



# Shared decision making with disabled children and young people



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Including all people

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“  
Tell a young person what you think, and you lose their trust. Ask a young person what they think and empower them for life.  
”  
- FLARE, (Council for Disabled Children, 2017)

# Introduction

**DISABLED CHILDREN AND** young people can often experience a lack of voice and agency across a wide range of aspects of life, such as education, family life, play, and the wider health system.

When thinking back to my own experiences as a disabled child and then as a young person, I can still identify many occasions where I felt inconsequential and ignored in situations that directly affected me.

On one such occasion, I vividly remember a specialist not talking to me as a patient, rather talking to my parents as though I was absent. An already traumatic situation was made worse by isolation and a lack of communication from the specialist. I remember being cross as a six-year-old that the doctor didn't talk to me; after all, it was me who was sick.

Over the years, there were many experiences like this one, each one adding another small layer of unnecessary trauma. Now as an adult who focuses on children's rights, I look back upon my own experiences and think, 'a lot of this could've been avoided if someone had just explained to me what was happening'.

Children and young people are often voiceless, with the professionals mostly engaging with their adult parents or caregivers. This is one of my motivating forces, having learnt and grown from my own experiences, I am very passionate about child focused and shared decision making. This resource is funded through the IHC Foundation.

This resource aims to improve how we as practitioners work with disabled children and young people. Children and young people, regardless of disability, have specific rights to participate, which include being involved in decisions that affect them, as well as having their views heard and taken seriously.

I developed this resource because I saw a gap in practical guidance focused on disabled children and young people. There are many wonderful resources out there on working with children and young people. Likewise, there are resources on supported decision-making with disabled adults. What resources are available on disabled children and young people tend to be focused on high-level research or consultation processes. I wanted a resource focused on everyday work with disabled children and young people.





## Rights

**CHILDREN AND YOUNG** people have a right to be heard; to have a say and actively participate in their own lives. This is a right guaranteed to children and young people under the United Nations Convention on the Rights of the Child (1989).

Through the United Nations Convention on the Rights of Persons with Disabilities (2007) disabled children and young people are guaranteed the same fundamental rights and freedoms on an equal basis with other children. This includes a right under Article 7 to their views being given the same weight and consideration as their non-disabled peers.

As well as having the rights to a healthy life such as the right to housing, food and water, clothing to name a few,

fundamentally, all children and young people have the right to:

- Have their views taken seriously.
- Freedom of expression.
- Dignity, independence, and active participation.
- Access to appropriate and relevant information.

Children's voices and expertise has been well explored in research and used in consultations. Yet, the views of disabled children and young people, especially those with learning disabilities, are often ignored in everyday practice by professionals when important decisions about the child or young person are being made. The disability sector itself is also patchy in its inclusion of the views of children in everyday practice.

Many of us have skills and strategies in place in our day to day work to ensure that the children and young people with disabilities that we support are involved in decisions regarding their care, but there is always room for improvement. Evidence shows that one of the biggest barriers for practitioners is a lack of guidance and support when it comes to working effectively with children and young people with disabilities. This resource aims to guide and strengthen practices to ensure we are listening to the views of children and young people in our work.

This resource covers some key ideas that we need to understand to ensure that we are working well with disabled children and young people. These are:

- The rights of disabled children and young people to be heard.
- The basics of shared decision making.
- The barriers to shared decision making.
- Strategies and tools for working with disabled children and young people.

When working with all children and young people, it is vital that we are child centred and that our practices are based on active listening, respect and engagement.



# Basics of shared decision making

**WHEN WORKING WITH** disabled children and young people, there are some key basics that we need to know. Firstly, it is vital to recognise that children and young people are diverse, and what works in one situation may not work in another. Stubbornly applying policies and procedures is not helpful; flexibility and creativity is a must. Some key basics are:

- Ask the child or young people how involved they want to be and in what areas. Some children and young people may want to be involved in some areas, but not in others. Good practice should include checking with the child or young person about the level of involvement they expect at the very beginning of your engagement with them. You should also continue to check in with them to determine whether they want more involvement in decision-making.
- Presence is not enough. It is easy to say that a child or young person is involved in the decision-making process simply by them being present. But unless their views and perspectives are being considered, being present is simply tokenistic and not an example of shared decision making.
- Be realistic. It is important to be explicit throughout the process about the level of shared power that the child or young person actually has. There are instances where the child or young person's wishes can't happen, but if this occurs it is important to acknowledge their wishes and explain why, in a way that the child or young person can understand, and not simply dismiss their wishes out of hand.

There are a variety of different models of shared decision making, we are going to explore two of them; Alderson & Montgomery (1996), and the Lundy model of Child Participation (2007)

## Model 1. Alderson and Montgomery's Framework (1996)

In this model here are four basic levels on which a child or young person can participate:

1. The first is being informed about what is happening.
2. The second is expressing an informed view.
3. The third is influencing the decision-making process.
4. The fourth is making the majority of the decisions.

Disabled children and young people often miss out on participating in decisions that affect them. Sometimes they do not even get to participate at the first two levels. Where possible, we should be aiming to support children and young people to participate at the highest level they choose.

It is important to recognise that some children and young people will not sit at certain levels due to a variety of reasons. This does not mean that their participation rights are inherently limited, it simply means that we must work with them in ways that are tailored to them to ensure they are an active part of the shared decision-making process.

## Model 2. Lundy Model of Child Participation (2007)

This model builds on the concepts of model one and is arguably more appropriate when working with disabled children and young people. It has much of the same concepts but presents them in a more holistic and adaptable way; adaptability and flexibility is key when working with disabled children and young people. The key concepts under this model are:

- Space: Children must be given safe, inclusive opportunities to form and express their views.
- Voice: Children must be supported to easily express their views.
- Audience: Their views must be listened to.
- Influence: Their views must be acted upon, as appropriate.

By putting the child or young person in a situation where they are not informed or able to express an informed view, we are effectively silencing these children and young people (directly contravening their fundamental human rights under UNCROC, 1989, and UNCRPD, 2007).

It is important that we as practitioners work effectively with these children and young people so that they are able to participate in the decision-making process to the best of their ability.

There are barriers to shared decision making, which are covered below. Most if not all barriers can be worked through with supported flexible and creative strategies.

# Barriers to shared decision making

**COMMUNICATION DIFFICULTIES ARE** some of the biggest barriers that we come across when working with disabled children and young people. When a child or young person communicates in ways that differ from traditional speech, it can be difficult to ascertain their wishes or views or explain what is happening if we are not used to communicating in this way.

Another barrier that we come across is low expectations. People can assume that disabled children and young people cannot be involved in the decision-making process.

We need to be ready and open to accept flexible, creative, and alternative ways of listening to the views and perspectives of children. We need to creatively find the best way to communicate with the child or young person.



# Guidelines, strategies, and tools for working with disabled children and young people

**WE ALL WANT** the best outcomes for the children and young people that we work with, but sometimes, we need guidance or strategies to achieve these outcomes. This section outlines some ways that we can promote and use shared decision-making to ensure that we understand the views and perspectives of the children and young people we work with.

Difficulties with communication are some of the biggest barriers to shared decision making. Communication can take many different forms, not just traditional spoken language. Some children and young people use screen readers, some use sign language, and others rely on unique forms of communication, which may be tricky to understand at first. These are all completely valid forms of communication, and we must work with the child or young person to understand what they are trying to communicate to us (Wheatley, 2018).

Communication can be fostered or facilitated in a variety of ways through creative techniques. It is important to note that not all techniques or strategies will work for all children or young people, so we must work collaboratively and carefully to ensure that strategies being put in place are appropriate and effective for the child or young person in question. Do not let preconceptions or embarrassment get in the way of figuring out the best way to communicate with the child or young person.

Some techniques include:

**Arts and crafts; communication through pictures for example.**

This was a strategy utilised by my parents; Dad drew (terrible) pictures of kidneys so that I knew where in my body was 'wonky' (as I called it when I was little).



**Drama or dance activities.**

When going through for procedures, I would always take my teddy, Rosie, with me. We would play out what would happen on Rosie first, and then it would be my turn. Rosie was a very cooperative patient, me, not so much.

**Observation and interaction with the child or young person in a variety of settings; school, home, community activities etc.**

This provides the opportunity to foster relationships with the child or young person outside of the traditional service setting and can lead to more coherent and effective decision-making supports being put in place.

**Consultation with people who surround a child or young person who uses unique communication methods.**

However, it is important to note with this that we must be mindful to not fall into the trap of using the views and perspectives of these adults in place of those of the child or young person.

I was very lucky as a child to have an amazing support system around me. My Mother is now a play therapist, and often says I was her first client. My Father was always there with a running silly commentary of the going-ons at the hospital. Even when I felt small and overwhelmed by the realities of being a child with a disability, I knew I'd always be listened to by my parents and family; it was the rest of the world that would prove to be a problem at times! The hope is with this resource that those who work with disabled children and young people can feel confident that they can work effectively and collaboratively these children and young people.



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## Helpful resources

**THERE ARE SOME** wonderful resources that are out there, and if you're after more information, check out some of these:

- Ministry of Social Development. (2003). *Involving children: a guide to engaging children in decision making*. Wellington: Ministry of Social Development.
- Smith, A., Taylor, N., & Gollop, M. (2000). *Children's voices: Research, Policy, and practice*. Auckland: Pearson.
- Wheatley, H. (2018). *21st century social work with children and young people with disabilities* (1st ed.). Dartington, Devon, England: Research in practice.

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 IHC FOUNDATION

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Lundy, L. (2007). "Voice" is not enough: conceptualising Article 12 of the United Nations Convention on the Rights of the Child" [Ebook] (pp. 927-942). *British Educational Research Journal*.

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# CCS Disability Action office locations

WE HAVE A long, proud history of delivering support, information and advocacy for local communities across our network of branches.



## Get in touch Whakapā mai

IF YOU'RE INTERESTED in more information or would like to get in touch we would love to hear from you.

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