results in poorer outcomes.

“If we had something like the Independent Living Fund, then you could have a mix and match of different funding agreed as a package, and so much money would be saved.”

“Funding is such a massive barrier to being able to put all those elements into place, because people pass the buck rather than actually getting around the table, putting all their money in one pot and meeting the needs.”

Similarly to pooled budgets, integrated and collaborative working was highlighted as key to developing and maintaining good community support. The frequent ‘siloeing’ of different services was identified as a barrier to realising independent living for people with learning disabilities whose behaviour challenges. Attendees identified community multidisciplinary learning disability teams as a crucial part of preventing crisis, as well as intensive support teams and ‘crash pads’/crisis accommodation for if people need more intensive specialist support within the community.

Attendees with experience of pooled budgets/integrated working being in place identified these as factors which facilitate good community support which both helps avoid admission/out-of-area placements and supports discharge from hospital into community settings.

Comparisons were raised between funding mechanisms within the UK and other countries such as Belgium or New Zealand, which have equivalents of the Independent Living Fund and pooled budgets between health and social care.

2. Ensuring money is being spent in the right places

Attendees raised the difficulty of building community capacity when resources are being spent on hospital places. This is a self-perpetuating cycle; while resources are being spent on hospital places, community services cannot improve and meet people's needs, meaning that more people will be admitted to hospital in crisis and hospital places will continue to be needed.

“While that money is being spent on hospital placements, it’s not going into improving the services for the people. And it’s about trying to put that support in before they even end up in that type of provision, but it’s so difficult when you’ve not got the resources there all the time.”

To tackle this, there needs to be concurrent investment in both community services and in hospital services¹. An attendee raised an example of how this has been done in practice in their area:

“There needs to be some kind of a period of double funding, where you are enabling that community provision to be further strengthened while still trying to bring people home. And we did that last year, we did that really successfully with someone who’d been in hospital for years. It’s not a cheap option, but his quality of life has improved massively.”²

The success of the above example, and others within the local area in question, was partially attributed to the area having an integrated team between health and social care, which also enabled/better supported pooled budgets.

¹ ‘Hospital services’ meaning both the cost of supporting someone with a learning disability who is currently in hospital, and also the process of discharging them

² The [Community Discharge Grant](#) (2020/21-2022/23) was a three-year grant which provided funding to meet double running costs to support people with learning disabilities and autistic people to be discharged from hospital. This grant ended in 2023 and there has not been a formal evaluation or any continued funding.

3. Perceptions of ‘challenging behaviour’

Attendees commented that when someone with a learning disability displays behaviour that may be described as challenging as a consequence of not receiving the right support, this creates an “endless loop” of challenging behaviour being responded to with restrictions, which in turn can cause more challenging behaviour, and community services refusing to support the person because of this.

4. Lack of suitable housing

Attendees highlighted the lack of suitable housing for people with learning disabilities whose behaviour challenges as a key barrier to realising independent living. Alongside the importance of ‘ordinary houses’, attendees highlighted that some people with learning disabilities also have physical disabilities and/or medical conditions which mean that they need physically accessible housing (as well as housing which is adapted to meet any needs associated with their learning disability), but that there is a significant shortage of accessible housing due to a lack of investment.

5. A strong data/evidence base

Attendees raised the insufficiency of data and evidence as something that makes it challenging to ensure that people with learning disabilities whose behaviour challenges have their right to independent living (with the right support) upheld. The need for local areas, in particular commissioners, to understand their local population and the needs of people within that (which requires them to have the right information and data about the people who live there) was emphasised.

“I definitely think that [transition]’s where it begins... knowing who those people are at that transition stage and knowing what the ideal future should look like for them is going to be hugely valuable”

Transition was identified as a ‘crunch point’ - both where problems emerge, and where there are (often-missed) opportunities to take actions that support independent living with the right support. Attendees highlighted the importance of local areas being able to identify people with learning disabilities whose behaviour challenges (and who are likely to need support as adults to avoid crisis/inpatient admissions) at an early stage, as this enables them to plan proactively to put support in place.³

³ See the write-up of the ‘Transition’ workshop for further information

Attendees also raised concerns that the focus on inpatient numbers may be overshadowing the “bigger picture” of people who are not receiving the right support – this included people who may be living in “the community” but in overly-restrictive settings, people who are at risk of admission to hospital, or who are inappropriately in residential schools or out-of-area placements.⁴ This “invisible” population also needs support, but because of the focus on

A third component related to insufficient data/evidence-base that attendees highlighted was that areas/local authorities/ICBs do not have the right data/monitoring systems in place to evaluate whether the money they are spending is leading to better outcomes for the individual. However, as one attendee noted from their experience, in cases where there is alignment between e.g., health and social care on what outcomes need to be achieved for the person to be living a good life, this clarity leads to more successful support.

6. Communication

Consistent communication was highlighted as a key enabler for independent living within

Examples of things that work well to support independent living

1. Individual Service Funds

Individual Service Funds (ISFs) were identified as examples of practice which support independent living for people with learning disabilities whose behaviour challenges. Attendees suggested that ISFs, which give people with learning disabilities and their families greater control and flexibility, could be expanded further to support independent living.

2. Coproduction with/supporting families

Attendees highlighted that families “plug the gaps” in the system, but that in many cases they are not receiving the right support and are scared to ask for help in case they are judged to be unable to take care of their relative.⁵ Coproducing solutions with

⁴ While residential schools and out-of-area placements may in some cases be right for the individual, attendees highlighted (supported by research/other lived experience evidence) that residential schools and out-of-area placements can often be a response to the right support not being available in the individual’s local area, as opposed to it being in their best interests

⁵ The 2025 Cerebra and University of Leeds report [Systems Generated Trauma](#) (Professor Luke Clements and Dr Ana Laura Aiello) was referred to by attendees as something which exemplifies these issues

families, and supporting them, was emphasised as a key component of where things work and as something that should be central to any reforms.

3. Micro-commissioning

Similarly to ISFs, micro-commissioning (sometimes also called individual-level commissioning or self-directed support) was identified as a practice that could help support independent living.

Working together to support independent living – Actions

Existing information and support for people with learning disabilities whose behaviour challenges and their families

Attendees highlighted existing mechanisms such as the Individual Service Fund and micro-commissioning. Alongside this, attendees felt that knowing what other people, families and areas have done is a key piece of support, as it enables them to think more creatively about what can be done and to follow a roadmap of how to do this.

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

The key issue discussed in this workshop was the need to address the current lack of suitable funding to enable independent living for people with learning disabilities whose behaviour challenges. Beyond this, attendees highlighted the need for better integration between different parts of the system, and to improve how services work together and with people with learning disabilities and their families.

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

Attendees identified:

- a) **Sharing examples of how independent living has been realised** – an attendee agreed to work with CBF and Mencap to produce a case study of their relative's experiences and how their support had been achieved, to be published and shared alongside other examples
- b) Support partnership working by **collating and publishing examples of what good partnerships look like**
- c) **Mapping what funding sources are currently available and how they work**
- d) Ensuring that people, families, and professionals have a **clear understanding of rights**

- e) Feed these discussions and findings into ongoing work, e.g., the Casey Commission and NHS England work on personal budgets

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