

Workshop: Empowering Families

Workshop co-facilitators: Jackie Edwards - Family Carer

Coral Gassama – Adult Policy Lead, Challenging Behaviour Foundation

The **aim** of this workshop was to consider how to ensure that family carers feel empowered when making any decisions about medication for their relative.

The **objectives** were to:

- Understand what empowering families means and why it is important
- Hear experiences from family carers about being involved in decisions about their relative's medication
- Learn from examples of good practice in this area
- Identify barriers to empowering families in decisions about medication
- Explore how these identified barriers can be overcome

Background

Empowering families to be involved in decisions about their relative's medication is essential.

"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)

In 2016, as part of STOMP, the Challenging Behaviour Foundation was asked to consult with relatives of people with a learning disability, autism or both about their views and experience when medication was suggested or prescribed. Feedback from families demonstrated that they were given little information and many felt that they had no choice but to accept the medication, even if they didn't feel it would benefit their relative.

Workshop Discussion

What does empowering families mean?

- Giving families a voice (knowing how to challenge decisions and asking for a 2nd opinion)
- Partnership working with professionals (families experiences of their relative respected and valued by professionals)

Share good practice examples of empowering families to be involved in decisions about their relative's medication.

- An example was shared from a family carer of how she worked with new professionals involved in her son's care to manage his medication. She also shared another example of how she worked with a school teacher by sharing with her articles of interests which helped the teacher in understanding her son's needs.

Identify barriers to empowering families

- Families not being involved in the decision making
- Families not knowing their rights and therefore not able to challenge decisions
- Power struggles and lack of mutual understanding between staff and families
- Personal beliefs i.e. staff seeing challenging behaviour displayed by someone with autism as normal

Explore how to overcome these barriers

- Reinforce good behaviour or professional standards
- Families given information about their rights especially their right to be consulted by professionals
- All staff to be given training in working with families

Actions

Action	Who?	When?
1. Explore potential initiatives around improving professional/family working through a number of means - i.e. CBF providing master class training to students on how to effectively work with families	Roger Banks to raise with the LD Senate, contact medical colleges on how to carry this forward Peter Pratt is on the learning disability workforce project – discuss involvement in this action	4 th September 2017
2. Link with the GMC to consider review guidance on working with families and work with them to develop their online resources. Use footage from campaign families films.	Roger Banks and Dan to find a contact CBF and Mencap	Initial contact by July 2017
3. Early years involvement, GMC to consider embedding this in training	Roger Banks	
CQC to check on evidence based medication practice	Nicholas Smith as CQC representative	
Review Open University piece of work on Carer Research and Knowledge Scoping Review by Professor Mary Larkin	CBF	August 2017

Further information/guidance/ background reading

Challenging Behaviour Foundation. (2016). Stopping Over-Medication of People with Learning Disabilities: a family carer perspective. www.challengingbehaviour.org.uk/learning-disability-assets/stompcarerperspective210517.pdf

NHS England. (2016). Stopping Over-Medication of People with Learning Disabilities. www.england.nhs.uk/wp-content/uploads/2016/06/stopping-over-medication.pdf