

Challenging Behaviour - National Strategy Group (CB-NSG)

Monday 27th June 2022 via zoom

Workshop 4: Future Planning: new challenges for people with learning disabilities and their families as they grow older.

Workshop Facilitator: Christine Towers & Cally Ward

Time: 11.25 - 12.35 am session, 14.20-15.30 pm session

The aim of the workshop is to: Consider the challenges faced by people with learning disabilities and their families as they grow older and what needs to be done to overcome them.

The Objectives are to:

- Identify the key areas of concern for families supporting someone with behaviour that challenges them as they grow older together.
- Identify how they might be supported to plan effectively for the future.
- Identify some of the implications for system change for social care practitioners, providers, commissioners.
- Identify actions needed to make this happen.

Background

Over the course of the 20th century many more people with learning disabilities lived longer and this trend continues, though significant concerns remain over premature mortality for many. The implication of this that many more family carers/ parents will no longer outlive their disabled child. There has been considerable academic research done on these cohorts of families growing older together across the world. In terms of an English policy context Valuing People in 2001 highlighted this group as a priority and set specific objectives for local authorities around planning for the future. Over this period, many resources were produced to help families plan together and to support providers and commissioners to get to grips with the implications of ageing. However, despite this many families continue to say, 'my greatest nightmare is what will happen when I am gone'. Several families have been in contact with the CBF expressing their fear about what will happen when they are no longer able to manage complex personalised care packages they have set up for their sons or daughters. This reflects the changing nature of social care and how this impacts on families planning for the future.

The workshop will focus on these key areas:

- Implications for families.
- Implications for social and health care systems.
- Actions for change.

Workshop agenda

- 1. Welcome and introductions (5 minutes)
- 2. Presentation to give the background and context for this work (15 minutes)
- 3. Group discussion: (30 minutes)

4. Actions (20 minutes)

(To be completed after workshop)

What is needed	How it will be done	Who will do it	When it will be done