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Speaking out

A guide for advocates for children and young people with learning disabilities

In association with
UK VOICE

NSPCC™
Cruelty to children must stop. FULL STOP.

Foreword

I am delighted to have been invited to contribute, albeit briefly, to this excellent guide. The authors are to be congratulated on both the thought and research which they have devoted to it and on producing a guide which is practical and written in plain English which we can all understand. It is refreshing to read a document of this importance that is without jargon and which sets out a step-by-step plan of action. The guide offers a clear warning against assuming that words mean the same to everybody, or that technical language is readily understood. Best of all, the guide is based upon a clear set of values which ought to inform all we do in support of young people with learning disabilities. I warmly welcome this document and commend it strongly in the hope it will be both well read and well used.

Lord Laming

Lord Laming of Tewin is a former chief inspector of social services, a leading member of several government enquiries and policy groups and one of the UK's most distinguished figures in the field of social care.

Acknowledgements

This guide has been produced by the NSPCC in association with Voice UK.

The National Society for the Prevention of Cruelty to Children (NSPCC) thanks the following for their contribution in producing this guide:
Students of the Primary and Post 16 Departments of Alderwasley Hall School, Derbyshire

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Contents

What is advocacy?

Most people can speak up for themselves. They can let us know exactly what they think, what they want us to know and what they want to happen. Some people can't.

They find it very hard to speak up for themselves. Sometimes they don't know how best to go about it. Sometimes people simply forget or ignore them.

This is why advocacy is so important. Children and young people with learning disabilities are probably the most vulnerable people we know. And because they can't always speak up for themselves they sometimes get other people – their advocates – to do it for them.

However, younger people in particular have a problem with the word "advocate". It is not a word they often come across. For example, during our research for this book, 10 children with learning disabilities were asked to define the word "advocate". Only one had any idea what it meant. So, it's important that when you introduce yourself as an advocate you explain fully what that means.

For us in this guide, advocacy is about speaking up for children and young people with learning disabilities. It is about getting their voices and wishes heard, understood and respected.

Advocacy is about making sure that children and young people with learning disabilities have a say in:

- decisions made about them or that might affect them
- planning services (such as arrangements for school, where they live, what help they need at home, going away from home)
- improving services.

Too often young people are left out of the decision-making process all together, or if they do take part, they are present but don't quite understand what they have to do or say.

As one young person said about a decision to send them to a special residential school: "I agreed with their decision, but I wasn't sure what they were saying at my review. I call it the 'nodding dog' syndrome. They ask me questions I don't really understand, and I sit there nodding."

As an advocate you must understand and respect a child and young person's needs and wishes. And give them a voice that is understood and respected.

This guide spells out what children and young people with learning disabilities have told us they think about advocacy and what advocates should and should not do for them. We have linked this into the government's *National Standards for the Provision of Children's Advocacy Services* and it should also be read alongside *Get it Sorted*, the government's guide to providing effective advocacy services for children and young people making a complaint under the Children Act 1989.

Where possible we have included the words used by young people themselves or through their advocates.

Where we have used different words or have summed up generally what young people were saying we have checked back with them that they are happy with the way we have said these things.

The word advocacy comes from the Latin word advocatus, which means "legal adviser" but can also mean "speaking up for people".

What is an advocate?

As an advocate it is your job to speak up for children and young people with learning disabilities.

You must do this independently. If you have any connection with the people who make decisions about the young person you are advocating for, you should take care that this doesn't get in the way of your ability to be independent.

You will also be trusted not to share any information without permission.

Children and young people with learning disabilities will expect you to be someone who:

- speaks up for them
- represents them
- has the information they need
- makes suggestions, shares opinions and makes their choices clearer
- is there to support and help them
- they trust.

You are in a position of great responsibility when children and young people with learning disabilities rely on you for information, advice, support, representation and to give them a voice. You are helping them to take control of their lives.

"They should be someone speaking up for you not judging you."

"Before and after the review, they say 'You're going there. No doubt about it'. Then at the review they say, 'It's up to you', which is a silly position to put me in, and I started crying. I wish I had an advocate to speak to. I made the decision to make people happy."

What makes a good advocate?

It's not enough to simply be an advocate. You need to be a good one. Children and young people with learning disabilities have strong views on what makes a good advocate.

They say you should be someone who is:

- able to get to know the child and young person well
- a good listener and able to understand
- good at communication and easy to understand
- polite and easy to get on with
- neutral and independent.

It is important that children and young people feel comfortable with their advocate and have a choice about who this is.

Some young people want their advocate to be young also. Others prefer someone older with more experience. Some would prefer a male advocate, some a female advocate or someone from the same ethnic community as them.

When asked about what good advocates should do for children and young people with learning disabilities, young people said that advocates should:

- take the time to listen
- remain neutral
- have a friendly, informal approach and not be too rigid about things
- be good at working with young people and give information in a way that suits them
- take time to get to know them and their needs
- not speak down to them
- only share information with others when they agree that it's OK
- not jump to conclusions
- consult them on all things.

"They are someone who does not do things for you, but who wants to support you. The advocate may come with you, but you are in control."

What makes a bad advocate?

Children and young people with learning disabilities also have very clear ideas about what makes a bad advocate.

They don't want you to be someone who:

- doesn't do what they say they will do
- doesn't listen and keeps rushing in with the answers
- doesn't treat them with respect
- uses words, phrases or jargon that they can't understand
- concentrates too much on what they think is "right" rather than what the young person wants
- doesn't treat them as a normal person.

"I was not asked about my views and feelings. I was left out of meetings between my advocate and other people."

Being a good advocate

To be a good advocate for children and young people with learning disabilities we feel there are some things that you should believe in.

Things like:

- being independent of those making decisions
- respecting what young people believe, want and need
- promoting and defending the rights and needs of young people
- responding quickly and accurately
- being fair and equal
- making things easy
- sharing information only with permission
- improving what you do.

"Sometimes you need an advocate to help you be involved."

Being independent of those making decisions

It is important to remember that you work for the child and young person with learning disabilities – and them alone. They must have faith that you are looking out for their interests and nobody else's. In order to do this you must be independent.

This means:

- not having any conflicts of interest so that you can concentrate on representing the child and young person at all times
- not allowing the fact that you may be employed by an organisation connected to their worries, such as a local authority or a school, to get in the way of your commitment to the child or young person
- not holding meetings in offices or places that might be connected to the worries of children and young people, for example, council offices or schools
- being trained to act independently
- understanding that you can be replaced as advocate if the child or young person wants this to happen or if they think you aren't doing your job as well as you should. As the child or young person has chosen to appoint you as their advocate they should also be able to ask for a different advocate.

"There can be a conflict of interest when the advocate is not independent. They might water down their views and comments because they don't want to upset their employer."

Respecting what young people believe, want and need

You are not the mind of a child or young person. You do not control their thoughts. You are their voice. You turn their thoughts into words.

This means:

- only giving help if it is wanted
- ensuring the child or young person controls the relationship as far as they are able
- only acting on their instructions – even when you don't agree with what they're saying
- taking the time to get to know the child or young person well, to understand how and what they're feeling
- always representing the child or young person's views even when these are in conflict with the views of their families, friends or the people they work with – including you
- providing the right information in an accessible way so that they can make good decisions for and about themselves
- finding out if they want to present their points of view on their own, together with you, or have you do it for them
- making sure you understand clearly what you have to say
- not putting words into their mouth – they are putting their words into your mouth, you should agree the words you use
- keeping things simple and jargon-free – and making sure others you meet do the same
- keeping them informed of everything you have or know relating to them and refusing to receive information which is to be kept from a child or young person
- making sure all decisions, good and bad, that affect them are recorded
- helping them understand any decisions that are made about them.

"Some advocates don't listen. They jump to conclusions that because we are disabled, we are not capable of having certain experiences."

Promoting and defending young people's rights

Article 12 of the *United Nations Convention on the Rights of the Child* recognises that children have the right to say what they think should happen and to have their opinions taken into account.

Making sure children and young people with learning disabilities, both individually and generally, know and understand what their rights are is the cornerstone of good advocacy.

A good advocate does their best to make sure young people succeed in getting their rights.

This means:

- finding out what a child or young person knows about their rights and what those rights mean
- keeping a list of people you can go to when you need to get legal or other specialist advice
- helping children and young people with learning disabilities get together to make their case, if that's what they want
- training to better understand how to promote and defend a child or young person's rights
- helping with the skills a child or young person needs to make their own case to the people who make decisions about their lives. This could include training on how to make a presentation, on how to communicate well, or on how to make people take notice of them.

"Advocates should explain our rights to us at the beginning, like the Human Rights Act, so we can understand and be more able to say what we want."

Responding quickly and accurately

There is little worse than if you ask somebody to do something and they take ages to get back to you. Advocacy is no different.

Speed is of the essence. However, do not risk accuracy by trying to be prompt in your response. Even the very best advocates don't know everything, so don't pretend that you do.

If you don't know or have the answer, or don't know who to talk to, let the child or young person know. But tell them that you will find out and get back to them as quickly as you can.

This means:

- knowing how to gather factual information
- agreeing about how to find things out
- agreeing who should do what next – and by when
- knowing when to seek help from others who are experts
- letting a child or young person know how long it might take (and if this proves to be wrong, letting them know why and when they can expect your answer)
- keeping them informed of what's happening (even when nothing is happening) so they don't feel they have been forgotten.

"Don't take ages getting back to us – we could miss out if you do."

Being fair and equal

Each child or young person is a unique individual with their own beliefs, wishes and needs. As you get to know the child or young person better, you will be able to make sure that their uniqueness comes through.

You must also make sure that every child or young person is free from any form of discrimination.

This means:

- making sure that nobody is discriminated against because of their age, sex, ethnicity, culture, religion, language, disability or sexuality
- making sure that you communicate with the child or young person in a way that they understand – this could be in symbols, pictures, signs, large print, audio tape, or through the use of technology
- understanding that children and young people with learning disabilities are sometimes unable to talk – you may need to learn how they communicate, which may be through body language or responses that need interpretation
- being aware of ways in which disabled children can be discriminated against
- being aware that children and young people with learning disabilities are more likely to be abused than other children because of general attitudes and awareness, the disability itself and because services do not adequately support and protect them.

> *“Don’t treat us all the same. We don’t all like two sugars in our tea. Some of us don’t even like tea. Treat us as we are – individuals.”*

Making things easy

You should make sure that children and young people with learning disabilities know that you exist and what you can do for them.

You could do this by ensuring that other adults who come into contact with children and young people with learning disabilities know about you, or the service you work for.

Information about you and the advocacy services you provide should be available in ways that are easily understood. You should carry out your work in ways that make things easy for each person you are supporting.

This means:

- asking them what they think about the information you provide – and what could make it better
- meeting in places that are warm, comfortable, easy to get to, safe and accessible for the child or young person you are supporting
- meeting a child or young person in a place that is good for them
- being available to meet at times that are convenient for the child or young person
- having a 24-hour telephone number (helpline) that can be used if necessary. Many big organisations have these but if yours doesn't you could give them the number for the NSPCC Child Protection Helpline or for ChildLine (see p19 for contact details)
- helping a child or young person who wants to make a complaint using the complaints procedure of services and organisations that they come into contact with. This might include health services, education, voluntary organisations and social services.

> *“The advocate may need to have communication skills to help interpret or translate what the young person is saying.”*

Sharing information only with permission

Children and young people with learning disabilities need to be able to trust you. They need to know that whatever they tell you will stay with you and that it won't go any further. This is all about trust and respect.

- They might test you out to see if you can keep things to yourself.
- You must only share information that you learn from the child or young person with other people if you have their permission.

However, if you learn something that puts the child or young person, or another child or young person, at risk of significant harm, then your duty has to be their protection. You should then pass this information on to either social services, the NSPCC or the police. You must explain this very clearly to the child or young person from the start – and check they understand it.

You must also make sure that, if you intend to tell somebody else, you tell the child or young person you are working with that you have made that decision and why. They should not find out from someone else what you are doing or what you have done.

This means:

- assuring the child or young person that everything they say will not be told to anyone else – unless they say that it's OK or you think they or another child or young person are at risk of significant harm
- not revealing any information even to family, friends, carers, doctors or other workers without the agreement of the child or young person
- giving the child or young person a summary of how this works in the most useful way for them, for example, audio tape or symbols
- not sharing records and information with anyone without the permission of the child or young person
- keeping information, files and records locked away when not in use
- having training on how and when to share information and how and when not to.

"I was very frustrated with my advocate because they broke a confidence by asking my mum about something that had happened to me – but my mum didn't know about it."

Improving what you do

You need to know whether or not you are doing a good job. One of the best ways to find this out is by asking the child or young person you are supporting how they think you are doing.

Children and young people with learning disabilities also need to know what to do if they are unhappy with you or with something that you have or haven't done.

This means:

- asking children and young people with learning disabilities to help with improving advocacy services – for example, helping with recruiting, selecting and training advocates, checking publicity and information, and being consulted about services
- checking regularly with each child or young person that they are happy with the way you are working with them
- having a clear, easy to use complaints procedure so that children and young people with learning disabilities can raise any concerns they have with your work
- assuring them that you won't think badly of them or take anything out on them if a child or young person does decide to complain – tell them it's OK to do so.

"I didn't like to tell my advocates I wasn't happy with them so I pretended I had to go away."

Notes

Contacts

NSPCC Child Protection Helpline

The NSPCC Child Protection Helpline is a free 24-hour service that provides counselling, information and advice to anyone concerned about a child at risk of abuse.

Please call us on 0808 800 5000 or
textphone for people who are deaf
or hard of hearing on **0800 056 0566**
or email us: **help@nspcc.org.uk**

We also offer helplines in five Asian languages and Welsh:

NSPCC Asian Child Protection
Helpline (Mon-Fri 11am-7pm):
0800 096 7719

NSPCC Cymru/Wales Child
Protection Helpline (Mon-Fri
10am-6pm): **0808 100 2524**

NSPCC
CHILD PROTECTION
HELPLINE
0808 800 5000

Voice UK

Helpline (10am to 4pm Monday to Friday): 0870 013 3965
Email: voice@voiceuk.org.uk

ChildLine

ChildLine is a free 24-hour helpline for children and young people in the UK. Children and young people can call the helpline on 0800 1111.

Resources

Relevant legislation

Great Britain (1989) *Children Act 1989: chapter 41.* London, Her Majesty's Stationery Office (HMSO).

Great Britain (1995) *Disability Discrimination Act 1995: chapter 50.* London, Her Majesty's Stationery Office (HMSO).

Great Britain (2000) *Children (Leaving Care) Act 2000: chapter 35.* London, The Stationery Office (TSO).

Great Britain (2000) *Care Standards Act 2000: chapter 14.* London, The Stationery Office (TSO).

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Advocacy and children's rights

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Department for Education and Skills (2003) *Every Child Matters.* London: The Stationary Office

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Communication

Gordon, R., Lacey, N., Marchant, R., Page, M., Ward, D., Williams, H., NSPCC, Joseph Rowntree Foundation and Triangle (2001) *Two-Way Street*. Leicester: NSPCC

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Disabled children and young people

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Social care

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