

Having a 'Say' in My Life: Disabled children's rights to participation

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Terminology

- ◆ A 'say'
- ◆ 'Voice'
- ◆ Listening
- ◆ Hearing
- ◆ Are these terms taken too literally?
- ◆ Other forms of communication?

UN Convention on Rights of the Child

Article 12: Right to express views freely in all matters affecting the child, ‘views of the child being given due weight in accordance with the age and maturity of the child’.

Article 13: Right to freedom of expression;freedom to seek, receive and impart information and ideas...either orally, in writing, in print, in the form of art, or through any other media of the child’s choice.

Article 23: Disabled children’s right to dignity, independence and active participation within their community.

Policy in England

- ◆ Recognition of participatory rights of children - *Children Act 1989*
- ◆ ..and of disabled children – *Department of Health Guidance 1991*: if children have complex needs, communication difficulties or severe learning difficulties, arrangements must be made to establish their views... a disabled child cannot be assumed to be incapable of sharing in decision making

National Service Framework for Children, Young People and Maternity Services 2004:

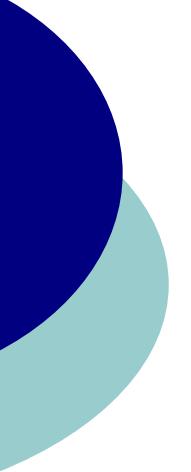
- ◆ services should ensure that 'disabled children and their parents are routinely involved and supported in making informed decisions about their treatment, care and services, and in shaping services.'
- ◆ '..professionals should ensure that disabled children, especially children with high communication needs, are not excluded from the decision-making process. In particular...children who rely on communication equipment or who use non-verbal communication such as sign language'.

Growth in children's participation

- ◆ General growth in children's participation:
 - ◆ In matters relating to their own care or treatment
 - ◆ In decision making re. development of services
- ◆ Some groups more likely to participate than others:
 - ◆ Older
 - ◆ Most articulate
- ◆ But acknowledgement of right and ability to participate for young children:
 - ◆ E.g. 'Mosaic approach'

Importance of disabled children's participation

- ◆ Disabled children are frequent users of services, including health and social care
- ◆ Important that they are involved in decisions about their own care and treatment and about development of services more generally
- ◆ Research shows:
 - ◆ Disabled children's ability to express views - children 'with experience of severe illness or disability, especially, can contribute unique and essential knowledge during decision making' (Alderson, 1993)
 - ◆ Children who do not use speech can express their views if they have the right support
 - ◆ Disabled children want respect for their views
 - ◆ One criterion on which they define a good service is having the opportunity to make real choices



Disabled children's participation: rhetoric or reality?

- ◆ Some good practice but not widespread
- ◆ Small numbers participating
- ◆ Mostly teenagers
- ◆ Involvement of those with complex needs or communication difficulties very limited
- ◆ Therefore, some disabled children not being afforded their rights regarding participation in decision making
- ◆ Recent research has explored why this is so

Views on participation

- ◆ Confusion about what participation should/could mean for these groups of children – ideal participation?
- ◆ Concerns over children's competence, understanding and abilities to participate
- ◆ Unease about interpretation of children's views

Is there a hierarchy of participation?

- ◆ Literature on models of participation often suggests a hierarchy – children sharing power and responsibility for decision making as the level to aim for
- ◆ Many professionals in the study appeared to see this as the ‘ideal’
- ◆ However level of children’s participation will vary depending on decisions involved, capability and choice of the child
- ◆ Study professionals’ attitudes changed with experience of participation....

Importance of participation

‘There might be little things like the children they’re spending time with they can’t bear to be with because they’re in the same class all day and they want to come in and they really don’t want to see that person again.. or every time they come in, because of the way the meal menu is they always have fishfingers and they hate fishfingers.. it could be very subtle things like that.’

‘He had little control over the plans and he probably had little choice about where he was moving to but at least if he could say what he hoped would be there.. it was a start... and what was going to make him comfortable was to take his comfy chair and to set his wardrobe out and his bed.. and to make this the same for him.’

Main barriers to participation

- ◆ Requires shift in attitude
- ◆ Lack of time and resources
- ◆ Lack of skills, training, confidence
- ◆ Fragile
- ◆ Lack of access to communication methods
- ◆ Formal structures
- ◆ Organisational/practical issues
- ◆ Lack of evidence on methodologies/ outcomes
- ◆ Fear

Enablers – general principles

- ◆ Addressing attitudes and concerns
- ◆ Understanding the meaning of participation
- ◆ Clarity on the purpose, objectives etc.
- ◆ Training, support and development of staff, children and young people
- ◆ Resources
- ◆ Information in appropriate forms
- ◆ Partnership working
- ◆ Informal, flexible and appropriate approaches
- ◆ Embedding of practice – e.g. recording of communication method on case files
- ◆ Evidence of outcomes

Managers...

‘You need to create a different culture where it will be an expectation. Because I think we have a lot of staff who feel, as many parents do, I did have a conversation with one parent who said her child could not communicate, and that’s the barriers you’ve got to work against. You’ve got to change the culture and attitudes and values around how valuable it is... Communication is the key to independence.’

‘It’s education, it’s getting people to understand that it does actually make a difference. Because if someone can’t see the sense of it or what it’s going to change, they’re not motivated to do it.’

‘I reckon 70 per cent is confidence, maybe 90 per cent is confidence but the confidence only comes from having some tools and understanding. Get the two things together and you’re away.’

Where are we now...mixed messages?

Aiming High for Disabled Children (2007)

Engagement of disabled children and young people in shaping services at a local level results in the provision of more appropriate services, and can help services work more efficiently and effectively, allowing for more flexible and tailored provision.....

To empower disabled children, young people and their parents, the Government will set a clear standard or core offer, and give disabled children and their parents the option to be fully involved in local service development and in designing their packages of care.'

BUT where's the money? £5million allocated for parents' forums

Progress?

- ◆ Aiming High for Disabled Children National Core Offer (2008): Standards disabled children can expect from local services
- ◆ ‘Disabled children and their families are routinely involved and supported in making informed decisions about their treatment, care and support, and in shaping services’
- ◆ Disabled children want staff to listen to them, ask them for their ideas, take notice of what they say and give them choices....Involvement of children and parents in planning services leads to more appropriate services.’
- ◆ BUT these are quotes from NSF 2004!

Making participation a reality

- ◆ A more inclusive society
- ◆ New understandings of communication as not just a verbal skill

- ◆ I may not have speech, but I have a voice
 - I can give my opinions, I can even argue (CDC/Participation Works).

- ◆ Listening is more than pointing your ears in someone's direction and computing the words which come out of their mouths. Listening can mean going for walk with someone and noticing what captures their interest. It can mean learning to recognise situations in which a person becomes upset, or becomes animated; it can mean watching a person's movements, or the activities they choose over others; it can mean creating opportunities for that person to experience new things and observing their response. (Mason, 2000: 77--8, quoted in Murray, 2004: 39).

Making participation a reality

- ◆ Resources need to follow the policy
- ◆ Training for practitioners
- ◆ Time needed for practitioners to engage with disabled children
- ◆ 'Most people in their lives miss what is growing around them. We who can't be speedy have the opportunity to be aware of the insignificant and make it important.' (Katherine quoted in Murray, 2004)

‘Top tips for participation’

What disabled young people want:

- ◆ Respect us
- ◆ Involve us from the start
- ◆ Listen to us
- ◆ Be open and honest with us
- ◆ Prove you’re listening to us
- ◆ Make it fun
- ◆ Involve all of us
- ◆ Make sure we get something out of it
- ◆ Give us time
- ◆ Support us to make our own decisions

‘We are used to people saying we cannot communicate, but of course they are wrong. In fact we have powerful and effective ways of communicating and we usually have many ways to let you know what it is we have in mind. Yes, we have communication difficulties, and some of those are linked with our impairments. But by far the greater part of our difficulty is caused by ‘speaking’ people not having the experience, time or commitment to try to understand us or to include us in everyday life.’ (Disabled people using Scope services, 2002: 1-2)