



Challenging Behaviour - National Strategy Group (CB-NSG)

Thursday 24th November 2022 via Zoom

Workshop 4:

Working with Families/People with Learning Disabilities

Workshop Facilitator: Sam Clark & Jackie Edwards

Time: 11.00am-12.45pm

The aim of the workshop is to:

- To identify best practice ways of working and involving people with learning disabilities and their families in issues that affect them.

The objectives are to:

- To discuss & understand the care and support experiences of people with learning disabilities. What works well? What can be improved and what are the barriers to good care and support?
- To identify ways to gather ideas and feedback on how to make people's lives better.
- Identify actions to include in a co-produced Transforming Care action plan for people with learning disabilities.

Background

Co-production has always been an aim of the CBF as we believe people with learning disabilities and their families should have a voice on issues affecting them.

In 2021 we published a report called [Stop Look and Listen to me](#). This report details methods developed by the CBF and the Tizard Centre to understand the views and perspectives of young people with severe learning disabilities. We did this as a pilot for the Seldom Heard project.

Barriers

Barriers to working with families and people with learning disabilities is a lack of investment in co-produced initiatives. People with learning disabilities often struggle to voice their needs and families are often best placed to support individuals to get their voices heard.

Many approaches rely on supporting and working with families for them to be effective, for example, early intervention, finding person-centered care and individualised housing solutions.

Furthermore, co-production needs to be meaningful and not tokenistic. Families and people with learning disabilities should be involved from the start and their views should be reflected by the policies that the government implements.

The 'Building the Right Support Action plan' does not adequately address these issues (see appendix).

Opportunities

The "Building the Right Support Action plan" identifies a range of key reviews and reports, many of which recommend co-producing initiatives with families. The CBF also has always invested in families and valued co-production. If we share best practice and highlight the benefits of co-production with our own co-produced Transforming Care action plan then we will be able to identify actions that will truly benefit people with learning disabilities and their families.

Workshop agenda (Timings TBC)

- 1. Welcome and introductions**
- 2. Presentation to give the background and context for this work**
- 3. Group discussion**
- 4. Actions**

Actions: (To be completed during workshop)

Action: What is needed	How it will be done	Who will do it	When it will be done
1.			
2.			
3.			
4.			
5.			

Appendix A
Working with Families and People with Learning Disabilities in the BTRS
Action Plan

Commitment	Content	Measure of Success	Key Concerns	What Else is Needed?
<p>3e - ADASS, LGA and the Building the Right Support Advisory Group to identify 'What Good Looks Like' which will be followed by a report that includes best practice examples, with an emphasis on initiatives that support citizenship and human rights</p>	<p>Co-produced report that will focus on 'what good looks like' to people with personal experience, and their families and carers</p> <p>Initial scoping consultation with people with lived experience and family members</p> <p>Select initiatives to review</p> <p>Identify any outstanding good practice initiatives, how they came about and the critical factors that enabled them</p> <p>Establish final report approvals and develop a communications plan</p>	<p>Feedback from a minimum of 100 responders with lived experience/family carers</p> <p>At least 25 initiatives screened and reviewed</p> <p>Agree a second clear consultation process on the draft final report and commence consultation</p> <p>Approval for final report established and a communications plan developed</p>	<p>What are we expecting to be different to past reports on 'what good looks like'?</p> <p>The report will "outline the 'must do' actions that are needed now to ensure that good change happens" - is there commitment to act on these? Does this include commitment to provide funding for these actions?</p>	<p>Commit to providing the required resources and funding to implement the 'must do' actions from this report</p>
<p>3j - Developing commissioning guidance to build the capability and knowledge of the commissioning workforce, designed to complement qualifications and training</p>	<p>Publish guidance, and hold webinars to promote the use of this guidance</p>	<p>Guidance published:</p> <p>Autism guidance</p> <p>Learning disability guidance (includes guidance around involving people with learning disabilities and families)</p>		

Other Action Plan Statements

Statement	Key Concerns	What Else is Needed?
Chapter 1 - "We recognise that families, loved ones and unpaid carers often make the best advocates"	There is "recognition" but there is no/limited support, and families can be sidelined when trying to advocate for their relatives	Ensure that families/loved ones are respected as advocates and provide support/training to families to enable them to act as advocates to support their relatives
Chapter 1 - "The people who are important to a person should be involved in reviews about their care and support, with the person's permission as appropriate, as they will have valuable insights and knowledge about what matters to the person"	Stating that they should be involved is a positive move, but this statement is not strong enough	Make the involvement of family members and loved ones (where appropriate) in C(E)TRs and other reviews mandatory, and publish guidance on how this should be done to ensure that their voices are listened to
Chapter 1 - "There is wider work underway to ensure people's views are heard, valued and acted upon"	What does this work involve? What are the timescales in question? What evaluation methods are being used to ensure that this work is effective?	Publish more comprehensive details of this 'wider work', with timescales for when this is to be completed
Chapter 2 'I' statements - "I will be involved in the development of my plan to leave hospital as soon as I am able"	What measures will be taken to ensure that people with learning disabilities are meaningfully involved in the process of discharge planning? How will the views of people that use alternative communication methods be considered?	Publish details on what steps will be taken to meaningfully involve people with learning disabilities in their care and discharge planning
Chapter 2 'I' statements - "I will be central to regular reviews of my care and will participate in ways that work for me to make sure that I can leave hospital as soon as possible"	What measures will be taken to ensure that people who use alternative communication methods are involved in these reviews?	
Chapter 2 - "It is important that an individual's plan to leave hospital is reviewed regularly and that their family and or the people who matter to them are able to be involved in this process (with the individual's permission, as required)"	Families currently struggle to be meaningfully involved in these processes – what measures will be taken to ensure that their views are heard and acted upon?	Publish details of what measures will be taken to ensure that the views of family members are taken into account when planning discharge from hospital

Chapter 3 'I' statements - "I live in my home in my community with the people I love and who love me"	We know that there are difficulties with getting a suitable home, particularly prior to admission (after which it can be possible to access different forms of funding) – what additional measures will be taken to resolve this and to ensure there is adequate community care available <i>before</i> an individual is admitted to hospital?	Ensure that adequate community support is available at an early stage, without requiring a person to go into hospital
Chapter 4 'I' statements - "if I need one, I have an Education, Health and Care Plan that my family and I are involved in developing, and my education setting is confident in delivering the support it sets out"	What new measures will be put in place to ensure that a) the views of people with learning disabilities and their families are listened to, b) that these views are incorporated into an effective EHC plan, and c) that the relevant bodies deliver this plan?	Publish answers to these questions
Chapter 4 – children and young people being placed far away from home	There is recognition of the distress caused by this separation and the financial burdens on families who want to keep in contact with their relatives – what will be done to tackle this?	Publish details of what measures will be put in place to tackle this issue