

Supporting young people with a Disability



Introduction

Disabled children and young people do not constitute a homogeneous group, and will present with the range of issues common to all advocacy, like maintaining contact with family and friends, bullying, complaints against providers, problems with social workers or care staff, education, housing or care issues.

In order to provide effective support, advocates need to think carefully about the specific barriers young disabled people face in speaking up, the impact of working closely with parents and carers, and communication methods specific to children with disabilities.

Barriers that Disabled children face

Prejudice

Prejudice can be a barrier, where people hold negative views and expectations of people who have a disability. To them, a disability means that the child cannot think, understand, learn or take part in decision-making. So they simply avoid involving them in the first place.

This discriminatory belief system results in people thinking '*this child doesn't have a view because they can't communicate*' (this was actually written on a young person's LAC review minutes)

Barriers that Disabled children face

Need to Protect/Paternalism

The 'need to protect' children with disabilities can also prevent their meaningful participation. Here, professionals and others involved in the child's life believe that having a disability must also mean that the young person is always in need of protection.

This can lead to the perception or belief that they should be shielded from difficult things like making decisions. It can also perpetuate the idea that Disabled children are always vulnerable and at risk.

This attitude fails to see Disabled children as active citizens who have voice, choice and power.

Barriers that Disabled children face

Accessible information

Lack of accessible information is another barrier to children with disabilities having a voice in decision-making. Many struggle to decipher the information they receive, which is often complex and not at all child-friendly.

If accessible information was given by trained staff who understood the child's communication styles, the young people would be able to take increased roles in decision making.

Barriers that Disabled children face

Experience in making decisions

Another real issue for advocates is that they are working with a group that has not been used to being involved or consulted for most of their lives. Many Disabled children are not used to being asked for their views or given opportunities to participate in decision-making.

The process of making a decision can be very alien to a child who has never been supported to make a decision before.

Communication and accessible information

Communication issues tend to dominate work with children with disabilities. Advocates fear that they may never know enough to understand the child's wishes and feelings.

It can take a lot of time and effort to develop a good understanding of the child's or young person's situation and life experiences - but as an advocate this is something you should commit to so you really get a sense of what is important to the child or young person.

Start with spending time with them!

Communication and accessible information

Advocates are likely to meet the family and carers of Disabled children as many of these young people live at home with their families. There may be other people in the young person's network outside the family who can help with communication and understanding, including school teachers and other support staff.

It is helpful to understand some of the advantages and pitfalls in involving others in gathering information about a young person's views, wishes and feelings.

Communication and accessible information

The real advantage of talking to others that they know them better than any one else. They may have known the young person for all of their life! They will have built trusting relationships with them and have valuable insights into their preferences. They will help you to understand how the young person communicates, expresses preferences and what is important to them.

The other people in the young person's network may also be helpful to build the young person's confidence to meet with an advocate and begin to develop a working relationship in the initial stages. They may even be the key to asking important questions in a way the young person understands, and in understanding their responses.

Working with others

Obtaining information with or from people other than the young person is not risk free however, and advocates would benefit from making preparations for these interactions. It is key that advocates keep focus on the young person as their client; as the person whose views and wishes they are supporting, and no one else's.

Sometimes, the advocate will come across points of views that are based primarily on the other person's views of what they believe is in the child's best interest, as opposed to the young person's wishes. It is not uncommon to hear parents say 'I know my child better than anyone' or 'I am the best advocate for my child'.

Separating the views of the child from those of their parents is a real challenge for advocates but something that is integral to effective advocacy.

Tactfulness

Research and experience confirm that advocates should take care not to disrupt children's networks of support. It is not uncommon for there to be differences between the young person's wishes and those of their family and other agency like social services.

Inevitably, it will often be necessary to be assertive and forceful in representing a young person's views and wishes. The right solution may also be possible by using tact: giving careful consideration in dealing with others to avoid giving offense, including choosing the most appropriate time and place to raise an issue.

Non instructed advocacy

Non instructed advocacy has developed within adult services by advocates traditionally working with adults who lack capacity or have dementia. A non-instructed model recognises that people have fundamental rights and needs, even though it might not be possible to obtain clear instruction from that person on how they would like their rights and choices to be promoted.

Non instructed advocacy

For many people with communication difficulties or who lack capacity, non instructed advocacy can be an effective way for an independent person to represent the child's likely views and preferences to decision makers.

Young people who experience difficulty in formulating or expressing their opinions are at a greater risk of being excluded from decision making processes. This can often be because it is more difficult to interpret and understand the young person who is using non verbal communication or because the young person cannot understand, due to learning disabilities for instance, the choices which are available to them.

Non instructed advocacy can play an important part in ensuring the rights of these young people are treated as equally as other young people.

Non instructed advocacy

Non instructed advocacy should never be used simply because the young person uses a non verbal communication method.

Underpinning advocacy is the belief that every person can communicate and has a right to have that communication taken into consideration when decisions are being made about that person (Art 12 CRC). There are a limited number of extreme circumstances (possibly limited to being unconscious) when a person 'doesn't have any wishes and feelings' and the advocate should be extremely suspicious when someone says the young person 'can't communicate' (Morris 2002).

Non instructed advocacy

It is well documented that on occasions adults fail to hear what a young person is saying simply because they fail to understand (or even ask about) the chosen method of communication. Morris provides examples such as professionals completing sections on forms which detail the child's wishes and feelings by entering "he is unable to communicate and therefore his view is not available" (Morris 2002).

Advocates must take care not to perpetuate the mistaken belief that just because the young person has difficulty in expressing their wishes and feelings that they do not have any. Similarly it is the advocates responsibility to communicate with the young person through their preferred methods.

In Summary

When providing advocacy to Disabled children and young people make sure you:

- avoid assumptions about the child based on their impairment or Disability
- don't assume the young person cannot make decisions
- understand the young person's communication preferences
- consider who you should work closely with to understand communication preferences
- spend time with the young person to truly get a feel for their life, what they enjoy, what is important and what they might want to happen
- challenge any discriminatory attitudes

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