



Challenging Behaviour - National Strategy Group (CB-NSG)

Are we ALL ready?

Wednesday 26th May 2021

Workshop 8: Self-Advocates and Families Campaigning Together

Workshop Facilitators: Gary Bourlet, Rachael Hall and Sammy Lamb

CBF Note-taker: Kate Newrick

Workshop agenda

Time	What
14.05-14.10 (5 mins)	Introductions and facilitators' overview of the issues
14.10-14.25 (15 mins)	Advocacy 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 more widely.

Introductory presentations:

SL (LDE) talked about the 'self-advocacy together' movement which focuses on getting people the right support in ATUs. She spoke about working nationally as well as the difficulties of building trusting relationships and working online.

GB (LDE) – talked about how self-advocates should be in charge of campaigns; be able to take more responsibility and campaign risks and work as equal partners with other interested groups. Self-advocates know better than anyone else what the solutions are, and should be listened to by decision makers. "By working together we are stronger together." Being a good self-advocate takes confidence, self-esteem and time (3+ years). Self-advocates should be allies with parent forums, service providers, and others.

RH (LDE) presented a video of a self-advocate talking about the benefits of self-advocacy, e.g. for reducing frustration and taking control. RH presented on the Right2Home campaign and how LDE was using its influence to strengthen the self-advocates' campaigns.

The presenters asked the group the following questions for discussion:

- What is the best way for organisations to support grass roots campaigns?

- What are the barriers to families and self-advocates campaigning together?
- How do we overcome them?

General discussion:

SH: As a social worker in a local authority, SH commented that local authorities don't have the structures in place that allow for self-advocacy. SL raised the issue of a lack of respect for self-advocates. SH commented that attitudes and how people are treated are important, and professionals shouldn't think they have all the answers. But equally, the pressures of the job means professionals don't feel confident enough to give people more/enough time. She personally needed to develop confidence so she can work in a way that she feels is right, having the time to help somebody, within the limitations of the system.

JC: As a family carer, she pointed out that she needs to be careful what "hat" she is wearing (that of a facilitator or a participator) because sometimes she needs to be both. Families have dual roles so sometimes things can get mixed up, and this can be a barrier. Training can help but awareness that this is a responsibility is the most helpful.

DC/SC: DC discussed how she met self-advocates in Sunderland, including paid roles in guiding and shaping services in that area. She wanted to know how widespread this was. One response was that there is some similar work in East Anglia (Opening Doors). There are roles, but they aren't common, and it would be good to talk to commissioners about how they have done it, and whether it has worked (evaluation)?

SB: Suffered the personal shock of coming into world of education and realising how awful the understanding of co-production/ person-centredness/ empowerment is. Failure to include the voices of young people or self-advocates. Professionals have no experience of self-advocacy and there are no connective processes in place. Institutional power imbalance is systemic.

SC: One barrier is how power works in the system. People want LDE to have more control. They incorrectly think that Right2Home 'belongs' to LDE. Organisations are trained to promote their own campaigns, not those of others. To counteract this, there is a need for 'behind the scenes' conversations – e.g. don't put your logo on it!

Need to talk about power *and* control! They are linked but they aren't the same. For example, if you are controlling things you think of yourself as being "helpful". Control is part of the big issue and we need to pay attention to it.

BM: Thinks her organisation (and others) don't 'get' the concept of self-advocacy. Organisations pay lip service to it but don't really hear the messages. People with LD should tell us about the best services as they are best qualified to do it. These people should be valued more! Organisations should commit to valuing self-advocacy. Why are self-advocates not in organisations/boards/management?

SB: Agreed! She explained that despite a background in PBS and an advocate for it, she hadn't really considered that there was a whole network of autistic self-advocates. A connected problem is the strong opposing ideas - not everyone is advocating for the same thing. Organisations also need to protect their brand too. Therefore, some navigation tools for organisations would be useful to help them navigate through very political situations.

Actions - how are we going to do it?

What is needed	How it will be done	Who will do it	When it will be done
A safe place to explore 'hat wearing' (where families are both facilitators and participators).	A strategy of how to deal with this situation would be good. Maybe this would involve training or getting together virtually to share information? Could call it: "Families have to wear different hats."	J. Clarke to have a discussion with C. Histed about how to take it forward.	First meeting took place June 2021.
'Self-advocacy together' should host a session about what they have learnt. We need to think more about the experience of working together through Right2Home, and create an opportunity to debate this more.	Session could address 'What's worked and what have we learnt? What it means to be connected but not to 'own it'.'	S. Clarke to organise	
There is a correlation between Right2Home and the 'Homes not Hospitals' campaign (British Association of Social Workers).	The campaigns are on the same page, so might an opportunity for crosslinking?	S. Lamb to propose this potential linkage at the next Right2Home meeting. S. Harker will provide the connection at BASW (Liz Howard). S.Lamb and S.Harker to liaise.	
A stronger young people's voice in education.	S. Broadhurst to collate and gather learning from LDE and present it to DfE to move the department away from shutting down Experts by Experience and self-advocacy voices.	G. Bourlet to find out more about self-advocacy groups doing work for young people, for example People First Cumbria/Dorset People First and then discuss with S. Broadhurst then to discuss this further with LDE.	

<p>Practical ways to help individuals have a voice e.g. J. Clarke gave an example of a daily diary used by her son's school and by their family.</p>	<p>This is a good practical example of best practice (eg daily reflection sheets). Other examples should be collated and shared in a learning network</p>	<p>All attendees to contribute examples</p>	
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