

Challenging Behaviour – National Strategy Group

Supporting adults with learning disabilities and their family carers as they grow older: what is needed and how can it be achieved?

Jenny Steeples, Family Carer

Marie Lovell, National Practice Innovation Lead, Skills for Care

www.challengingbehaviour.org.uk

E: nationalstrategygroup@thecbf.org.uk

©The CBF 2025

Aims and outcomes of workshop



Attendees will have increased knowledge/understanding of

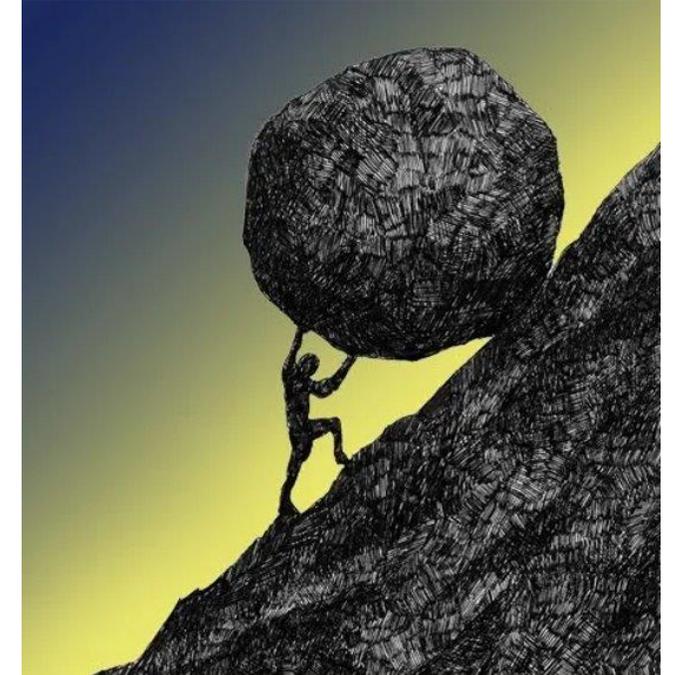
- The issues that people with learning disabilities whose behaviour challenges and their families face as they grow older
- What support older people with learning disabilities whose behaviour challenges and their families need

Attendees will have worked collectively to

- Identify actions that can be taken to ensure that older people with learning disabilities and older family carers get the right support

Why we began this work:

- It has long been recognised that there is not enough focus on or work underway to identify and support older families to **plan a positive future** for their relative with a learning disability.
- Many of these families are either living at home and growing old together or are managing personalised services in alternative accommodation to ensure their relative has a good life.
- Either way, it's a terrifying prospect and concern for families and their relative with a learning disability that the **quality of life of the person will be worse and the transition traumatic.**
- International research shows this is not a unique UK issue, and despite public policy initiatives which have tried to address it, the evidence suggests **little has changed.**



"What happens when I am gone? The thought of it keeps me awake at night."

"It feels like climbing a mountain"



"It feels so overwhelming, I don't know where to start."

"I wouldn't have a clue what you do, Mum"

What has happened so far?



1 Focus groups with older family carers

2 Co-Produced Action Plan with key policy asks to better support older family carers

3 Planning for the Future Resource

Co-Produced Action Plan: What is needed?

- Knowing how many people with learning disabilities live with family carers, and their ages
- Forward planning – working with people with learning disabilities and their families to identify what support they might need in future, and how this can be put in place
- Work with people with learning disabilities and their families to think about what might be needed if a family member can no longer provide support – e.g., if there is ill-health, the family home is no longer suitable, or bereavement



Planning for the Future resource – helping to take the first steps

- Template developed by a family carer to help other family carers pull together all the important information about their relative with a severe learning disability
- Once filled out, document can be shared with family members, friends, or with professionals such as social workers.
- The resource includes:
 - key details about your relative
 - what is important to your relative
 - what is important for your relative
 - signposting to where other information, including important documentation, can be found



INFORMATION SHEET

All our information sheets are available to download free of charge because we believe that money should not be a barrier to getting the information you need when you need it.

Please see the end of this information sheet for details of how to support us.

We want to make sure our resources are helpful. Please spend a few minutes giving us some feedback: [feedback form](#)

Taking the first steps towards planning for the future – template

This template is a document to help you:

- pull together all the important information about your family member with a (severe) learning disability - what is important to them, and what is important for them.
- signpost the person reading it to where they can find important documentation

The aim is to make this information **accessible** to people who are not used to finding and using it.

The document can be shared with other **family members**, or other people who might support your relative like **advocates** or **social workers**.

Context

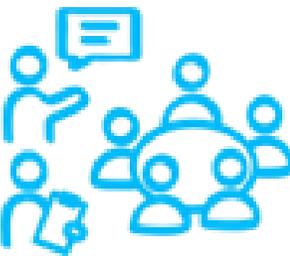


This template was put together by a family carer who works for The CBF. She started writing this document because she holds lots of information about her relative in her head rather than having it written down, and other important information that is written down is separated into lots of different folders stored in different places around her house.

She realised that if she was ill or was, for whatever reason, absent from her caring role, it could be difficult for other family members to know where the important information that they need to be able to support and care for their relative was located.

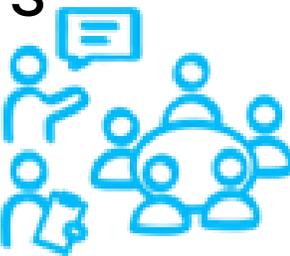
Older Family Carer Focus Groups

- Over past two years, CBF and Mencap have been holding several focus groups with family carers (including adult siblings), who are looking towards the future
- The aim of these sessions has been to explore some of the biggest concerns for families as they look to plan for how their loved one will be supported in the future



Key themes : Why this is important

- Not all knowledge about a loved one is written down – routines, rituals, and traditions are just 'known' amongst those closest to their loved one, rather than captured in any care plan
- Need to consider faith and spirituality
 - Having documented evidence, including pictures and videos, goes a long way in ensuring that a loved one can continue to be supported
 - No one can tell that story like a parent or sibling
 - Writing things down also stops family members from having to repeat traumatic events

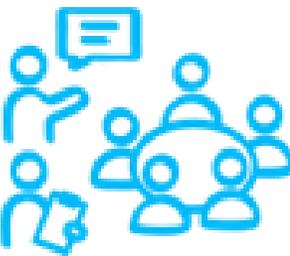


Key themes : Planning for the future – an emotional process

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

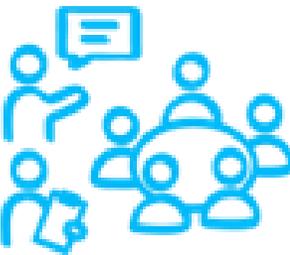
This can be made more difficult by the trauma experienced by families

Impact on siblings



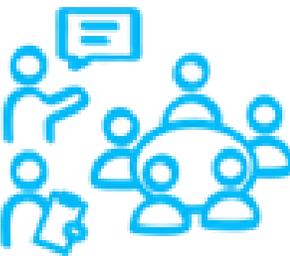
Key themes : The Process

- It has practical and emotional elements
- Planning early leads to better outcomes
- Planning needs to be seen as a dynamic process
 - Family carers should be offered the support and input from services throughout
 - Not everyone has a family member advocating for them



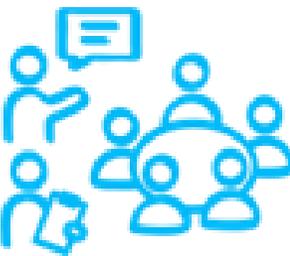
Key themes : Losing a loved one :

- Sensitivity and careful thought is needed around funeral arrangements, and how to explain to a loved one that their family member has passed away
- Some suggestions included:
 - Going on memory walks
 - Toys with a button that has a recording of their family member's voice
 - Recordings of stories being told



Key themes : Practical Elements

- Managing healthcare
- Benefits – Universal Credit and savings
- Housing and adaptations



Discussion questions

- What actions would address the issues we've covered?
- Is there anything you think is missing?



Three things to think about:

- **One piece of information or support available right now** that relates to older family carers and their relatives
- **One 'big, systemic issue'** related to older family carers and their relatives, and **where we could work together to co-produce change**
- **One practical solution** relating to this issue that you or others in the meeting **could implement tomorrow** to make a difference

