

# Working with adults, children and young people with additional needs:

## An Introduction to Down's Syndrome

We hope that you will find this 'introduction' leaflet helpful. It is not intended to replace conversations that you will need to have with children, young people, their families, and the professionals who know them. Those conversations are essential to understand the uniqueness of each family member you work with to ensure that you can engage with them in the most meaningful and supportive way. Links to relevant charities, information services and research are embedded at the end of this leaflet.

Down's syndrome is caused when a person has an extra chromosome in their cells. About 750 babies will be born with Down's syndrome in the United Kingdom each year. Down's syndrome affects people of all ages, races, religions and economic situations.

A person with Down's syndrome will have a degree of learning disability and characteristic physical features. Their strengths, talents and level of ability will be different for each person.

There are some health problems associated with Down's syndrome, for example heart problems and difficulties with sight and hearing. These physical health conditions do not affect everyone with the condition.

When referring to a person who has Down's syndrome, it is important that we place the person first: "Amanda has Down's Syndrome" not "Down's syndrome child Amanda." In the UK, the condition is typically referred to as Down's Syndrome, but Down syndrome is also accepted.

### Planning for meetings, interviews and direct work

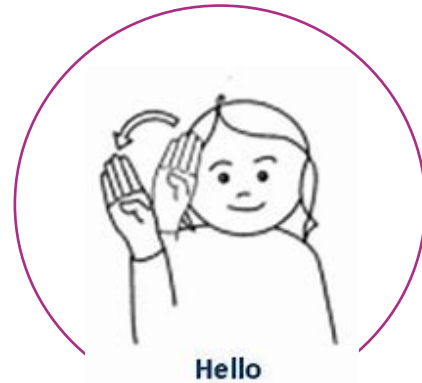
A person with Down's syndrome may need you to adjust how you would usually undertake direct work, interviews or observations of time spent with their family. It is important that you establish what they need from you to make this an effective piece of work. Speaking with the child, young person or adult and their family members and the professionals who know them will guide your planning. **These are some general tips to think about:**



- ✓ When deciding whether in person or remote working is more appropriate you need to be sure whichever you choose will allow you the opportunity to understand the child's needs, the care-giving environment and enable them to engage meaningfully. It is important to ask if they have a preference.
- ✓ Although parents may want to support their children in interviews, this may not be appropriate and may impact on how open the child can be with you.
- ✓ Avoid jargon and long words that may be hard to understand.
- ✓ Think about using different communication practice aides (more on these below).
- ✓ Some children and adults with Down's syndrome experience stammering or 'dysfluency,' give the person time to finish what they are saying.
- ✓ Let them take the lead to set the pace-listen.
- ✓ Give enough time for the direct work, interview or observation of contact.
- ✓ Don't be afraid to be creative.

## Alternative Methods of Communication

Makaton and Signalong are Sign Supported English Systems. Many people with a learning disability use or recognise signs, either alongside or instead of spoken language. Basic signs (greetings and introductions) can be used to establish a rapport. Links to websites where this information can be found are at the end of this document.



Widgets and other picture exchange systems are symbols and images that can help with communication. These can be customised for an individual and can include words as well as pictures. They can be used creatively to ask questions about likes, dislikes and wishes, as well as used to communicate wants and needs. Links to websites with information on these communication systems can be found at the end of this document.

## Introducing Yourself to Children & Families

The templates for the introductory letters are editable. These letters can be sent to a child, young person or adult to introduce yourself and share details about the purpose of your interview/visit. Use of pictures, images and jargon free language is appropriate in these letters. All information should be provided in accessible formats.

If a letter is not appropriate, think about how you can introduce yourself in advance of the interview. Would a **call or video call** be useful?

After the direct work/interview has finished it is important to know how your recommendations to the court and the outcome of any hearing will be shared with the child. Would they like you to write to them again or use other ways of communicating? Is this best communicated via solicitors, family members or professionals, and if so, why? 'Easy read' letters and judgements are becoming more widespread within the family court and you can advocate for these from the judges and magistrates. These outcome letters can form a valuable part of a child's life story work. Even if the child cannot understand the letter at their current age or developmental stage it is something they may be able to understand as they get older.



## Safeguarding:

Children, young people and adults with additional needs are at greater risk of abuse due to communication barriers, the signs of abuse being misunderstood or minimised, increased isolation and greater dependence on others for their care, a lack of education to help them to stay safe, and inadequate support. It is important to work proactively to protect vulnerable children and adults, be professionally curious and respectfully challenge others if we have concerns.

### How can you be sure you're making the right adjustments?

The short answer is you can't. However, if you're flexible and willing to try different approaches, you're far more likely to succeed.



#### Using Cafcass Direct Work Practice Aides

Cafcass direct work practice aides are designed to be used with all children, young people and adults.

Here are some tips and ideas to help you use them:

- Limit the number of 'pages' or screens you are using from the practice aides. This allows for clear questioning with visual support. Don't try to complete the entire practice aide unless this is something the child or young person wants to do and can manage.
- Share the sections of the practice aide you intend to use with the adults who care for the child or young person in advance of the session. This could include educators or support staff. They may be able to offer guidance to you about how best to engage with the child or young person.
- Include pictures or images in letters to the judge. These may convey the message the child or young person wants to communicate effectively and will allow the court to hear their voice.
- The 'Dictate' software can be used to allow the child to interact directly and see their own words on the page.
- Don't feel you need to do all the direct work yourself. Adults that the child or young person are familiar with may be key to helping you understand how best to communicate. Working alongside educators, carers and support staff may provide opportunities to amplify a child's voice in a way that you could not do alone.
- [Cafcass resources for professionals](#)

Remember, connection before content.

The importance of planning and relationship building cannot be underestimated.

Mencap- [Down's Syndrome | Mencap](#)

Down's Syndrome Association- [Down's Syndrome Association \(downs-syndrome.org.uk\)](#)

Signalong- [Signalong - The Communication Charity](#)

Makaton- [Home \(makaton.org\)](#)

Widget- [Widget Software | Widget Symbols Help Communication](#) and [Widget SymbolWorld: Categories : index](#)

PECS- [My PECS - Free PECS Cards and Images](#)