

Choices and Voices

**Advocacy and participation for
disabled children and young people –
ideas and key messages**



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Acknowledgements

This guide would not have been possible without the children, young people and families who took part in the Mencap children's advocacy project. We would like to take this opportunity to express our thanks for their warm welcome, cooperation and positive support of the project.

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The project had the benefit of an advisory group made up of a partnership of staff from voluntary and community, education and statutory organisations. We would like to thank them for generously giving us their time and support, as well as guidance and ideas – many of which are included within this guide.

Finally, thank you to the staff at Mencap, including Nuala Phillips and Margaret McDaid, for their help and support with the children's advocacy project and the development of this guide.

Lisa McGrath
September 2010

Introduction

This guide was produced after an 18-month pilot advocacy project which took place in the Western Health and Social Care Trust in Northern Ireland, from April 2009 until September 2010. The aims of the project were to:

- set up and deliver an advocacy service for disabled children and young people
- encourage their participation in decision making
- improve the knowledge base around the practise and benefits of advocacy for disabled children and young people.

The project worked with young people individually and in groups, and in particular with those coming up to transition in special and mainstream schools. The work focused on building their knowledge and confidence and encouraging them to take an active part in planning for their own future.

Transition is an important time for young people with disabilities, as decisions are made about what options they have after school, and what their future will look like. Transition officers in health and social care, education and the voluntary sector help to prepare young people and their families for the future and guide them through the transition process making it easier and less daunting.

Some times a young disabled person may need help to express their own views during a decision-making process. This is where advocacy can help them to have their voice heard.

The information in this guide is based on the knowledge, skills and experience gained during the children's advocacy project. Many of the ideas and key messages have come from the children, young people and families who took part in the project. We are happy to have had the opportunity to find out what works best for them and to share our learning here.

The quotations throughout are the voices of some of the children and young people who took part in the project.

About advocacy



Tell me
about some
of the things
you like.



*“I like
drama.
And I like
money!”*

Advocacy is the process of ensuring that someone has the opportunity to be heard and have their views respected in all matters that affect their life. Advocacy can help a child or young person to find out about proceedings they are involved in, think about the decisions affecting them and express what they want to say.

An advocate gives support to anyone who finds it difficult to have their views heard. They offer time and commitment, help them to convey their wishes, make informed choices and gain greater control of their lives. It can help to understand the role of an advocate in the following terms:

An advocate can:

- help children and young people with a learning disability be involved in and understand proceedings or decisions that are being made, think about their options and say what they want
- ask questions on behalf of a child or young person
- make sure that the voice of the child or young person with disabilities is heard and responded to
- work to make things happen and change, by asking the right questions and finding out information help children and young people to make choices and have more control of their own life.

An advocate does not:

- break confidentiality for no reason
- become a referee in a dispute or argument
- say what is best for the child or young person or tell them what to do
- persuade a child or young person to agree with others
- take control away from the child or young person or keep information from them.

Children and young people who have disabilities can benefit from advocacy support for different reasons. They may need help at particular times in their life, such as transition from school and from children's to adult health and social services. They may have difficulties in a range of settings, such as at school, the hospital or a youth club, and have no one to talk to and help them resolve it. They may need support during times when decisions are being made about their life, such as planning meetings or annual reviews.

Most often, parents and carers are the first and strongest advocate a child or young person will have. Their social worker, a support worker, a teacher or carer will also act as an advocate. Having an independent advocate, someone from an agency that does not deal directly with their care and education, can help ensure that the distinct voice of the child or young person is heard and valued.

Advocates form a partnership with a child or young person. They establish the methods of communication they use and begin to get to know them. They learn how they prefer to communicate, the things that matter to them, as well as their likes and dislikes.

The advocate offers support (it is up to the child or young person if they wish to accept), information and representation, with the aim of empowering the young person and enabling them to express their own needs and wishes. Or they can represent their views on their behalf if this is what they prefer. An advocate can provide a mixture of support, signposting, information gathering and sharing, as well as time, to help the child or young person to understand what is happening and to facilitate their participation.

Advocacy is about helping a disabled child or young person to be heard. It is closely linked to the principles of human rights, disability discrimination and equality of opportunity.

The United Nations Convention on the Rights of the Child (UNCRC) is an international human rights treaty that grants all children and young people a comprehensive set of rights. For example: Article 12 of the UNCRC gives children the right to say what they think should happen, when adults are making decisions that affect them, and to have their opinions taken into account. Article 23 states that children who have any kind of disability should have the extra care and support they need to live full and independent lives.

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)

was adopted by the General Assembly in December 2006 and ratified by the UK government on 8 June 2009. UNCRPD states that:

“It is essential that children with disabilities are heard in all procedures affecting them and that their views be respected in accordance with their evolving capacities ... Engaging them in such a process not only ensures that the policies are targeted to their needs and desires, it is also a valuable tool of inclusion since it ensures that the decision-making process is a participatory one. Children should be equipped with whatever mode of communication is needed to facilitate expressing their views. Furthermore, State parties should support the development of training for families and professionals on promoting and respecting the evolving capacities of children to take increasing responsibilities for decision making in their own lives.”

(Paragraph 32)

Different models of advocacy support

Every disabled child and young person is unique, and they may need different kinds of advocacy support at different times in their lives. What is common to all types of advocacy is that the person who it is for, in this case a disabled child or young person, is always at the centre of the advocacy process. It is about making sure that what that young person wants to happen is established, and finding the best way of getting that across to the people who need to know and who are involved in the decision-making process. Advocacy can be like tools in a tool box, and the different types can be used together or separately depending on the circumstances, the job that needs to be done and the wishes and preferences of the child or young person concerned.



Self-advocacy

Self-advocacy is speaking up for yourself. It is what most of us do, but it isn't always easy and requires confidence and skills, which some disabled children and young people may need support and experience to attain. Many disabled young people are very good at knowing or telling others what they want to happen, but they sometimes find it hard to get others to value and accept their views or listen to them. Self-advocacy groups are a good way of encouraging young people to gain the experience and skills they need. They give young people with disabilities the opportunity to meet together with their peers, usually supported by a facilitator, and talk about issues and interests that are important to them. They are a useful way for young people to support each other and gain the knowledge, skills and confidence to have their say.

Citizen or volunteer advocacy

This is a long-term partnership and occurs when a young person with a disability is matched with a volunteer who has the interest, skills and knowledge to support the young person over a longer period of time. The benefits of having a volunteer advocate mean that the young person can build a trusting relationship, have someone to talk to and meet up with regularly, who can then really understand their views, and is less likely to feel isolated and excluded.

Non-instructed advocacy

Disabled children and young people who are not able to communicate verbally still have the right to have their say and be involved in decisions that affect them. Establishing a method of communication that both the advocate and the young person can use and understand is the basis for successful advocacy. When the spoken word is not used, there are many alternatives, such as signing, gesture, pictures, storyboards, communication passports, touch and body language. When communication is more difficult to establish or is not present at all, for example in the case of a child with profound disabilities or complex needs, non-instructed advocacy may be undertaken. This is a developing area of advocacy support and is based around close observation of the child in daily life and involvement of those closest to the child to help ascertain their likely preferences, wishes and needs.

Issue-based advocacy

This is when a disabled child or young person gets support from an advocate about a particular issue, usually for a time-limited period. This type of advocacy support is given to meet a particular need and ends when the need is met. It provides more intensive support than volunteer advocacy and can address issues such as extra support during the transition process, ascertaining views of young people who have communication difficulties, support to participate in decision-making meetings and annual reviews.

Issue-based advocacy



What makes
you happy?

*“I am happy
playing with
my friends.”*

The children’s advocacy project was involved in supporting a number of children and young people through issue-based advocacy and, while no individual cases are mentioned to protect confidentiality, below are some of the ideas and approaches that were used and which worked well. Establishing an advocacy relationship with a disabled child or young person takes time, patience and commitment. There are a number of steps that can make the relationship, and therefore the outcome, more successful.

Get to know the child or young person

The first few meetings with a child or young person will be important. The aim is to show respect, listen, show you understand and are clear about the issue, and establish trust. Meeting somewhere they are comfortable is a good idea. For the first few visits, the young person may want to meet at home but, depending on their age, may eventually be happy to meet in a more ‘neutral’ venue, for example a coffee shop, meeting room, in school or at a respite centre. The right to make a choice will be a common theme throughout the duration of the advocacy support so encourage the young person to choose where they want to meet you – a first step towards empowerment.

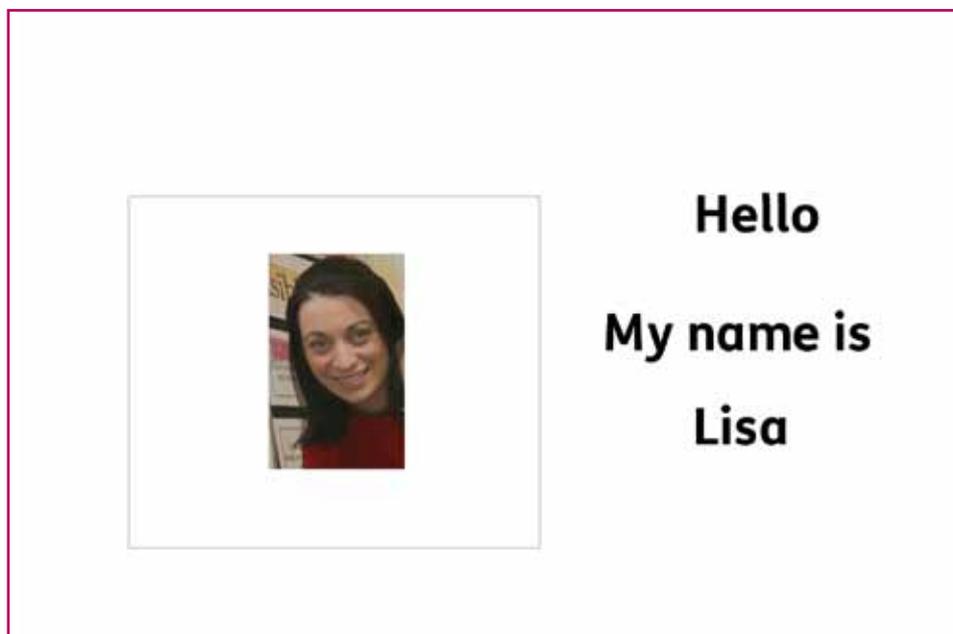
It is important to stress that, at the beginning, things may seem to move slowly, especially if you are meeting the child or young person once a week or less frequently. However, this ‘getting to know you’ stage is essential to building trust so the young person feels safe and listened to, but also gives you, as their advocate, time to become

familiar with their likes and dislikes, communication preferences etc. These are key factors to get as much as possible out of a time-limited service.

Explain your role

Explain your role to the child or young person and be clear about what you can and cannot do. Be clear with them that they can speak in confidence to you and that you will respect confidentiality as long as it is safe for the child or young person. Don't make promises you cannot keep. It can help to establish these boundaries with children and young people as they feel safe with boundaries in place. Emphasise the independent nature of your role: that you are not there to act as a referee in a dispute or to give your opinion on an issue. You are simply there to support them to communicate their needs, views, wishes and choices to the people who need to know.

A successful idea that was employed during the children's advocacy project was to use PowerPoint slides on a laptop, explaining in very basic terms a little about yourself, your job and what you will and will not be doing. You could use pictures and symbols to support your communication or you could print the slides out individually, laminate them and loop them together as a hand-held tool. Experience has shown that some children find the informality of this approach, particularly at initial meetings, helpful and it can be used as a tool to initiate conversation or a memory prompt the next time you meet the child or young person. The slides below are an example:





Things I like



Watching movies



Reading



Walks in the countryside



My job is to...



Listen to children and young people



Make sure adults hear what you have to say

I can help by ...



Going with you to meetings with adults



Being with you when adults ask you important things



Explaining your views to adults

Support from parents or carers

It is essential to build a positive relationship with parents and carers. As expected, parents of a child or young person with disabilities feel protective and responsible. They may be wary of their son or daughter speaking to someone privately or when they are not present. It is important to remember these are perfectly natural fears and your job is to reassure parents and carers about your role and the boundaries of the advocacy relationship: an independent person there to give back up so the young person can express what they are feeling and what they want to happen. You are not an adviser or someone to make judgement about what is in the best interests of the child or young person.

Parents and carers of a disabled child or young person have often been their advocate from birth. Many parents and carers are their child's 'champion' – eager to do whatever it takes to ensure their child's needs are met. However there may be occasions when the young person's views differ from their parents' but they may not have the confidence to speak up about it or want to upset their parents. In this case, building a constructive dialogue and having a good relationship with the parents and carers can help support the young person to have their say.

Many parents welcome an advocate's involvement. They often express relief that someone independent from a service provider is encouraging and supporting their son or daughter to take an active role in decisions about their life and to speak up for themselves. It is a step towards independence, which many parents and carers are happy to see.

Bringing support to a close

It is important to stay focused on the advocacy issue in hand and to remind the child or young person, as well as their parents and carers, that support is time-limited. Once the



need has been met, or issue resolved, the advocacy support will end. Disabled children and young people have many people moving in and out of their lives. Depending on the needs they have, there may be any number of professionals involved at different times, such as doctors, community nurses, physiotherapists, speech and language therapists, as well as support workers, carers and social workers.

It is important to remember the temporary or intermittent nature of some of these connections and how this will affect the young person. Sometimes they can get fatigued from the number of people coming in and out of their lives and may not see the point in engaging with yet another person. By explaining that you are here to help for a certain length of time and will be stepping out at the end of that time, the young person can see clear boundaries, understand your role and is less likely to be disappointed or distressed when the advocacy support ends.

In the final few sessions, recap on what has taken place during your time supporting the young person. Emphasise the positive outcomes for them, for example they are more confident, feel better about themselves, have learnt new skills and can speak up for themselves. Make the final session a positive experience, draw attention to their commitment and achievements, and make sure they know how to request advocacy support if they need it again in the future.

Key messages

Advocacy support may be needed to:

- ensure young people's views are heard and listened to
- support young disabled people (who are supported or living away from home) who are involved in formal meetings
- facilitate better involvement of young disabled people who are involved in decision making
- ensure young disabled people get the opportunity to communicate their needs, express their wishes and make choices.

Benefits of advocacy support:

- Enhanced quality involvement of disabled children and young people.
- Positive impact on the knowledge and awareness of professionals.
- Better-designed and targeted service provision.
- Increased confidence and self-esteem of children and young people with disabilities.
- Positive self-identity as a disabled young person.
- Raised expectations for disabled children and young people and their future.

Encouraging participation

What do you want to do in the future?

“I want to learn to drive and have my own car.”

Participation means disabled children and young people taking an active part in choices and decisions in their own lives. We have already seen how **issue-based advocacy** can support a child or young person to have a say and take part in decision making.

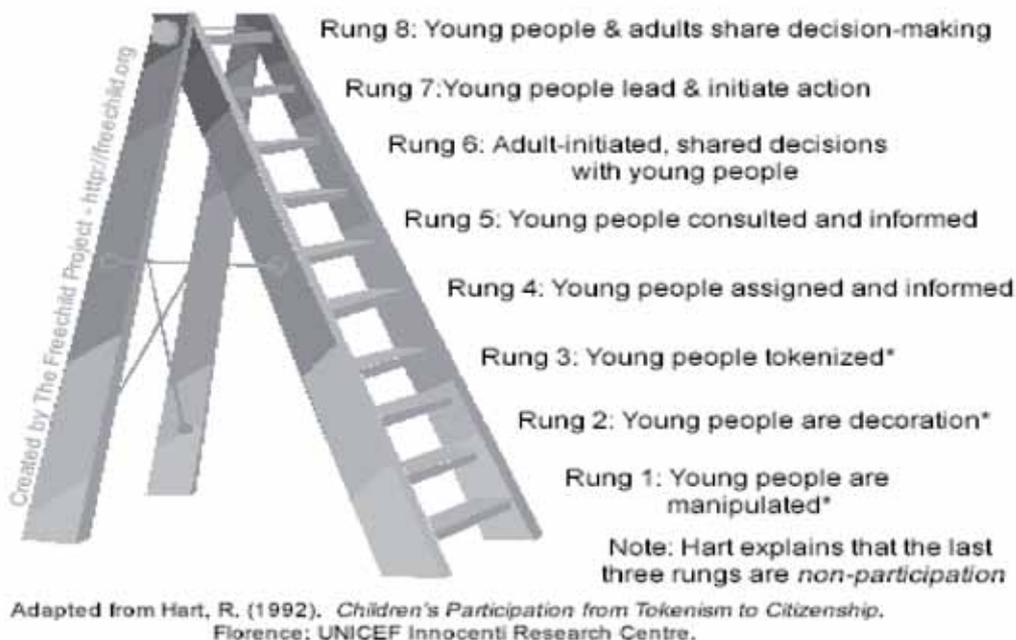
Participation can take place within an **organisational context**: most projects, organisations and services have a system in place to involve children and young people, whether it is in planning a new service, evaluating an existing project or even recruiting new staff.

A tool such as **Roger Hart’s Ladder of Participation** can be a useful way for organisations to assess the levels of involvement that children and young people already have, or to assess the level of participation that an organisation or project would like to achieve.

The ladder categorises the extent of children and young people’s participation, considering levels of input and involvement, in partnership with adults. Meaningful participation isn’t necessarily about moving up the ladder from rung to rung, but rather it is a fluid concept, based on the needs of the children and young people involved and the changing needs of the organisation or project.

Rather than looking at participation in an organisational context, the children’s advocacy project focused on participation in a personal context: preparing disabled children and young people for participation in decisions affecting their own lives.

Roger Hart's Ladder of Young People's Participation



Children and young people with disabilities are more likely to be subject to medical interventions and health and social care assessment, planning and decision-making processes. Sometimes agencies and professionals may find it difficult to discover ways to involve disabled children and young people in these processes. Involvement and participation will take different forms depending on the different needs of children and young people, and one of the first steps is to raise awareness of the importance of taking an active role in making choices and decisions about their own lives.

The following ideas come from the experience gained during the Mencap pilot advocacy project, during which an awareness-raising group work programme was developed, and then delivered to young people approaching transition in two special schools.

This is a new phase in the lives of young people with disabilities and brings with it challenges, choices and decisions to be made about the future. Comprehensive work is already undertaken with all transition-age children by transition officers from education, health and social care and other agencies. Consequently, the intention of the programme developed as part of this children's advocacy project was to encourage some of the young people to begin thinking about their future and what part they were going to play in planning it.

Some young people are very good at describing what they want to do in the future, and some need more support. All children and young people, especially those with a

disability, are used to having most big decisions made for them as they grow up, by parents and carers. It sometimes takes a considerable mind shift for a young person to think about making such decisions for themselves. Some may be too reliant on adults and comfortable with not having very much input. Some are afraid and don't have the confidence, skills or knowledge to begin speaking up for themselves, and some may not want to upset parents and carers or other adults by taking more control over their own lives.

The group work programme undertaken as part of the Mencap pilot project took place once a week over four weeks. Sessions were kept brief and flexible, no longer than 60 to 90 minutes, and were adapted according to the abilities of those in the group. There were between 8 and 12 in a group, which allowed for plenty of interaction and discussion.

At the beginning of each session it was useful to have a session plan, in written and picture form, so everyone knew exactly what we would be doing. The young people came up with their own group contract, highlighting issues such as respect, good listening, taking part and taking turns and when to take a break.

Session 1 involved introductions, setting ground rules and making sure everyone was clear on the purpose of the programme and what we hoped the outcomes would be. We looked at choices we make every day, big life decisions, feelings about what lies ahead and the choices to be made in the future.



Session 2 followed on by looking at needs and wants and the differences in the two, for example everyone needs water, food and shelter but we may want a mobile phone or a holiday. This led to a discussion and activities about children's rights. The group discussed rights which they may not have considered before, such as the right to take part in meetings about their life, have their say in meetings and receive feedback and information. They also discussed the importance of recognising that rights bring responsibility, and how they now are in a position to take responsibility for some of their own decision making.

Session 3 was 'All about me' and encouraged the young people to think about their likes and dislikes, their needs and wants and their hopes and dreams for the future – taking into account what they had learned and discussed in the previous weeks.

Session 4 concentrated on recapping what was covered during the programme and giving the young people the opportunity to evaluate the programme and have their say. Each young person was congratulated on their effort and awarded a certificate in recognition of their participation.

Evaluation was an important part of the programme: members of the group were given the opportunity to say how they felt the sessions had gone. Sometimes they wrote their views down on sticky notes, other times they drew emotion faces, for example 'happy', 'sad', 'bored'. Having a range of accessible evaluation activities meant that young people could express their opinions in a way that suited them, and gave them a voice that was listened to.

Key messages

During the participation group work programme run by the children's advocacy project, one of the issues that concerned young people was **meetings**, such as annual school reviews, transition-planning meetings or other meetings where decisions are made about a young person's life. The group discussed why it was important for young people to attend and take part, how they felt during the meetings and what could be done better during meetings to make young people feel comfortable, safe, respected and listened to.

Below are some ideas which, if put into practice before, during and after, can make meetings a more positive experience for disabled children and young people

Before a meeting

Involve the child or young person in setting up the meeting room and arrange for them to be there first; it can be very daunting to walk into a room full of adults sitting around a table.

Have an advocate or supporter available to sit with the young person and support them throughout the meeting.

Agree a 'time out' signal with the young person beforehand, which they can use if the meeting is getting too much or they need a break.

Ensure everyone at the meeting introduces themselves and clearly explains their role. It may be useful to have a pre-arranged seating plan, which the young person can have in front of them to remind them who's who.

Check whether the young person would like the meeting taped or if someone can be identified to take notes on their behalf.

During a meeting

Ensure the young person gets the opportunity to have their say. If they do not use speech, or don't yet have the confidence to speak within a larger group, it may be a good idea to have a PowerPoint presentation already prepared, with their views, feelings, choices and questions on it. We found this a useful way to ensure that young people's voices were heard.

Encourage everyone present to use clear and accessible language, avoiding jargon at all times.

Ensure questions are pitched at the right level for the young person's needs and that choices offered are realistic and meaningful.

Allow time for the young person to process information, consider their views and respond to discussions at their own pace.

Check regularly that the young person has understood a point or a question, and also if they have asked a question, that it has been answered.

After a meeting

Check that the young person is clear about what will happen next or what the outcome of the meeting is.

Agree who will take responsibility for providing feedback to the young person. For example, if actions have been agreed, feedback should be given to the young person on progress.

Provide the child or young person with a summary of the meeting soon after it happens, either verbally, in writing or using pictures or symbols

If a decision has been made which the young person does not agree with, or is not happy with, make sure time is taken to explain why, and that they are given the opportunity and support to make a complaint if they wish to.

Effective communication

How do you
feel about
leaving
school?

***“I can’t
wait to go to
college.”***

At its most basic, communication is, for all of us, the way we interact with the world around us. It is how we make choices, control our lives and express our feelings, thoughts and wishes. Communication is always two-way and is always possible in some form.

Some children and young people with disabilities do not communicate using formal communication such as speech. Some use symbols, signing and pictures, while others rely on gesture, facial expression and eye movements to communicate with those around them. Even when a child or young person with profound disabilities seems to have little or no intentional communication, it is still possible, using observation and interpretation, to facilitate communication on their behalf.

Often it will take time, patience and creativity to establish meaningful two-way communication. Every child and young person is unique and so their communication needs and methods will be unique to them.

While working on the children’s advocacy project, we discovered that many of the obstacles to disabled children and young people having their say in decision making were due to communication. Below are some ideas that can be helpful when working in an advocacy or support role with children and young people with disabilities.

Key messages

Acknowledge if you are struggling to understand or interpret and don't be afraid to ask the young person to repeat themselves. They will appreciate that you are making the effort to communicate in their way.

If the child or young person has little or no verbal communication, talk to those who know them best about how they communicate their likes, dislikes and views.

Recognise your feelings: it's normal to feel embarrassed and frustrated if you find it difficult to understand a young person's communication. Be honest with them, acknowledge your difficulty and suggest you move on and come back to that particular topic later.

Allow plenty of time for establishing communication. Force yourself to slow down and interact at the child or young person's pace.

Avoid the temptation to fill silences. The child or young person may just need extra time to process information, form their thoughts and communicate back. Pauses in conversation are ok.

Non-verbal communication is extremely important for disabled children and young people. Use and observe facial expressions, hand pointing or arm movements, eye contact and smiles or frowns. Expect unusual sounds or movements. Observe for signs of anxiety (flushed face, rapid breathing) and also for signs of boredom or lack of interest; sometimes a child doesn't communicate because they aren't interested in what you have to say!

Adjust the tone and volume of your voice to match the child's needs and be aware of your physical position in relation to them. They may need you to sit to the side to enable eye contact, or to be at their level if they use a wheelchair.

Use reflective listening skills: constantly check with the young person, repeat what they have communicated back to them and confirm that you have understood exactly what they are telling you.

When facilitating communication between a disabled young person and someone else, repeat exactly what they have communicated to you, without rephrasing, disagreeing or adding an opinion.

Pay attention to the environment: minimise possible distractions such as loud noises, ensure the child or young person is physically comfortable and in a position that allows them to communicate freely.

Always respect the privacy of a child or young person, and don't share information without consent.

Where to find more information



Tell me
about
you.



*“I’m a
good friend.”*

More information and resources about advocacy, participation and communication with disabled children and young people can be found through the links below:

Information on advocacy

www.actionforadvocacy.org.uk

www.advocacyresource.org.uk

www.asist.co.uk

www.voypic.org

Information on participation

www.ci-ni.org.uk/participation_network.aspx

www.freechild.org/ladder.htm

www.participationnetwork.org

<http://sites.childressociety.org.uk/disabilitytoolkit>

Information on communication

www.callscotland.org.uk

www.communicationmatters.org.uk

www.makaton.org

Organisations with information on disabilities

www.autismni.org

www.bild.org.uk

www.cafamily.org.uk

www.cedar-foundation.org

www.childrensociety.org.uk

www.disabilityaction.org

www.downs-syndrome.org.uk/about-us/northern-ireland-office.html

www.mencap.org.uk

www.autism.org.uk

www.pmlnetwork.org

www.positive-futures.net

www.rnib.org.uk

www.rnid.org.uk

www.scope.org.uk

www.sense.org.uk

Information on children's issues and rights

www.barnardos.org.uk

www.childrenslawcentre.org

www.ncb.org.uk

www.niccy.org

Contact details:

Lisa McGrath
Mencap
17-19 Bishop Street
Londonderry
Northern Ireland
BT48 6PR

Tel: 028 7126 2227

Email: lisa.mcgrath@mencap.org.uk