



# Involving disabled children and young people in the decision-making process<sup>1</sup>

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<sup>1</sup> This document has been produced in response to the research report entitled '*All Decisions: ensuring disabled young people's views and feelings are heard in decisions about their own lives*' published by The Disability Advocacy Project in February 2006.

## **Introduction**

### **About this guide**

The Children's Society's Disability Advocacy Project has developed this guide to provide practical advice on how to include disabled young people<sup>2</sup> in decision-making about their lives to ensure that their views, wishes and feelings are heard.

### **Who should use the guide**

This guide is aimed at professionals working directly with disabled young people. These may include:

- Social workers
- Residential workers
- Teachers
- Learning support assistants
- Independent reviewing officers
- Key workers, advocates
- Participation workers
- Children's rights officers
- Health professionals
- Mentors
- Managers.

The guide may also be useful for family, friends and carers.

### **When should this guide be used?**

This guide should be used as a reference tool to best practice when guiding disabled young people through any decision-making process. This includes everything from day-to-day decisions about what clothes a young person wants to wear, or what food they want to eat to major decisions about where they want to live, go to school, or the medical treatment they receive.

### **Context of resource**

This guide accompanies the 'My Life, My Decisions, My Choice' learning pack for disabled young people. The pack includes a poster and a set of discussion cards designed to help disabled young people understand, explore and communicate their thoughts and feelings.

The 'My Life, My Decisions, My Choice' learning pack is a great tool to help you explore the issues of rights and participation with the disabled young people you work with. It is available free of charge from the Disability Advocacy Project. Please contact us at:

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**W: [www.childrenssociety.org.uk/disabilityadvocacyproject](http://www.childrenssociety.org.uk/disabilityadvocacyproject)**

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<sup>2</sup> For the purposes of this guide we refer to disabled young people. By this we are referring to disabled children and young people up to the age of 25 years old.

## **Summary of contents**

This guide provides detailed information on how to:

- ◇ prepare yourself when involving disabled young people in decision-making
- ◇ prepare disabled young people
- ◇ involve disabled young people in decision-making meetings
- ◇ feedback outcomes to disabled young people.

## **4 key points to remember throughout the process**

### **1. Be flexible and tailor your approach**

There are many different approaches and methods you can undertake when involving disabled young people. This guide provides a starting point, but you will need to be flexible in your approach, adjusting it to each individual's needs, wishes, likes and dislikes. It is crucial to ensure the level of decision-making is appropriate for the young person. This sometimes means breaking down big decisions into smaller decisions that are relevant to their everyday life.

### **2. Be creative**

Remember that all young people can communicate but it may mean you need to be creative with your own skills. Try to make it fun for the young person to participate.

### **3. Practice**

Decision-making skills are developed through practice. Often disabled young people are denied opportunities to practice these skills. Ensuring young people are meaningfully involved in decision-making is a skill that requires dedication and practice.

### **4. Time**

It takes time to plan, involve and feedback to disabled young people. You may need to try out a variety of approaches and methods to meet an individual's needs. Allowing enough time will lead to more successful results.

## ***How to prepare yourself when involving disabled young people in decision-making***

Before involving a young person in any decision-making process you will need to find out about them and consider how to meet their needs. This section provides guidance on how to plan and prepare.

### ***Introductory visit***

- ◇ If you do not know the young person it is vital to set up an introductory visit to meet them and to introduce yourself. This will give you the opportunity to find out how to best accommodate their communication and decision-making needs.
- ◇ It is important that you contact the young person prior to every visit or meeting. If it is the first time, you should send through a photo of yourself in advance to help the young person prepare for your visit.
- ◇ It may also be helpful to talk to other people working with the young person to share your ideas and find out more about the young person and their preferences. You could do this as part of your introductory visit.

### ***Planning your visits***

- ◇ When arranging a visit try to involve the young person from the beginning by asking where and when they would like to meet you and accommodating their requests where possible.
- ◇ Be prepared to use a mixture of communication methods and think about how you might use these in your planning. A process of trial and error may be required in order to find out what the young person best responds to.
- ◇ You need to be flexible in your approach to communicating with a disabled young person. It is useful to be aware of a variety of communication methods, including formal methods such as; speech, sign language, body movements, gestures, pictures, symbols, eye contact or facial expressions, plus more informal methods such as drawing, playing and other activities.
- ◇ When preparing to work with disabled young people to determine their views, choices or preferences, plan a number of ways to do this. For example, if you want to find out about a young person's views on their school, think about what you could do if they don't want to talk about school on the day of your visit. Think about some activities you could do with them based on school subjects, such as mathematics, drawing or writing activities.
- ◇ Create a back-up plan for those situations when the young person does not respond to your initial activity or task. Your primary goal is to engage the young person so try to make the tasks as fun as possible. This will ensure the best results and a greater attention span.
- ◇ It may be helpful to build in time to observe the young person. Observing the young person can be as important as talking to them.
- ◇ Allowing enough time to cover off all considerations is crucial to successful planning. Remember you may need to allow for additional time with the young person, depending on their individual needs.

## ***How to prepare disabled young people for decision-making***

Disabled young people sometimes require support to help them prepare for decision-making. This section provides guidance on how to work with disabled young people to prepare them for the decision-making processes.

- ◇ Young people may not always want to participate in decision-making or making a choice. They have a right to say no and this should be respected. But you should encourage and support them to have input and be represented in decisions about their life.
- ◇ If a young person does not want to be directly involved, then you must give consideration to how their views, wishes and feelings could be presented. For example, you could use a photo storyboard, DVD, or examples of their work.
- ◇ Young people should be offered a variety of mediums so they can express their views and/or participate in decision-making. You should regularly check that they are happy with the way this is being done and offer different options if required.
- ◇ All young people should be invited to attend their meetings but they do not have to stay the entire time. Ask them how long they would like to stay and which part of the meeting they would like to attend. Try to arrange the meeting to cause minimal disruption to the young person's daily routine.
- ◇ When preparing the young person for any meetings make sure the young person knows when the breaks will be, when the session will end, and how they can say when they have had enough.
- ◇ When a young person is attending a meeting it is important to help them prepare so they understand the process. They should understand what the meeting is about, who will attend and what decisions need to be made. This will help them to choose what information they want to present. This is often the role of an advocate or key worker.
- ◇ A young person should be offered dedicated support to help them participate. It is important that the young person chooses who this person will be. The helper can also represent the young person's views if the young person does not wish to attend the meeting.

## ***How to involve disabled young people in decision-making meetings***

Involving disabled young people in meetings requires extra consideration. This section provides guidance on how to make the process as effective as possible.

- ◇ Ensure everyone at the meeting with the young person introduces themselves, explains their role and how they will be involved.
- ◇ Always make sure everyone uses language that is easy to understand and accessible to the young person. Your preparation with the young person will allow you to judge their level of comprehension, so ensure you pitch the language of the meeting appropriately.
- ◇ Make sure the questions you ask are at the right level for the young person's individual needs. The choices offered should be meaningful and realistic. It may be helpful to break down big decisions into a series of smaller decisions that are directly related to their daily routines.
- ◇ Giving concrete examples of the choices available (i.e. an activity, food, contact with family) can help young people understand more fully and aid their decision making process. It also encourages them to express their views.
- ◇ Allow time for the young person to respond and make choices. It is important that decisions are discussed at an appropriate pace.
- ◇ When a young person is communicating their views and choices in a meeting, follow their lead. If they have made a choice it is useful to explore why they made that choice and how they feel about it.
- ◇ Attention spans will differ so it is important to factor in time for breaks. Allow the young person time to go away and come back to the task if they want to.
- ◇ Record and document all communication methods used by the young person to gather a complete picture of their views, for example, words, body and head movements, symbols, photos, signing etc.
- ◇ Disabled young people can express a lot in their behavior and how they engage with others. This should be noted as well as the views they express directly.
- ◇ If you have tried a number of different approaches in one meeting and the young person is not engaging be prepared to cut a meeting short and try again another day.
- ◇ After each meeting review what has and hasn't worked and use this to plan for future meetings with the young person.

## ***How to feedback outcomes to disabled young people***

Feeding back to a young person is an important part of the decision-making process. This section provides guidance on how to approach a feedback session.

- ◇ Care, time, and consideration should be given as to how best to provide feedback. The young person has shared their views and choices and it is important that they should be told how these have been taken into account in the decision-making process.
- ◇ A summary of any meetings should be provided to the young person. This could be done by direct discussion or in writing, using pictures or symbols if appropriate.
- ◇ If a decision has been made that is not in favour of the young person, you must explain why the decision has been made. Being part of the process, having the opportunity to express opinions, and understanding they have been considered is very important for the young person.
- ◇ Young people's choices should be considered even if they involve elements of risk – these risks should be considered and managed.
- ◇ Make sure you keep the young person up to date with what is happening after the meeting even if progress is slow or there is little to report.
- ◇ Disabled young people have the right to complain and you should ensure they have the opportunity to do so. They might not use the word 'complain' but may say they are 'unhappy' or it 'doesn't feel right'. They have the right to an advocate to help them make a complaint.

## ***More information***

For more information and resources on how to involve disabled young people in decision making and participation activities please visit The Children's Society Disability Resource website at [www.childrensociety.org.uk/disabilitytoolkit](http://www.childrensociety.org.uk/disabilitytoolkit).

The website includes:

- ◇ An online database of resources that provide information to support disabled children and young people's involvement and participation.
- ◇ Practice examples of how to involve disabled children and young people.
- ◇ Research and policy about disabled children and young people's involvement in decision-making and participation.

This website is action focused and aims provide professionals with solutions to the barriers they encounter when working with disabled children and young people. The interactive website encourages users to share their own resources, practice and ideas.

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