

Empowering Families

Co-facilitators: Jackie Edwards and Coral Gassama

- What does empowering families mean

- Why is empowering families important

“Families are usually the main source of love, care and support for children and adults with learning disabilities. This is especially the case for people with complex needs. Even when people leave home, they do not leave the family. Families continue to offer a lifetime of involvement, support and advocacy.”

(Valuing People Now, 2009)

- What families told the Challenging Behaviour Foundation
 - “We were consulted but all our doubts / objections politely set aside. We were not too forceful as we're grateful for placement after hospital sectioning (2 years) and felt we had to accept it whilst disagreeing .”
 - “I was involved, my views were considered, but I wasn't provided with the information I needed to make an informed decision (i.e. about the harmful effects of medication). Over the years I've informed myself. Now that I am informing professionals about the harmful effects of medication they listen, document and then disregard my views. But we're working on this and we're being more insistent about getting our views across more assertively. Even so, the majority of MH professionals continue to be very obstructive and difficult to work with.”

- What families told the Challenging Behaviour Foundation

- “I was at crisis point with my sons challenging behaviour and I was told by CAMHS that medication was the only option”
- “I felt helpless and powerless to influence the decision to double medication dose earlier this year. Found out that we had a right to be consulted but psychiatrist ignored this and said that he knew best, despite meeting my son once in clinic”
- “I have been provided with very little information about medication which has been prescribed. I have simply been told what my son was being given, and sometimes he told me himself.”

- Examples of good practice

- What are the barriers to empowering families

- What do we need to do next to ensure that all families feel empowered when they have to make decisions about medication for their relative

- Summary