



Challenging Behaviour - National Strategy Group (CB-NSG)

Are we ALL ready?

Wednesday 26th May 2021

Workshop 7: Involving people with learning disabilities in decisions

Workshop Facilitator: Jill Bradshaw
CBF Note-taker: Siobhan Humphreys

Workshop agenda

Time	What
14.05-14.10 (5 mins)	Introductions and facilitators' overview of the issues
14.10-14.25 (15 mins)	Seldom Heard Voices- project presentation
14.25-15.05 (40 mins)	Discussion and action planning

Workshop objectives:

- Share work that has made a difference
- Identify key actions that have a positive impact
- Agree actions to develop/implement/ share learning and approach more widely

Presentation

Presentation about the Seldom Heard project was delivered by Jill Bradshaw (JB), followed by a discussion.

Discussion

Key points from the discussion included:

- Getting the context right enables communication
- Best interest decisions are poorly understood and implemented
- Families have to fight for communication needs to be acknowledged and supported
- Family carers are valuable communication experts and should be treated as such. Carers know the person well so they can interpret how the individual communicates.
- It is important to capture how people communicate and record it so it can be shared with healthcare professionals.
- Advance crisis planning and hospital passports are key. Conversations and planning with the hospital need to happen well in advance of the first visit.

Giving a view, for all of us, takes place in context. The greater the level of communication challenge experienced by an individual, the more attention needs to be paid to the ways in which:

- opportunities for giving a view are provided;
- information about the decision or issue is conveyed;
- personalised and scaffolded strategies are implemented;
- responses from the individual to this support are interpreted by those around them.
- Health professionals have to be more creative and flexible and plan further in advance. This all takes time, and all this should happen within a supportive communication partnership, including families/carers who are expert communication partners.
- Meaningful consultation work is possible but takes reasonable adjustments, creativity, and time (this is not always understood):
 - For example Scottish Commission for Learning Disabilities (SCLD) have done some work with Keys to Life expert group to consult with ten people. To do this meaningfully, they cascaded the information about the consultation several weeks before using a variety of communication styles large print, easy read, vocalisation and individualised Makaton.
- SCLD are hoping to work with people with learning disabilities on their leadership programme.
- CQC new project as part of transforming regulation in area – longer contact with people in services we know are poor/lack information, to try and engage with people – will look to adapt that to get that communication going (with covid restrictions).
- With committed communication partners, the Seldom Heard project has gone ahead with only virtual contact (minimum contact between the person and partner was weekly).

Action Planning

What is needed	How it will be done	Who will do it	When it will be done
Resource about good engagement principles	Draft principles based on examples of Linda Mitchell's experiences as part of Scottish Commission for Learning Disabilities	LM to draft resource – members of CB NSG to distribute resource to networks	By next CB NSG meeting
Sharing the project work from the presentation – awareness raising package re what to do – Seldom Heard project learning	Draft an awareness raising package for professionals re what to do – based on the seldom heard project learning	Jacqui Shurlock (JS)/Jill Bradshaw/ Suzi Sapiets (SS)	By next CB NSG meeting
Children should be supported to be involved in EHCP planning	This provision is in law but not in practice – need to	CB NSG members to influence	Ongoing

	influence the implementation		
Preparation – forward planning (if need to go into hospital; planning before not connected to a specific visit) clear at policy level	Influence this policy area – need planning to be clear in this area	CB NSG members to influence	Ongoing

The Action planning discussion included these key points:

- CB NSG members should incorporate the 3 key factors for communication: reasonable adjustments, creativity and time into their ongoing/future work and messaging in this area.
- The development of a Crisis App might improve crisis planning – a virtual just in case –. A phone app would be useful as can log things as they occur, that could be then sent to people when in a crisis. An app does not currently exist, but PAMIS have developed digital passports.