

Overarching Themes and Recommendations from the Challenging Behaviour – National Strategy Group 1.5.25 meeting on the Mental Health Bill

About the Challenging Behaviour – National Strategy Group

The Challenging Behaviour – National Strategy Group (CB-NSG) is a multistakeholder organisation bringing together people with a learning disability, family carers, and a wide range of professionals and organisations to strategically drive forward change.

The CB-NSG is an action-focused group that exists to improve policy and practice around supporting children, young people and adults with learning disabilities (including those who are also autistic) whose behaviour challenges.

The meeting on May 1st brought together people with lived experience and a wide range of other stakeholders – including psychologists and psychiatrists, housing and support providers, commissioners, learning disability nurses, legal professionals, VCSE representatives, researchers, and representatives from both children’s and adult learning disability services in local government/ICBs - to discuss the Mental Health Bill and what actions need to be taken to ensure that the changes within the Bill are as impactful as possible. The focus was on three areas identified as having the potential to make a significant difference to people with learning disabilities and autistic people:

- Care (Education) and Treatment Reviews
- Dynamic support registers and commissioning duties
- Intensive Support Teams and alternative/emergency accommodation

This document covers some of the overarching themes and recommendations identified within these three areas. Please see the individual write-ups for greater detail on these areas.

Reactive in crisis vs proactively providing support to prevent crisis

There needs to be a greater focus on proactive support and early intervention/prevention. Attendees in the C(E)TR and DSR groups stated that, from personal and professional experience, support is being put in place too late, with the DSR in particular being used as a way of gatekeeping access to support (e.g., you are not eligible for a particular kind of support unless you are on the DSR).

Because an individual is lower priority¹ when they are not in crisis, clinicians and those working in other services (e.g., social care, housing) find it difficult to put in place proactive support to meet their needs, due to resources being prioritised on addressing current crises.

The impacts of this are:

- Children, young people, and adults with a learning disability and/or who are autistic are unable to access support at the time it is first needed, leading to their **needs increasing** and a **higher likelihood of experiencing crisis in future**
- Families and carers experience harm (e.g., **mental and physical health issues**)², which can **reduce their ability to continue to care for their relative**
- Interventions which are only implemented when the individual/their family are already in crisis are **less effective** than they would be were they implemented earlier

Evidence demonstrates that early intervention provides both cost benefits and better outcomes for individuals³.

Outcome measurement

Attendees raised concerns that current metrics are not sufficiently capturing outcomes, and that this is leading to insufficient prioritisation of resources in areas such as early intervention. With the changes to detention criteria in the Mental Health Bill reliant on strong community support, attendees recommended that a shift in metrics to focus more on outcomes in the community would support this change. There were concerns that the current ‘measures of success’ for people with a learning disability/autistic people are based solely on reducing numbers within inpatient units, which attendees felt did not sufficiently incentivise the development of strong community support that improves quality of life.

An example of good practice can be found in the Black Country’s development of an outcomes framework.

Keyworkers

Keyworkers were highlighted as a strong example of good practice by families and other professionals. There was significant interest in the ongoing pilots of keyworkers for adults

¹ This was the experience of multiple professionals

² [Broken](#) (Challenging Behaviour Foundation, 2020); [A survey of complex trauma in families who have children and adults who have a learning disability and/or autism](#) (Baker et al., 2021)

³ [Investing in Early Intervention](#) (2022); [Early Intervention Factsheet](#) (2024)

(currently keyworkers are only available for children and young people aged 25 and under), and support for this being extended further.

Keyworkers not only provide support to the individual and their family in navigating the system, but also provide support to those within the system by facilitating joint working, ensuring recommendations are actioned and providing monitoring/oversight.