Challenging Behaviour National Strategy Group - Feedback on draft BtRS Action Plan

November 2021

The feedback in this document has been collated from the discussions at the Challenging Behaviour National Strategy Group Meeting on the 22nd of November. Core members of the CB-NSG include family carers, people with learning disabilities, representatives from the Royal College of Psychiatrists, British Psychological Society, Royal College of GP's, NHS Trusts, researchers, service providers and a range of practitioners, regulators, commissioners and third sector representatives. The group is action and outcome focused and comes together twice a year[1].

We have collected the CB-NSG feedback around the following five questions:

1. What needs to be in the plan that would make a real difference?
2. How we ensure the recommendations of recent reports are embedded into the action plan? (See CB-NSG webpage for a summary of recommendations and reports)
3. How do we ensure we invest in families?
4. How will we know if it's working? What must be measured and reported?
5. How will people (who?) be held to account?

Summary of Key Messages:

The feedback provided by the CB-NSG included recommendations for improvement around key issues including accountability, funding, timely and effective discharge, workforce skills and capacity and trauma support.

Key suggestions for ensuring the plan improves the quality of life of all individuals with learning disabilities and autistic people:

- The plan must be based on a thorough analysis of what has and has not worked so far and must address the issues highlighted in numerous reports and reviews

[1] National Strategy Group - Challenging Behaviour Foundation

- The plan must be a holistic and co-ordinated combination of proactive (prevention and early intervention) and reactive (addressing what has gone wrong) actions
- The plan must be outcome based and person centred.
    - There was a consensus that the action plan must be focused on the individual and aim to implement person-centered approaches throughout. The importance of person-centered care is highlighted in the Evaluation of Building the Right Support (What matters most for improving care and support: a report on the views of people that are less listened to in current policy)[2]: "*A key theme of BRS is the idea of person-centered approaches, supported by personalised care and support plans" pg 12*

- There must be a strong focus on early intervention and early, deliverable, and timely discharge plans. Currently there is a clear lack of bespoke guidance on children and young people.
- The plan must have tangible and deliverable actions and a clear implementation plan. This means clearly stating how individual actions will be resourced and funded.
- Listening to the views of people with learning disabilities and autism, their families and advocates must be central to the delivery of the plan. A model was suggested where senior individuals make recommendations and then work side by side with local teams to support the implementation of actions.
- The plan must include clear targets about how to create and maintain a well-trained, skilled and resilient workforce. The plan must address the sustainability of skills across the health and care workforce.
- The plan must have an overall focus on creating robust accountability and oversight, both in the community and in inpatient units.

[2] Evaluation of Building the Right Support What matters most for improving care and support: a report on the views of people that are less listened to in current policy, September 2019, B0952 - Report - Independent evaluation of Building the Right Support - People less heard report.pdf (strategyunitwm.nhs.uk)

1. What needs to be in the plan that would make a real difference?

Key Recommendations:

- The plan must set out a clear strategy for covid 19 recovery. Since March 2020 many individuals with learning disabilities and autistic people have not had proper assessments/support. This must include how the community workforce will be supported going forward.

- There must be a core set of care standards for care providers and Clinical Commissioning Groups (CCGs)/Local Authorities (LA's) in each local area.

- The plan must include a clear section on accountability, addressing who is holding providers/CCGs/LA's/BTRS to account. The actions for ensuring accountability must include how families will be informed of progress or lack of. Family carers must be consulted in the development of processes of oversight, to ensure that the responsible organisations and individuals are held to account on what matters.

- The plan must include an action for CQC to strengthen inspections and their disciplinary process when inadequate care is discovered at a facility so that inadequate facilities are not allowed to remain open and continue providing poor quality care. For example, St Andrews Healthcare has been in special measure for over a year[3].

- Funding must be allocated to early intervention, and to transition services supporting individuals and their families with the move from child to adult services. It is well known that if not well supported, this can be a challenging period for individuals, leading to crisis and admission to inpatient settings.

- The action plan must aim to include the redevelopment of Personal Budgets. This suggestion is supported by the findings of the Evaluation of Building the Right Support

[3] Inadequate inpatient settings - Challenging Behaviour Foundation

(Phase 4 Summary report of learning from the evaluation)[4] so that families have more control over their relative's care. Provide families of those with complex needs a higher standard rate budget that will allow them to pay for care, training, supervision etc.

- The plan must address existing **perverse funding incentives**. The consequences of this were highlighted by recent media coverage of Mr. Hickmott who has a learning disability and has been detained for over 21 years[5].

- The plan must strengthen the processes for challenging inpatient treatment, including improving the quality of CTRs and the range of experience of clinicians involved. Currently CTRS are weakened by a lack of clinical challenge. There must be increased opportunities for challenging admissions, for example making space for questioning the purpose of an admission etc. The action plan must consider including a national evaluation of CTRs to assess the outcomes delivered for individuals.

- The plan must provide clarity on the role and recruitment of senior intervenors, including the number of senior intervenors, who/ how many individuals they are responsible for and how this will be carried forward. From our current understanding of the senior intervenor roles, there is little to suggest they will have a significant impact on the current inpatient population.

- The plan must include clear actions around the implementation of trauma informed care. We know that the cycle of poor care and admission and readmission to inappropriate services, as well as the continuous fight for access to appropriate support can be traumatizing for individuals and their families. See Tea, Smiles and Empty Promises for

[4] Evaluation of Building the Right Support: Phase 4 Summary report of learning from the evaluation (Final), September 2019, FINAL P4 Learning report 040919 (with correct links 231121).pdf (strategyunitwm.nhs.uk)

[5] 100 people held more than 20 years in 'institutions', BBC article written 24/11/21

evidence of how the system has continued to traumatize families since Winterbourne View in 2011[6].

- Resources and support around trauma need to be made widely available and staff/professionals must be trained in trauma informed approaches.

- The Department for Education must be involved in delivery of the plan. Education has a central role in the lives of children and young people with learning disabilities and autism.

- There must be an expansion of the current key worker pilot to ensure that everyone who needs impartial, advocacy support has it, to make sense of the complex systems, to mediate and build relationships. Currently it is offered only to those at risk of admission- rather than using an early intervention approach.

- The plan must include clear actions to reduce the complexity of the system providing support to individuals across their lives. Navigating through the system can be a significant challenge for individuals and families with serious negative impact (See Broken report)[7]. An alternative is the model suggested by Hilary Cottam in Radical Help - https://www.hilarycottam.com/radical-help/

- The plan must include guidance on terminology, including a clear definition and understanding of challenging behaviour and making sure professionals and care staff are aware of the impact of their language, for example, using non-judgmental and non-blaming language when communicating with people who have learning disabilities and their families.

'Behaviour can be described as challenging when it is of ***such an intensity, frequency or duration*** *as to threaten the quality of life and/or the physical safety of the individual or others and*

[6] Tea, smiles and empty promises: Winterbourne View, and a decade of failures - a collection of family stories, 2021, Tea-smiles-and-empty-promises-family-stories.pdf (challengingbehaviour.org.uk)
[7] Broken: The psychological trauma suffered by family carers of children and adults with a learning disability and/ or autism and the support required, December 2020, Broken CBF final report (challengingbehaviour.org.uk)

is likely to lead to responses that are restrictive, aversive or result in exclusion.' Challenging Behaviour – A Unified Approach[8]

2. Recommendations from recent reports must be embedded into the action plan.

It is fundamental that the action plan analyses, builds on and enables the delivery of recommendations from existing reports and reviews, rather than starting again from scratch.

See this **CB-NSG webpage** for full details of actions from recent reports.

Key Recommendations:

- The action plan must incorporate evidence-based recommendations from recent reviews and reports including:
    - Norfolk Safeguarding Adults Review (Cawston Park)[9]
    - Out of Sight – who cares?[10]
    - Baroness Hollins's letter[11]
    - Broken report[12] (especially the co-produced trauma definition included in Broken CBF final report, complex trauma, and other key messages from Broken report)
    - Institutionalising Parent Carer Blame[13]

[8] Challenging Behaviour: A Unified Approach (Royal College of Psychiatrists et al, 2007)
[9] Norfolk Safeguarding Adults Board Safeguarding Adults Review: Joanna, Jon & Ben, 09/09/21, SAR-Rpt-Joanna-JonBen_FINAL-PUBLICATION02-June2021.pdf (norfolksafeguardingadultsboard.info)
[10] Out of sight – who cares?: Restraint, segregation and seclusion review, October 2020, Out of sight – who cares? (cqc.org.uk)

[11] Baroness Hollins' letter to the Secretary of State for Health and Social Care about the Independent Care (Education) and Treatment Reviews, 21/07/21, Baroness Hollins' letter to the Secretary of State for Health and Social Care about the Independent Care (Education) and Treatment Reviews - GOV.UK (www.gov.uk)
[12] Broken: The psychological trauma suffered by family carers of children and adults with a learning disability and/ or autism and the support required, December 2020, Broken CBF final report (challengingbehaviour.org.uk)

[13] Institutionalising parent carer blame The experiences of families with disabled children in their interactions with English local authority children's services departments, Luke Clements and Ana Laura Aiello, 20/07/21, Final-Parent-Blame-Report-20-July-21-02.pdf (cerebra.org.uk)

- BtRS evaluation[14]
- Tea, Smiles and Empty Promises: Winterbourne View, and a decade of failures – a collection of family stories [15]

3. How do we ensure we invest in families?

Key Recommendations:

- Investing in families must be central to the action plan. Families often support their relative throughout their life and are therefore a central part of the workforce. Despite their central role, families often do not have access to information about support and services that should be available to them and their relative.

- The plan must address the information and support gap for family carers. This might include a 'hub model' so families have one point of contact where they can find out (by phone or internet) about services and support available locally. Families should be proactively connected to their local support and services. Information for families must include independent help and support choosing suitable care providers.

- The plan must empower families with information, support, and resources to enable them to access high quality support for their relative. For example, families must have access to Personal Budgets but alongside this there must be a guarantee that a range of high-quality support options are available for them to access.

- The plan must include focused actions to develop a skilled and resilient workforce, including family carers. The workforce must be valued and supported so that they can provide the best quality of care to people with learning disabilities and autistic people. The evaluation of Building the Right Support recognises the importance of workforce development '*There is a clear need for workforce strategies and implementation planning (nationally and locally) that include social care as well as health…**a workforce strategy***

[14] Evaluation of Building the Right Support: Final Reports | The Strategy Unit (strategyunitwm.nhs.uk)
[15] Tea, smiles and empty promises: Winterbourne View, and a decade of failures - a collection of family stories, 2021, Tea-smiles-and-empty-promises-family-stories.pdf (challengingbehaviour.org.uk)

should clearly define what multiagency professionals and capacity per population are required for learning disability / autism teams and support teams working in the community.'[16]

- Actions around workforce development must focus on person-centred training. This must include understanding challenging behaviour, evidence based positive behaviour support, as well as how to build positive relationships with family carers. The unique skills and experience of family carers should also be recognised through paid roles in the delivery and implementation of the action plan.

4. How will we know if it's working? What must be measured and reported?

Key Recommendations:

- The most important measure of success will be improved outcomes for children and adults with learning disabilities and autistic people and their families. In order to fully understand the impact of the action plan, information must be collected and reported around quality of life for individuals, rather than how much more money is being spent on their care.

- All data collected (and analysis of data) relating to actions in the plan must be publicly reported. This must include data on restrictive interventions, use of PRN, discharge data, including delayed discharge, how many people are no longer detained, and how many people are living in the community and accessing community support. Accurate and transparent data collection is essential for ensuring the progress can be monitored and responsible organisations/ individuals held accountable.

[16] Evaluation of Building the Right Support: Final Reports | The Strategy Unit (strategyunitwm.nhs.uk)

- There must be a national system of recording and reporting of data on restrictive interventions across education, social care, and health settings. Currently there is insufficient monitoring and therefore little understanding of restraint and seclusion taking place.

- Spending should be recorded and monitored to identify perverse funding incentives. There must be a holistic approach to evaluating spending to capture impact of quality of life for individuals and their families.

5. How will people (who?) be held to account?

Key Recommendations:

- The plan must define the consequences for relevant bodies of not adhering to commitments in the action plan.

- The action plan must address how Integrated Care Systems and the structures within them will be monitored and held to account to ensure that they are considering the needs of people with learning disabilities and adhering to the BtRS action plan.

- Commissioners must be held to account for beds commissioned in inpatient services, particularly when the inpatient service is rated as requires improvement or inadequate by the CQC (including providing independent support and advocacy for individuals who remain in poor services). Implementation of the plan must include holding commissioners who buy inpatient units accountable for the unit meeting the necessary quality standards.

- To improve the accountability of services commissioned and care provided in local areas, families must be linked into local decision making and commissioning. The action plan

must set out how this will be achieved through the new health and social care structures as they are implemented.

- The Care Quality Commission, and NHS England must be held to account for ensuring all new services meet the relevant best practice guidance (Right, Support, Right Care, Right Culture) so that no new segregated institutions are registered.

- The action plan must include a framework for holding service directors to account when services are found to be failing. The plan must consider applying the legislation on disqualification of company directors to prevent situations such as in the case of Winterbourne View, where the lack of accountability allowed some of the directors to go on and work at different services[17].

- Service providers must be held to account for recruiting and training individuals with the necessary skills and experience to support individuals with learning disabilities and autism. Training must include understanding closed cultures, and how to report instances of abuse or mistreatment within care settings.

- The Department for Education must be fully engaged in the delivery of the action plan, alongside the Department for Health and Social Care.

[17] Parents fear for pupils' mental state at £53,000 fee school - BBC News