

Supporting family carers to take the first steps in planning for the future



Thank you

We would like to thank the family carers who have shared their experiences and insight into these issues, and who have helped shape this work – their input and feedback has been key to the development of the resource and the support

Introduction: why we started this work

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

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.



The CBF has been talking with and listening to families who are concerned about what happens in the future if and when they are not able to provide and coordinate the care and support for their loved one

“It feels so overwhelming I don't know where to start”

What the CBF has been doing: Peer Support

- Bringing together and facilitating conversations with a group of families who are worried about the future
- Working together with these families about what works best for them to start planning, whilst recognising it is both a **practical** and **emotional** journey
- Recognising that each family's circumstances will be **unique** and priorities vary, but there is much to learn from each other and highlights the **importance of peer support**.
- Helping them **make a start** by bringing together in one place the information that is needed to support their family member – not just 'where do they go next' but 'what needs to go with them'
- To share the learning with a wider group of families, via the CBF, about how the pulling together of information can help make that **crucial first step**

Small steps – such as helping their relative to allow other people to support them with particular tasks – are as important a part of this process as the 'big things' like securing housing and the right care plan

Planning for the future needs to begin early – **the sooner the first steps can be taken, the easier it will be**

Focus Groups: what family carers told us

Parents don't want **siblings** to feel obliged to take over responsibility for managing support, but they are also worried about what happens if there isn't anyone who can take this on

Experiencing the **trauma** of going up against a system and professionals that do not value your knowledge or experiences, particularly when being sidelined leads to your relative being hurt or not receiving the right support, makes it very difficult to 'let go' and let someone else take over

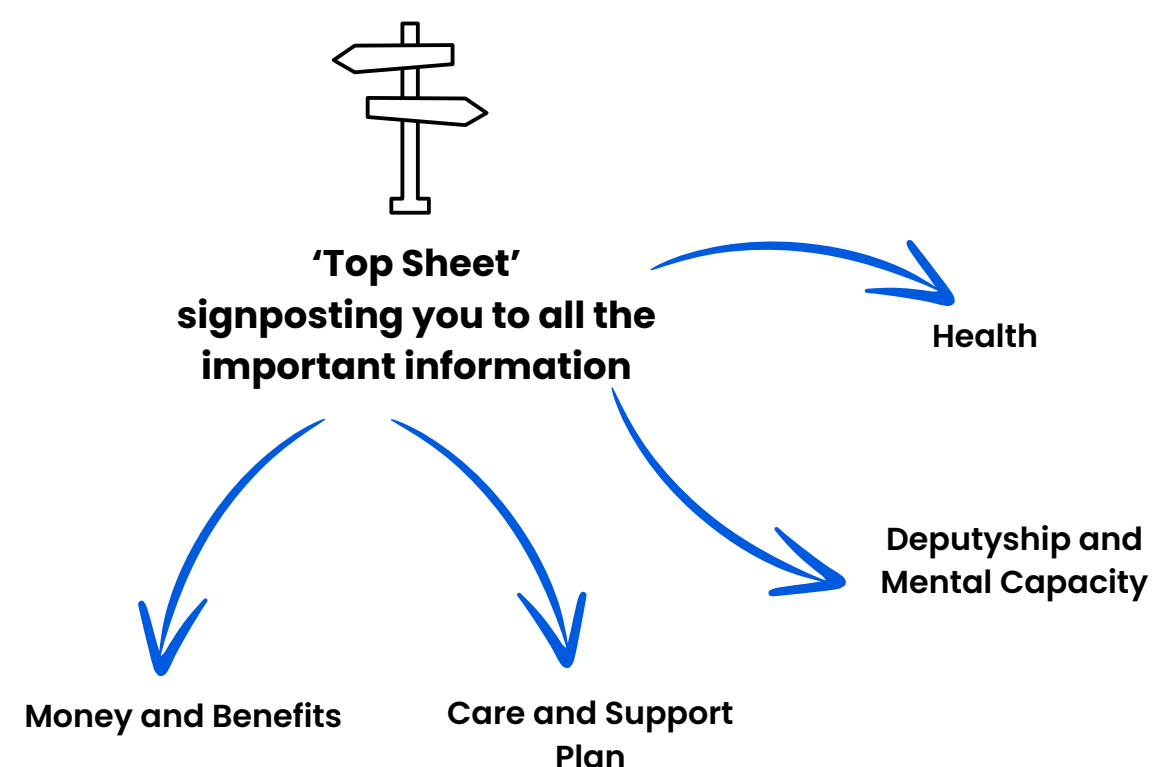
Making a start

A resource has been developed by a family carer to:

- **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 reader 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

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



The 'top sheet' provides a jumping-off point to start to make plans for the future

Next Steps

We want to hear from you – what are your thoughts, ideas and reflections on this work?

If you are a family carer, have you started planning for the future – and if not, what barriers are stopping you, and what would help to overcome these?

If you are a professional, do you work with families to support them to help plan for the future? What work are you doing, or could you do, to support this?

“It feels like climbing a mountain”

