Communication with Children with Severe or Profound Intellectual Disabilities:

A Guide for Parents

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Contents

Introduction 4

Part 1: What is communication and why is it important? 5

Part 2: How do I find out more about my child's communication? 14

Part 3: Intervention (approaches to support communication) 22

Summary 30

Glossary 31

References 34

Resources 40

About the authors 42

About the peer reviewer 43

Introduction

This guide has been developed to help families and carers of children with severe or profound intellectual disabilities to understand more about communication challenges and to suggest helpful strategies to improve communication. This guide looks at communication within a partnership and considers the skills and challenges for both people within communication exchanges. Professionals working with families and carers of children with severe or profound intellectual disabilities may also find this guide informative. Some children with severe to profound intellectual disabilities also show signs of autism or have underlying genetic syndromes or sensory or physical conditions that mean their needs are very complex so we have taken these into consideration when writing this guide.

Part one of the guide explains the general importance of communication, what types of communication difficulties are common in children with severe or profound intellectual disabilities and the possible consequences of communication challenges. Part two describes ways in which more information about communication can be gained. Part three describes some ways in which communication can be supported. We have also included two examples of children with complex needs. These are not real children and the examples are designed to illustrate some communication abilities and challenges relating to communication in children with severe or profound intellectual disabilities. A glossary of key terms (highlighted in purple) and list of useful resources are provided at the end of this guide.

Part 1

What is communication and why is it important?

Connecting with other people helps us to feel we 'belong'; in our family, in our classroom or in our group. Communication can occur through a number of different modes; speaking, manual signs, gestures (e.g. waving, pointing), vocalisations, body language and facial expression[1].

We communicate to share our experiences, ask for things we want, refuse the things we do not want and to tell people how we feel. Good communication gives us choice and control over our everyday lives. It works well when our communication partners recognise our attempts to communicate and share our language. Communication for children is essential to their quality of life and wellbeing, influencing their ability to form and maintain relationships, make choices, and communicate needs[2,3,4].

Communication is also a human right. Article 19 of the Universal Declaration of Human Rights[5] states that everyone has a "right to freedom of opinion and expression", including the right "to seek, receive and impart information and ideas through any media and regardless of frontiers". Similarly, the UNCRPD (2007) states that people with disabilities can "exercise the right to freedom of expression and opinion, including the freedom to seek, receive and impart information and ideas on an equal basis with others and through all forms of communication of their choice"[6]. Everyone has the right to communicate to their full potential. Regardless of disabilities or restrictions that might make effective communication more difficult, children have the right to use their communication in order to participate in society and to take part in the activities around them.

How does communication and language typically develop?

One way of understanding how communication develops is by thinking about the communication form, content and use[7].

Form

Throughout development of language in the first few years, children are continually using combinations of different ways to communicate. For example, they use body language, facial expression, gesture or body movement. Some might also use signs, words, phrases, sentences or proto-words and others might use vocalisations like a shriek, a laugh, a loud shout, a shushing noise or blowing. These are all different forms of expression.

Children also learn (through understanding the social environment and communication skills) to interpret and understand other children's forms of expression and those of the adults around them.

Content

As children use their language and communication skills, they slowly learn that it carries a message. This message is the meaningful content of what is being expressed by the child or understood by the other person and shared between them.

Use

When children are able to adapt their communication to fit with a particular context (for example, saying or signing happy birthday, clapping at the end of a performance) they show that they have some understanding of how communication and language have different uses in different social spaces and places.

Children start to develop communication and language abilities from birth. We can divide these abilities into receptive abilities and expressive abilities. Having receptive language and communication abilities mean that you can understand something of what other people communicate to you. Having expressive language and communication abilities allow you to convey meanings to other people. On pages 7 and 8 you will find a summary of some stages of communication development. It might be useful to remember that not all children develop language and communication skills in a clear order. They might develop some skills from different stages at the same time or be late to develop others.

Stages	Language abilities	Examples of skills
Pre-language skills	Receptive and expressive abilities	• respond with reflex responses (mouthing, holding, sucking). • 'look' selectively (visual activity is more than random – in the dark will search out shapes and outlines). • start to notice objects and to have a mental idea of these.
Stage 1	Receptive abilities	• turn to a sound when they hear it. • respond more to human voices than to other noises around them. • watch their caregiver's face when she/he talks to them.
	Expressive abilities	• learn to smile when the caregiver talks to them. • make coo-ing noises. • change the coo-ing noises into distinct vocalisations – 'oo-oo-oo' and 'ya-ya-ya-ya'. • start to 'babble' making sounds like 'bababab', or 'paba'. • start to use their voice in different ways; making a sing-song sound or going from quiet to loud.
Stage 2	Receptive abilities	• start to become better at reading their environment. (They can tell by what their caregivers do around them - like getting a bath towel and running the bath - that this means a bath is coming. They don't need to understand the word 'bath' to work out what is going to happen). • begin to work out the meaning of words for example, 'bath' and other words which are always spoken within a related context.
	Expressive abilities	• start to make sounds as if they are imitating the sounds they hear other people make when they talk. • can use emphasis of sounds to communicate emotion and feeling through their tone of voice. • start to take turns in the 'conversation', babbling back and forth with an adult. • this is the stage just before intentional communication and symbolic understanding develop.

Stages	Language abilities	Examples of skills
Stage 3	Receptive abilities	• begin to understand that vocalisations and speech have meaning. This is the beginning of symbolic understanding. Strings of sounds become mapped onto their object or activity or feeling. So 'banana' is a yellow fruit, 'shoe' goes on my foot and 'wet' is something to do with getting changed. • begin to understand many more familiar words in context like 'milk' or 'car' and some words out of their close context (such as the word 'biscuit' offered in the unfamiliar context of the doctor's surgery).
	Expressive abilities	• start to use 'proto-words'. This shows they are beginning to understand that words function as a 'symbol' for something else. This is the beginning of their use of symbolic language. Symbolic language can be spoken or it can be signed. These are words that familiar adults find it easier to understand than strangers. For example 'nana' might mean banana to the family but it could mean a number of things to a stranger. • use over-generalisation and under-generalisation. • begin to use words, gestures, signs or symbols with the intention of communicating something. This is known as intentional communication.
Stage 4	Receptive abilities	• learn to recognise new words, first by linking them to their context and then by working out what they symbolise. • start to expand the number of single words they can understand quite quickly but still might not understand a long phrase or sentence. • start to recognise simple commands to do things like 'look over here' and 'eat up'.
	Expressive abilities	• use words or signs that sound or resemble the words that family carers use. • judge when to use these words or signs to get something or to say something. • start to put two words together, for example 'mummy shoe'.

What do we know about communication challenges in children with severe or profound intellectual disabilities?

Although the exact numbers are not clear in the research to date, communication challenges are reported in between 50% and 100% of people with an intellectual disability. Communication support needs are even greater in people with more severe and profound intellectual disabilities[8]. There is also greater variability in the communication abilities and the communication support needs of those with more severe intellectual disabilities[9,10]. These may include difficulties with understanding what others are communicating to them (known as receptive communication) or expressing themselves to other people (known as expressive communication). Many people with severe or profound intellectual disabilities are reliant on other people to interpret their communication. They may not use any formal means of communication (such as speech) or they may use a few words or signs. People with severe and profound intellectual disabilities and autistic people make up some of the key groups in society who would benefit from communication intervention[11,12].

Why do communication challenges occur in children with severe or profound intellectual disabilities?

In children with severe to profound intellectual disabilities, there may be several reasons for communication challenges. A child's communication needs and communication profile should be considered in the context of other factors related to their primary diagnosis and any secondary diagnoses. Other personal factors such as personality, age and stage in life, as well as general physical health, can also affect a child's communication abilities day to day. On an environmental level, individual living circumstances and conditions can also impact on communication opportunities and development. Some (but not all) of these factors are outlined in more detail below.

Sensory impairment

Several studies have highlighted that the prevalence of hearing/visual impairments are much higher than expected in intellectual disability populations[13,14] and can often go undetected and subsequently under-treated. We rely on seeing and hearing social interactions around us to learn how to communicate. For example, we know that children with a hearing impairment are more likely to have delayed speech[15]. Individuals who speak few or no words are often unable to self-identify their poor vision or hearing, or deteriorations in their hearing or vision, and therefore annual screening and monitoring should be advocated.

- Single sensory impairment refers to a visual or hearing impairment in the context of intellectual disability, physical disabilities, or autism.
- Multi-sensory impairment, dual-sensory impairment and deafblindness are terms that define combined sight and hearing loss that adversely affects a child's access to education and communication opportunities.

Physical characteristics

A number of physical health conditions may affect speech production. For example, hearing loss caused by recurring middle ear infections may affect speech production. Oral and facial characteristics, such as cleft palate, low muscle tone and dental overcrowding can also affect speech production. Muscular and motor difficulties that may be more common in children with complex needs may underlie some difficulties with speech articulation and co-ordination.

Social characteristics

Selective mutism and social anxiety are important considerations if the frequency or form of communication differs across context, or changes in communication are observed in particular settings or with certain individuals.

Autism

Autism (or autism spectrum disorder) is a neurodevelopmental difference characterised by restricted or repetitive behaviours and interests, and difficulties with social interaction and communication. Communication differences include: eye contact, difficulties with communicative joint attention, delays in expressive language, delayed gesture use, and repetition of words and phrases[16]. Here, it is important to note that communication difficulties may also occur as a result of anxiety, sensory impairments and intellectual disability. Although the prevalence rates of co-occurring autism and intellectual disability vary drastically, it is estimated around 8-21% of people with severe intellectual disability also meet diagnostic criteria for autism[17,18].

Genetic syndromes

Individuals with a particular genetic syndrome associated with intellectual disability may experience communication challenges that are related to aspects of the syndrome. Some genetic syndromes associated with communication challenges are outlined in the table below.

Syndrome	Communication challenges
Angelman syndrome	Angelman syndrome is characterised by minimal or completely absent speech[19], with most people speaking fewer than 15 words[20]. Children and adults do however use non-symbolic communication to request or comment, such as reaching or arm flapping[21]. In Angelman syndrome gesturing is the most common form of communication[22].
CHARGE syndrome	In CHARGE syndrome, multi-sensory impairments relating to both vision and hearing may underpin the absence of symbolic communication. The specific profile of hearing loss differentiated those who did and did not develop symbolic communication[23]. This is a particularly important consideration when determining the effectiveness of hearing aids in some children.
Cornelia de Lange syndrome	In Cornelia de Lange syndrome, expressive language is considered more severely affected than receptive language abilities[24,25]. Speech may be affected due to physical characteristics that impair speech production, such as low muscle tone or hearing impairments[26,27]. The communication profile in Cornelia de Lange syndrome is also characterised by low levels of intentional communication[28] but relatively high gesture use[29]. In some cases, selective mutism in Cornelia de Lange syndrome is thought to be associated with social anxiety[30].

Down syndrome	In Down syndrome, speech articulation and co-ordination may be affected by muscular and motor difficulties, as well as differences in overall oral structure (e.g. large tongue and narrow palate)[31].
Fragile X syndrome	In fragile X syndrome, social anxiety may underpin some difficulties with expressive language, with selective mutism observed in females[32] and language perseveration (repetition of a sound, word, or topic) observed in males[33]. In fragile X syndrome, it is important to note, anxiety, autism, and executive function difficulties may all in part underpin difficulties relating to expressive communication. In some cases, hearing loss caused by recurring middle ear infections may also affect speech production[34].
Kleefstra syndrome	In Kleefstra syndrome, expressive language delay is common[35], with most people communicating using single words[36]. It has been suggested that specific oral and facial characteristics in Kleefstra syndrome, such as low muscle tone and feeding difficulties, may underlie some physical difficulties with speech production[37]. This is known as childhood apraxia of speech.
Rett syndrome	Rett syndrome almost exclusively occurs in females, as it is caused by mutation to the MECP2 gene on the X chromosome. MECP2 plays a very important role in brain development, and as a result Rett syndrome is characterised by a period of regression and a loss of previously learned skills after the first year of life[38,39]. Most notably, loss of words and intentional communication is reported, with 87% of children showing language regression (56% losing single words, and 38% losing the ability to babble[40]; although eye contact is largely preserved.

What are the possible consequences or risks associated with having communication challenges?

In addition to fewer educational and social opportunities, communication challenges may lead to behaviours that challenge. Having difficulties communicating can make it more difficult to identify health needs, and pain and discomfort may be harder to recognise.

Behaviours that challenge

Communication difficulties are common in children with an intellectual disability who engage in behaviours that challenge such as self-injury, aggression or property destruction[43,44]. Communication is one way in which we are able to influence other people, control our environment and what happens to us, and have our needs met. If a child has difficulties communicating, it is likely that they may not understand what other people are communicating and find it difficult to express their needs. As a result, behaviours that challenge might develop. Behaviours that challenge can be difficult to understand and very upsetting for all involved. It's important to remember however that:

- behaviours and emotions happen for a reason;
- behaviours that challenge can signify that something is not right for the person experiencing or displaying them, but this is not always the case;
- behaviours that challenge can sometimes indicate the person needs some help and support, but again this is not always the case;
- people might have few (or no) other ways to communicate these things.

You can find out more about behaviours that challenge here: Managing Challenging Behaviour - Cerebra and here: Responding to challenges Positive Approaches to Support

Untreated pain and discomfort

Children may also find it difficult to communicate that they are in pain, uncomfortable (too hot/cold) or to express emotions or feelings. Both physical health conditions and mental health conditions are more common in children and individuals with intellectual/developmental disabilities[45-52]. For example, some particularly painful/uncomfortable physical health conditions such as ear infections, gastrointestinal conditions, dental problems and constipation are more common[53-56] and, as a result, they may experience more pain/discomfort than other people. There is some evidence to suggest that anxiety, low mood and sleep problems are also more common in this population[50,57]. As families, carers and health care professionals are often reliant on children's ability to self-report these internal states in order to identify and treat physical and mental health conditions, it is a pressing concern that they are more likely to be undiagnosed and untreated[58-61].

For more information about pain in children with intellectual disabilities, please see: Pain: A guide for parents – Cerebra.

Link between behaviours that challenge and pain and discomfort

There is some research supporting the idea that untreated pain arising from undiagnosed health conditions in people with an intellectual disability is associated with behaviours that challenge, which subsequently reduces when the health condition is treated[62-68]. In these cases, behaviours that challenge may be functional for children and a possible indication of distress in the absence of expressive communication.

Feeling physically or mentally unwell may affect the degree to which every day activities/objects are preferred or tolerated[69-72]. Research has shown that children with an intellectual disability who are in pain or uncomfortable may find activities that they usually tolerate or are happy to engage in, unpleasant/uninteresting. Consequently, they may withdraw from these activities or engage in behaviour that challenges (such as self-injury or aggressive behaviours). This may also be the case when children feel anxious, tired and/or have low mood[70-72].

In addition, self-injurious behaviour itself may actually directly reduce pain/discomfort. For example, if a child repeatedly bangs their head, there is some evidence to suggest that this may create a temporary reduction in pain while the nervous system processes and responds to sensory input from another source in the same way that we may experience a temporary reduction in pain when we rub a sore knee. Another explanation for this effect could be that head banging produces chemicals in the brain that create an effect like a pain killer. Behaviours that challenge in the context of pain and discomfort may also be a reflex action that the child has no control over in response to pain.

Key points:

- Communication is a basic human right, and is essential for our quality of life and wellbeing, to share experiences, maintain relationships, make choices, and communicate needs.
- Communication can be better understood by thinking about its form, content and use.
- It is important to know how much a child can understand (receptive communication) as well as how they express themselves.
- Not all children develop communication at the same rate or following clear stages.
- Communication difficulties can make behaviours that challenge more likely to occur.

Part 2

How do I find out more about my child's communication?

Professionals (e.g. speech and language therapists (SLTs) or special educational needs (SEN) teachers/assistants may want to find out more about how your child communicates to help them to decide how best to communicate with them, and how to support them to develop their communication.

To do this they are likely to use one or more assessments. An assessment is a structured way to gather information about your child's communication. Communication can develop throughout your child's life and assessments provide a starting point for working together to develop communication skills. They can identify both strengths and areas where your child can progress[73].

The SLT or SEN teacher/assistant is likely to use a variety of approaches or assessments to gather the information about your child. They may talk to you about your child's communication, ask you to complete some checklists, spend time observing or playing with your child or ask your child to complete some tasks[73-75].

You can use the information you have collected about your child's current abilities during the activities above to start thinking about the priorities for progressing your child's communication skills. There is some additional guidance on this in part 3 on page 22.

What to expect from your first speech and language therapist appointment?

In order to see a speech and language therapist (SLT), you can to speak to your GP, paediatrician or health visitor or sometimes you can make a referral directly to the service yourself. Some SLT assessments take place in Child Development Units or local health centres or clinics or may occur online or over the phone.

The SLT may visit your child in their educational setting or at home. You should be invited to any initial assessment and kept up to date about any further assessments that are made. The SLT will be interested in finding out more information about your child's communication and other skills.

It can be helpful to spend some time before the assessment making a list of any questions you would like to ask and noting down key information about how your child communicates and anything that you have noticed. Some of the checklists in this guide might help here.

Context: communication environment and partner

Professionals may also want to look at the opportunities in the person's environment for communication and also at how you and your child interact with each other . It is important to remember that "*Communication is about two or more people working together and coordinating their actions in an ongoing response to each other and the context.*" ([76]p.48).

Although we often think about communication skills as being present or absent, our ability to communicate is always influenced by the context, the environment and our communication partner.

Children who have very few formal communication skills might be very successfully able to communicate when they are in a familiar environment.

This is also enhanced when they are supported by communication partners who: 1) have a high degree of skill, 2) have intimate knowledge of the individual and 3) can determine what is most likely to happen given what the child is doing at that time.

Conversely, a child might be able to use quite sophisticated communication skills through the use of signed communication. In a non-signing environment, they are unlikely to be able to take part in a successful communication exchange. Most of us can understand more than the words we use. Children who are non-verbal (who do not easily use words, signs, gestures or symbols to express themselves) might be able to understand at least some of what other people communicate. This depends on two key factors:

1. Communication is always embedded in context and children use the environment and the situation they are in to make sense of what is being said long before they learn the meaning of the words, signs or symbols that are being used.
2. The communication partner, caregiver or family carer plays a central part in supporting the language they use often by tailor-making environmental cues they know their child can understand (like making the sound of the water splash in the bath for a child who has low vision) before repeating 'let's have a bath'.

It is really important to get your child assessed by a speech and language therapist who will be able to give you a better understanding about what stage of language and communication your child is at.

Early pre-language behaviours

Before learning to communicate effectively and consistently, children use many pre-communication behaviours to show they are connecting with people, events and objects in the world around them.

They could be behaviours that are happening as a result of reflexes that they have very little control over, like being startled by a loud noise and jumping or putting their tongue out when hungry. They could be more consistent behaviours that you recognise as communicating some really important things to you. These behaviours relate to the pre-language stage and stage 1 outlined previously (see page 7).

Try to observe your child in a normal routine day. What does she/he do when she/he is hungry, thirsty or in pain? How do you know if your child needs to be changed or toileted? How does she/he behave when she/he likes something or does not like something? The responses could be simple reflexes – a reflexive head turn, a yawn. It could be crying or the use of certain facial expressions or vocalisations. They could show you something by making eye contact or avoiding eye contact or by moving an arm or a leg in a certain way.

Use the communication checklist on below to identify any early or pre-language behaviours that you think your child might use to communicate.

Communication checklist 1 (adapted from[77])

Early pre-language behaviour and Stage 1	Description and Example	What my child does
Hungry	Any behaviour that leads you to think that your child is hungry. For example crying, a specific vocal noise or looking towards the kitchen.	
Thirsty	Any behaviour that leads you to understand that your child might want a drink. They might be restless, start reflexive rooting, moving lips and tongue.	
Pain	This could be any behaviour that you feel is out of the ordinary that you interpret as unusual and rouses your attention. Body movements, facial grimaces, crying.	

Needs changing or toileting	Perhaps your child does not alert you to this. If they do, it could be with pointing, making a facial expression or any other indication using vocalisation, body movement or eye movement.	
Yes/no	Can your child communicate yes or no in a consistent manner? For example does he or she usually use eye contact or blinking or an arm movement for 'yes' and something different for 'no'?	
Like	Again, your child might make a particular sound if they are eating something they like or if they are enjoying the bath. What might that sound or facial expression or movement be?	
Do not like	The opposite of above! How does your child show that they do not like something? She/he might turn their head away or shout or make a particular facial expression that you recognise.	
Happy	If your child is happy, do they give you the same indication as for 'liking' something? Do they do something different to show they are relaxed and content? Like cooing, looking around, rocking or sighing? They might engage in a rhythmic movement of their body or arms/ legs.	
Sad	How do you know if your child feels sad? Is there a facial expression they show when you are leaving or going out? Is it the same or different to 'not liking' something?	

First meanings (adapted from[78])

These first meanings can be conveyed very simply through any form – verbal (proto-words, words, signs) or non-verbal (facial expression, vocalisation, natural gesture i.e. pointing, body language or symbol). These cover stages 2 to 4 of the developmental stages in Part 1 (see pages 7 and 8).

Children use different behaviours to request what they want, tell us something, reject an offer or comment on something. They might also use words or sounds that are close to words. Most children at this stage will be ready to start learning that they can have an impact on their surroundings by communicating with others. They will be nearing a level of what we call intentional communication.

The 'first meanings' outlined below need your child to understand interaction and communication on some level and to be able to express him/herself through some form or another.

As previously mentioned, this could be through verbal communication (words and signs) and non-verbal communication (body language, facial expression, body movements, gesture and vocalisations including laughter).

Think about these first meanings.

- How does your child show or lead you to understand that they are trying to convey any of these meanings?
- Note down what she or he does to show you when they are trying to convey some of these first ideas to you.

Communication checklist 2 (adapted from[79])

First meanings Stages 2-4	Description and example	What my child does
Showing something	Acknowledges the existence of something by looking at it, and at you or pointing or saying a word.	
Communicating 'gone'	Communicating that something is gone or requesting that she/he would like it to be gone – pointing to an empty bowl, making a noise and looking at the bowl. Taking his/her hand away from a toy.	
Communicating / requesting repetition	Requesting more of something or a repetition of it. This could be as subtle as lying very still until you rock the swing. Then laughing and waiting silently again for you to rock.	

Showing that something is not there	Noticing and drawing attention to something that was there but is gone. A table or chair moved from its place. This could be communicated by eye contact, facial expression, pointing or other gestures.	
Showing that something has changed its place	'Comments on' the location of something like the car being in a different parking space. Indicates if something is in the wrong place like shoes in the wrong slot in a shoe rack. This can be through using vocalisation, looking at the shoe, at you and back at the right slot.	
Indicating what belongs to whom	Can indicate if a piece of clothing or item belongs to him/herself or someone else by pointing or by moving the item towards the person.	
Rejecting something	Shows when she/he does not want something or wants it to stop.	
Showing it 'wasn't me'!	Able to communicate that it was not them who took the extra biscuit or ran across the road.	
Getting someone to do something	Recognises that people can carry out actions – could use eye contact to request that someone kick a ball or tie my shoe. Might say 'me' when they start to play with a favourite toy.	
Showing they recognise objects and their use	The child will show that they understand that objects have functions and can be acted upon. She/he might look at the soap and say 'bath'.	
Action	Could show anything that involves an activity or a change of state e.g. indicting 'up' by looking up or saying the word, gesturing or acting 'jump'.	
Communicating the properties of something	Commenting or showing that something is hot, cold, hard, soft, wet, etc.	

What communication stage is my child is at?

Going through this process of observing your child's communication behaviour should help you to be able to work out roughly what they are good at and what stage(s) they fit into. Below is an example to show you how one child's communication profile can be interpreted to determine their stage.

Thomas

Thomas is six years old and has severe learning disabilities. He is a happy, affectionate child and is independently physically mobile, who loves playing outside in the garden with his dog, dancing to music, doing animal puzzles with his older brother and helping to clean the car. Thomas can understand some single words like 'stop' and 'car' (receptive abilities). He seems to understand these better when there are clues for him like knowing that this is the usual time to get in the car or seeing the bucket and sponge for washing the car, or when he shouts too much and is told to 'stop' along with a hand gesture. He does not always respond to these words outside of these routine events. Thomas does not communicate using single words, but frequently makes babbling sounds (expressive abilities). He can say 'mamama' for his mother, 'dadada' for his father, and 'bababa' for everything else. The people around him can distinguish between happy and unhappy babbling sounds - he will babble with a loud positive inflection when he is enjoying something, but grunt or use a low pitched sharp babbling sound when he is frustrated or unhappy. Based on this information, Thomas is mainly communicating at a stage 2, according to the communication table on page 6.

The above communication checklists may also be helpful to complete every six months to see if there are any changes in your child's communication over time, particularly if you are actively supporting your child. Your responses may also form the basis of a communication passport for your child.

Communication checklist 2 (worked example with Thomas)

First meanings Stages 2-4	Description and example	What my child does
Showing something	Acknowledges the existence of something by looking at it, and at you or pointing or saying a word.	Looks, points, says 'bababa' whilst pointing
Communicating 'gone'	Communicating that something is gone or requesting that she/he would like it to be gone – pointing to an empty bowl, making a noise and looking at the bowl. Taking his /her hand away from a toy.	Tips something upside down if it's empty
Communicating/ requesting repetition	Requesting more of something or a repetition of it. This could be as subtle as lying very still until you rock the swing. Then laughing and waiting silently again for you to rock.	Smiles at person, leads person to the item, places person's hand over item to repeat it

Showing that something is not there	Noticing and drawing attention to something that was there but is gone. A table or chair moved from its place. This could be communicated by eye contact, facial expression, pointing or other gestures.	Looks at 'space' where it was and shakes head
Showing that something has changed its place	'Comments on' the location of something like the car being in a different parking space. Indicates if something is in the wrong place like shoes in the wrong slot in a shoe rack. This can be through using vocalisation, looking at the shoe, at you and back at the right slot.	Frowns, says 'bababa' with worried expression and looks at the new location
Indicating what belongs to whom	Can indicate if a piece of clothing or item belongs to him/herself or someone else by pointing or by moving the item towards the person.	Gives item to person, leads person to their item
Rejecting something	Shows when she/he does not want something or wants it to stop	Pushes item away or turns head and / or body away or moves away
Showing it 'wasn't me'!	Able to communicate that it was not them who took the extra biscuit or ran across the road.	Does not do this
Getting someone to do something	Recognises that people can carry out actions – could use eye contact to request that someone kick a ball or tie my shoe. Might say 'me' when they start to play with a favourite toy.	Leads person to activity space or items, Says 'mamama' or 'dadada'
Showing they recognise objects and their use	The child will show that they understand that objects have functions and can be acted upon. She/he might look at the soap and say 'bath'.	Uses item as intended – puts spoon to mouth, puts brush to hair, puts key in door
Action	Could show anything that involves an activity or a change of state e.g. indicting 'up' by looking up or saying the word, gesturing or acting 'jump'.	Acts out some actions physically like jumping. Indicates 'go' on remote control car by clapping once
Communicating the properties of something	Commenting or showing that something is hot, cold, hard, soft, wet, etc.	Does not do this

Part 3

Intervention (approaches to support communication)

It can take time to obtain a referral for a speech and language therapy assessment but there are some strategies that can be applied. These strategies are good practice and can be implemented whilst you are waiting for more specialised help and support.

1. **Gaining attention**. Children with complex communication challenges may need very direct approaches before they realise that someone is communicating. This might include saying the person's name, waving, touching, etc.
2. **Giving time**. Children often need additional time to process what is being said. Wait after you have said something and then wait a bit longer.
3. **Less is often more**. Using shorter phrases and 'chunking' information can be very helpful. Think about keeping it simple and giving one piece of information at a time. For example, 'Get your coat' is easier to understand than 'Can you come with me now and we will find your coat and put in on'. Sometimes people worry that short instructions can seem a bit 'harsh' or 'unfriendly' but with practice, you can still use a warm tone and positive facial expression.
4. **Make it as clear as you can**. We all use additional cues to help us understand what is happening and what is expected. You can use additional cues that occur naturally in the environment e.g. pointing to or holding up the item that you are talking about 'here's your shoe', talking about something as it is happening 'we are going through the gate'. You might also use natural gesture too e.g. beckoning, body movement.
5. **Noticing signals and responding consistently**. Some children might really struggle to let you know what they want and how they are feeling. What have you noticed about what they look like, do, sound like when they seem to be enjoying or not enjoying something? Can you keep a note of these 'indicators' and share with other people?
6. **Sharing information about communication**. Communication passports aim to improve communication, the idea is that if key information about the child's communication strengths and preferences are shared. The child will have a better and more consistent experience of communication. You can start to keep note of key aspects that are important to/for your child.

   For example, things your child is good at, things that help your child, what s/he can communicate, what your child finds hard to communicate, what distracts him/her, how to help him/her. Communication passports include digital and paper formats for co-producing information that is based on formal assessments. It explains what is important to/for the person, how they communicate and how to support communication. They are designed to be accessible to all. For more information about creating communication passports, please see: https://www.communicationpassports.org.uk/creating-passports/.
7. **Be predictable**. Try and use the same words to refer to things. The more consistent the approach across people and environments, the easier it will be for children to work out. Having a natural routine or rhythm to the day can be helpful.
8. **Try and reduce distractions**. It is easy to forget how busy, noisy and unpredictable our environments can be as we 'tune out' background noise. Children with complex

communication challenges might not be able to tune out the noise from the radio or focus on you when there are lots of people around.

9. **Have lots of practice**. Children might take a long time to develop a new skill and so it is important to provide lots of opportunities for children to take part in successful communicative exchanges.

10. **Make it fun**. Take time to enjoy communicating with your child. What ways are they responding? What do they seem to enjoy when interacting with you?

11. **Provide more support when you need to**. There are so many factors which impact on our ability to communicate. It's hard when we are tired or upset or anxious or ill or cross or fed up. If your child seems to be struggling more in certain contexts then see if you can provide more support e.g. reduce distractions, use additional strategies, show your child what you mean.

12. **Use a structured approach**. We all rely on structure and usually have recordings of this structure e.g. diaries, calendars, lists, etc. Children with complex communication needs will also benefit from structure in their lives but we might need to find more creative ways of communicating this structure.

    Structure is helpful as it enables us to predict what is happening and increase our understanding of events. What you select will depend on the communication and cognitive skills of your child.

    a. For *children with more complex communication challenges* who are not yet using formal means of communication, you may want to introduce **cueing** as a communication strategy. You might think about visual, auditory, tactile, smell, positional cues that could signal to the child what is about to take place. You might also need to think about other naturally occurring cues, such as following a set routine, person-place indicators (such as the nursery building and nursery teacher).

    b. For *children who have at least some formal ways of communicating*, you might want to think about **objects of reference**. These objects are used more formally to indicate an event e.g. a spoon is used to communicate to the person that it is time for food. You might want to think about what objects you could use.

    c. For *children who communicate using speech or signs or symbols*, you might want to think about **visual timetables**. These often begin with information on 'now and next' but can be built up to show a morning or a whole day. They use symbols or photos to indicate to the person what will be happening. TEACCH is one example of an intervention that uses visual structure to organise the environment and tasks and might also be of interest. It is often used in educational settings.

Intervention approaches

Where to start

Often the best thing to focus on first is the smallest thing that you feel could make the biggest difference to you and your child's communication. Small, easy goals to start off with are best. These usually are goals that are still within the stage that you have identified your child to be in. It's a good idea to talk to a Speech and Language Therapist, a teacher or someone else who can collaborate with you to decide how to approach the goal and what you can do to start achieving it.

Intervention often begins with a conversation between the professional, you as the parent or carer, and the child. Professionals may wish to work with you the child you care for using one or more interventions or specific approaches to communication.

We have provided a little more information on some of these:

Name of Intervention/ Approaches	Description/Definition	Resources/Links
Intensive interaction	This approach is commonly used to develop the communication and social interaction of children who do not use traditional speech to communicate. It involves a parent/carer and child engaging in communication interactions like mirroring body language and vocalisations[75].	For more information, please see: (https://www.intensiveinteraction.org/)
Multisensory approaches	These include sensory stories, multi-sensory stories, and narrative approaches. The parts of the story that can become multisensory, e.g. including touch, smell, sound, are identified[80].	For more information, please see: (https://pamis.org.uk/services/multi-sensory-storytelling/)
Augmentative and Alternative Communication (AAC)	These can be split in to two types; unaided forms, such as sign language, and aided approaches, such as pictures or a communication device.	For more information, please see: (https://www.callscotland.org.uk/information/severe-and-complex-support-needs/)

Objects of Reference	This approach uses objects (or even smells or tastes). They can be linked with an activity (e.g. a piece of swimming costume material to indicate swimming) or completely independent of it (e.g. a small disc to indicate a ride in the car). They can be used to signal to the child what is about to happen, and may be built up to provide a way of offering choices, and can develop into a visual timetable of activities for the child over time[81-83].	For more information, please see: (https://www.oxfordhealth.nhs.uk/wp-content/uploads/oxtc/resources/An%20easy%20guide%20to%20objects%20of%20reference.pdf)
Single message devices	An example of a single message device is a Big Mack. This involves the use of micro-switches to indicate needs and to gain attention of other people for social contact[84-86].	For more information, please see: Inclusive Technology (http://www.inclusive.co.uk/ablenet-bigmack-p2039)
Multiple message devices	These use symbols and/or photos and contain a series of recorded messages.	For more information, please see: Communication Aids (https://www.callscotland.org.uk/home/)
Signed communication	Makaton is an example of signed communication. This involves the use of manual signs, alongside spoken communication to communicate the key words.	For more information, please see: (https://www.makaton.org/)
Symbols and photos	This involves the use of photos or symbols (e.g. Widgit) to help people to understand information e.g. as a way of letting people know what is going to happen or to support choice-making.	For more information, please see: (https://nottscountypb.org/symbols-we-use-in-nottinghamshire/)

Considerations for children with sensory impairments

Deafblind children may have been under the care of local paediatric services since birth, however the full extent of deafblindness in some children is not realised until much later in development. All children recognised by local authorities as deafblind require follow-up by the child development team with access to specialist audiology and ophthalmology services. For some children, glasses and hearing aids can help, although it is important to note some children with partial vision or hearing may also experience sensory distortions or increased sensitivity to sight and sound when these are used. It is also important to consider that as a result of their visual/hearing impairments, some children may struggle with their balance and co-ordination. This should be held in mind when communication interventions prioritise touch cues and tactile signing within an adapted learning environment.

There are a few practical aspects to consider within a communication exchange or within a communication learning environment if your child has sensory impairments:
● Picture cards need to be adapted for visual impairment, which involves making symbols bigger, clearer and less cluttered, and not laminating cards to reduce glare.
● Person-focused adaptations can be made to the child's communication environment based on their individual needs, such as amplifying speech, proximity between communication partners, and signing within their field of vision (which may involve signing more closely, or signing within a small visual field).
● The use of tactile communication can be useful, and signs may be adapted to be touch-focused. This may involve adapting 'non-manual' signs (e.g. nodding head to mean yes) into a manual sign that can be communicated via the hands. Here the use of on-body signing and co-active signing may be useful.
● Identify opportunities to utilise calendar systems, choice making and 'burst-pauses' to develop reciprocal communication and shared understanding.
● Using 'objects of reference' may also be an appropriate approach to establish associations and develop a shared language for choice making.
● The needs of the child, their multi-sensory impairment and ability to communicate will change over time. Communication interventions need to be tailored to the child based on outcomes of the assessment and the degree of educational and service provision.

Useful information on accessing support and supporting deafblind children in an educational setting are available here:

https://councilfordisabledchildren.org.uk/sites/default/files/uploads/files/earlysupportmulti-sensoryimpairmentsfinal2.pdf

https://gov.wales/sites/default/files/publications/2019-12/191209-support-for-children-and-young-people-with-multi-sensory-impairment-in-educational-settings.pdf

! It is important to note that there are many communication interventions available to children with multiple complex additional needs, and it can be very complicated to work out which one is the best fit for your child. It can also be difficult to determine the 'evidence-base' for these interventions.

Mencap have developed a useful guide summarising which communication methods are out there, and which ones have been formally evaluated: https://e-space.mmu.ac.uk/198309/1/Mencap%20Comms_guide_dec_10.pdf

Considerations for children who experience anxiety

Anxiety is difficult to diagnose in children with severe intellectual disability who speak few or no words. This is because a professional diagnosis of anxiety relies on the individual being able to self-report their thoughts, feelings and emotions. These assessments have been developed for the general population, but not for individuals with an intellectual disability who are not able to self-report. Children who have more complex communication challenges may not be able to communicate their experiences of anxiety in the same way (e.g. telling someone they feel scared or worried), but that does not mean the anxiety does not exist.

Here, it is important to highlight the underlying contribution anxiety may have to the presentation of communication difficulties in children with an intellectual disability. Communication difficulties and signs of anxiety often overlap (e.g. reduced eye contact, social withdrawal, repetitive behaviours). There are also a number of neurodevelopmental disorders known to be associated with increased rates of anxiety and difficulties with verbal communication, including Cornelia de Lange syndrome, fragile X syndrome and autism, as previously outlined in Part 1. The contribution of many underlying factors is very complex. For example, it may be difficult to identify whether a child is quiet, fidgety and withdrawn because their communication needs are not being met, or because they are feeling anxious, or both. It is important to hold two things in mind:

1. **Anxiety may exacerbate existing communication difficulties.**
   A child who is anxious may evidence atypical eye contact, and may find it more difficult to engage in communication exchanges, to express their wants and needs, to respond to cues from others.
2. **Anxiety may make communication teaching or implementing communication interventions more challenging.**
   A child who is anxious may find it harder to concentrate during communication activities, to engage effectively in generalisation exercises, to respond to changes in the learning environment.

It is important to spot the non-verbal indicators of anxiety in children who cannot verbally communicate. If you are concerned your child may be anxious a key starting point would be to identify whether they present with emotional, physical or behavioural indicators of anxiety, which may include: crying, shaking, tearfulness, pale complexion, restlessness, irritability, fatigue, trouble sleeping, changes to heart rate, changes to body temperature (sweating, fast pulse), repetitive movements, fidgeting, overactivity, aggression, self-injury, screaming, avoidance of certain situations, and inability to concentrate.

If you think your child is displaying signs of anxiety, it is important to:

1. Make people who work with your child aware of their anxiety profile (e.g. will disengage from task, will cover ears, will rock back and forth, will clench their body) so anxiety can be recognised quickly when it occurs.

2. Inform people who work with your child of their calming strategies (e.g. calming music, ear defenders, sensory toys, comfort blanket), to encourage a consistent response to reduce anxiety.

There is more information relating to anxiety in intellectual disability in the Cerebra anxiety guide and mental health NICE guidelines:

https://cerebra.org.uk/download/anxiety-vc

https://www.nice.org.uk/guidance/ng54/resources/mental-health-problems-in-people-with-learning-disabilities-prevention-assessment-and-management-pdf-1837513295557

In terms of communication, providing clear and simple information can be helpful. You might need to help your child to communicate even more than you typically do. Try to make things as clear as you can by providing additional cues.

Considerations for children experiencing pain and discomfort

As we discussed previously, children with severe or profound intellectual disabilities often have complex co-occurring conditions and it is worth thinking about these when prioritising your child's communication targets.

If your child has physical health conditions meaning they experience pain and discomfort, it may be important to think about teaching your child a way to tell you when they are in pain. Alternatively, it might be that the people in your child's environment (home and school) will need to learn to recognise the behaviours that your child displays when they are experiencing pain and discomfort. It is sometimes worth video recording your child when you know that they are experiencing pain and video recording them when they are not and look for the behaviours that differ between the two situations. These pain-associated behaviours are likely to be your child's pain signature.

You may also like to try using an observational assessment called the FLACC (Face, Legs, Activity, Cry, Consolability) pain scale (https://cerebra.org.uk/download/flacc-pain-scale-infographic/). More information about pain, including the FLACC pain scale, is available via the Cerebra Anxiety Guide: A Guide for Parents (https://cerebra.org.uk/download/anxiety-guide-a-guide-for-parents/).

Considerations for children who display behaviours that challenge

For children who engage in behaviours that challenge such as physical aggression or property destruction and particularly self-injurious behaviour, it is important to seek support from health professionals (such as a clinical psychologist or professionals working in specialist learning disability services). They will want to complete an assessment and may carry out a functional assessment to try and work out what the function of the behaviour is. By 'function', we mean what does the behaviour that challenges achieve for the child. It is important to note that behaviours that challenge are not always functional. For example, there are also other reasons why a child may engage in challenging behaviour, such as for the sensory consequences associated with the behaviour (e.g. eye poking may lead to seeing stars).

Some of the most common social environmental functions of behaviour that challenge in children with an intellectual disability are to gain access to attention and to escape from demands[87]. Children may also engage in challenging behaviour as it reliably leads to access to favourite items, activities, locations, people, and avoidance/escape from non-preferred activities, items and locations[87].

You may want to use the checklists we have provided to think about how your child is able to use their existing communication (or other skills they have) to:

- Avoid something that they do not enjoy
- Gain something that they like.

It can also help provide lots of access to preferred items and, if practical and possible, finding ways to make the things that they do not enjoy, more pleasant. For example, you might want to provide more help with non-preferred activities and tasks. It can be helpful to try to increase the amount of choice and control you can give your child.

Behaviours that challenge can sometimes be reduced by teaching alternative behaviours that help the child to achieve the same outcome. This approach is called Functional Communication Training (FCT) and research has shown behaviours that challenge can be replaced by more adaptive behaviour[88,89]. Although it is rarely as straightforward as this. If a child repeatedly engages in behaviours that challenge that reliably lead to them receiving a preferred item (carers trying to distract the child), then it may be a good idea to think of and teach another behaviour that could reliably lead to the child receiving the item, such as signing, pressing a switch to request the item, handing over a picture card or pointing. It is recommended that any attempts to replace functional behaviours in this way are overseen by a professional with experience of working with children who engage in behaviours that challenge.

An example of FCT is presented in the case study below.

Ayla

Ayla is 6 years old and has severe intellectual disabilities. She enjoys playing puzzle games on her iPad, watching Disney films, arts and crafts, and eating dinner with her family. Ayla attends a Special Educational Needs (SEN) school. Although Ayla has shown behaviours that challenge throughout childhood to some extent, they are becoming increasing difficult to manage. At home, Ayla shows behaviours that challenge more often when it comes to using her iPad (e.g. when the iPad is not available, or is taken away at bedtime and mealtimes). Her parents have incorporated more structured uninterrupted iPad use into her visual timetable before dinner and before bed. These interventions at school and home have reduced the frequency of some of the behaviours that challenge. Her parents have also sought further advice from a professional. A functional assessment identified that some of Ayla's behaviours function to gain access to preferred items. In addition to the changes already made, Ayla is taught a functionally equivalent replacement behaviour. Over several weeks, and with consistent practice, Ayla is encouraged to press a Big Mack switch which says - 'iPad please'. With time, practice and consistency of response, there has been some further reduction in behaviours that challenge.

For more information about managing challenging behaviour please see Cerebra's guide to self-injurious behaviour and managing challenging behaviour:

https://cerebra.org.uk/download/self-injurious-behaviour-in-children-with-intellectual-disability-2/

https://cerebra.org.uk/download/factsheet-managing-challenging-behaviour/

Considerations for children with a diagnosis of autism

If your child is autistic, you might want to use the assessments and information we have provided and focus a little more on providing routine and predictability. It may also be really helpful for you to be able to communicate to your child what is happening next. You may be able to use visual cues to do this such as objects of reference and pictures and activity schedules. Using more visual communication might be helpful in general.

For more information about sensory processing, please see Cerebra's guide: https://cerebra.org.uk/download/sensory-processing/

Summary

Within this guide, we have covered the importance of communication, stages of communication, communication in the context of neurodevelopmental disorders and additional complex needs, communication checklists and assessments, and finally strategies for intervention. A glossary of key terms and list of useful resources are also provided at the end of this guide. Communication difficulties are common in children with severe or profound intellectual disabilities, but the exact profile of communication challenges varies between individuals, no two children are the same. It is important to seek additional specialised help and support when needed, and prioritise the communication needs that are specific to your child. Your child's communication needs and abilities may change over time, so regular monitoring and open discussions with professionals and care providers working with your child are important.

Glossary

Behaviours that challenge (also known as challenging behaviour) – behaviours that are challenging to both the individual and the people around them such as self-injury (hitting self / banging head on surfaces), aggression (hitting others) or destruction of the environment (tearing posters, fabric, pushing items off a shelf).

Burst-pauses – introducing an extended pause to build anticipation within a social interaction, as a social cue to encourage the communication partner to request or express enjoyment - e.g. when playing with bubbles, holding the bubble wand to your mouth and saying 'ready, steady ...' - pause. By waiting an extended period of time to say 'go', the communication partner is encouraging the child to point or communicate 'go' to request the bubbles.

Childhood apraxia - difficulty with motor co-ordination from the brain in controlling facial muscles for speech.

Chromosome – a long DNA structure that carries genetic information in the form of genes.

Cleft palate - occurs when a child is born with a gap or opening in the roof of the mouth.

Co-active signing – a form of tactile signing; physically guiding or manipulating another person's hands into the manual sign (e.g. taking the communication partner's hands and physically guiding their hands to form the sign 'more').

Communication passport – individualised document that summarises a person's communication abilities, needs and preferences which is usually shared with all caregivers. The aim is for everyone to have a clear understanding of how to communicate with your child and to have a consistent approach.

Cueing – prompts used by the communication partner to signal that a communicative response is expected (e.g. pictures cards, verbal instruction).

Executive function difficulties (also known as executive dysfunction) – challenges relating to 'brain skills'; cognitive processes that can influence behaviour, such as planning, memory, attention and task switching.

Expressive abilities (also known as expressive language) - the skills necessary to form thoughts and express them using appropriate word and grammar combinations. This may also include gesturing and facial expressions, especially in early childhood.

Functional assessment – an assessment to identify the function of a behaviour. Typically used to identify the function of challenging behaviour, such as aggression or self-injurious behaviour. Assessment methods include informant questionnaires and interviews and sometimes naturalistic observation or experimental manipulation of the behaviour (functional analysis).

Gastrointestinal conditions – the gastrointestinal tract connects the mouth to the anus. Conditions or diseases that are gastrointestinal relate to the mouth, stomach, and intestines, such as reflux, vomiting, and constipation.

Genetic syndrome - a condition that occurs as a result of changes to a person's DNA.

Intentional communication - develops as a child becomes aware that they can use their communication skills to influence other people. This can happen slowly. A child could use a certain

sound or word that family carers recognise as consistently meaning something specific. When this word or vocalisation is used consistently, it can show that a child is beginning to develop intentional communication.

Language regression - loss of previously acquired language skills, e.g. loss of words that a child used to speak, being unable to recognise words that were previously understood.

Mental health condition – conditions that affect your mood, thinking and behaviour such as anxiety and depression.

Multi-sensory impairment – combined visual and hearing loss, where vision and hearing difficulties co-occur.

Neurodevelopmental difference - conditions that affect brain development resulting in changes to behaviour, memory and learning (including genetic syndromes, intellectual disability and autism).

Non-manual signs – signs that are non-manual do not incorporate the hands, but instead rely on body position, head movement, or facial expressions, e.g. nodding and shaking the head to mean yes and no.

Non-symbolic communication (also known as pre-symbolic communication) - Communication that does not rely on words and signs and may not have a shared meaning with others (e.g. gestures, facial expressions).

Objects of reference – objects used to represent peoples, places, activities and events (e.g. lunchbox representing the school canteen, a rubber duck indicating bath time).

On-body signing – a form of tactile signing; the communication partner traces or physically prompts onto the hand, arm, face of the individual who is deafblind to communicate through the sense of touch (e.g. the communication partner uses their hands on the individual's mouth to create the sign for 'drink').

Over-generalisation - children might use one 'proto-word' for several things. So 'nana' could mean banana or it could mean any fruit.

Physical health condition – conditions that cause observable change or illness to the human body such as diabetes, constipation, epilepsy.

Proto-words - These are sounds that are similar to but are not quite words e.g. mama, dada.

Receptive language - the ability to understand words and language.

Selective mutism - communicating only in certain contexts (for example, with familiar caregivers and not communicating in the presence of unfamiliar people or in unfamiliar contexts).

Severe or profound intellectual disabilities (also known as profound multiple intellectual disabilities) - children and adults have more than one disability, the most significant of which is a profound intellectual disability. Individuals have great difficulty communicating, often requiring those who know them well to interpret their responses and intent, and frequently have other, additional, disabling conditions. These include physical disabilities, sensory impairments, sensory processing difficulties, and complex health needs. See: Standards-PMLD-h-web.pdf (pmldlink.org.uk)

Single sensory impairment - impairment to either vision or hearing individually.

Social anxiety - intense fear when in social situations with other people, which can lead to hyper-arousal, withdrawal and avoidance.

Symbolic understanding - develops alongside cognition. Once a child is able to establish an idea in their mind about what an object is, and its function, they are then more able to generate an image of that object when it is not there. The next step is to map that idea (for example their idea of 'bath') onto the word 'bath'. This is known as symbolic meaning. The word 'bath' symbolises what we know is a bath.

Tactile signing - physical on-body sign language, either with the child placing their hands over the communication partner's hands while they are signing (co-active signing), or physically signing onto the hands/body of someone who is deafblind to communicate through the sense of touch (on-body signing).

TEACCH – stands for Treatment and Education of Autistic and related Communications Handicapped Children. An intervention program to enhance communication and daily living skills, based on structured teaching, incorporating physical cues and visual schedules. See: https://www.autism.org.uk/advice-and-guidance/topics/strategies-and-interventions/strategies-and-interventions/teacch

Touch cues - physical directions communicated through body touch to indicate movement or change (e.g. tapping at the child's feet to signal shoes are being put on).

Under-generalisation - children might not realise that 'shoe' means everyone's shoes, not just their shoes.

Visual timetables – a physical representation of an individual's schedule or routine to establish what will happen over a period of time. They can involve two stages (now and next) or multiple stages (morning routine), and often involve picture cards or photographs.

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Resources

Creating communication passports

https://www.communicationpassports.org.uk/creating-passports/

Routes for Learning assessment guidance and route map

https://hwb.gov.wales/api/storage/ec52e14b-62d4-4bb0-9617-0a315662c671/curriculum-2022-routes-for-learning-assessment-booklet-final-web-ready-e-130720.pdf

https://hwb.gov.wales/api/storage/06ee7de9-52d0-4c2e-b5a8-f4928fc823a0/curriculum-2022-routes-for-learning-routemap-final-web-ready-e-110620.pdf

CALL Scotland

https://www.callscotland.org.uk/information/severe-and-complex-support-needs/

Websites

National Autistic Society

https://www.autism.org.uk/

Challenging Behaviour Foundation

https://www.challengingbehaviour.org.uk/

Positive Approaches to Support

https://www.positiveapproachestosupport.co.uk/

Mencap

https://www.mencap.org.uk/

Hands In Autism: Information on how to create visual schedules

https://handsinautism.iupui.edu/wp-content/uploads/2019/05/How_To_Visual_Schedules.pdf

Related Cerebra Guides

Cerebra have a number of guides written for parents of children with an intellectual disability which you may find helpful.

Self-injurious behaviour in children with an intellectual disability.

https://cerebra.org.uk/download/self-injurious-behaviour-in-children-with-intellectual-disability-2/

Managing challenging behaviour

https://cerebra.org.uk/download/factsheet-managing-challenging-behaviour/

Pain in children with severe intellectual disability: A Guide for Parents

https://cerebra.org.uk/download/pain-a-guide-for-parents/

FLACC Pain Scale Infographic

https://cerebra.org.uk/download/flacc-pain-scale-infographic/

Anxiety A guide for parents.

https://cerebra.org.uk/download/anxiety-vc/

Sleep: A guide for parents.

https://cerebra.org.uk/download/sleep-a-guide-for-parents/

Sensory processing: A guide for parents

https://cerebra.org.uk/download/sensory-processing/

https://cerebra.org.uk/download/sensory-processing-hints-and-tips-general-information/

https://cerebra.org.uk/download/sensory-processing-hints-and-tips-hyper-reactivity/

https://cerebra.org.uk/download/sensory-processing-hints-and-tips-hypo-reactivity/

https://cerebra.org.uk/download/sensory-processing-hints-and-tips-sensory-seeking/

Information and support for parents of a child recently diagnosed with a genetic condition

https://cerebra.org.uk/download/information-and-support-for-parents-of-a-child-recently-diagnosed-with-a-genetic-condition/

Cognitive Difference: Cognitive Inflexibility and Impulsivity

https://cerebra.org.uk/download/cognitive-difference-cognitive-inflexibility-and-impulsivity/

About the authors

Dr Susan Buell, University of Dundee

Susan is currently a lecturer in Applied Health Sciences, School of Health Sciences, at the University of Dundee. Susan is a speech and language therapist by profession. She worked clinically for 15 years with children (and their families) in the UK and Latin America who had a range of complex communication conditions. Since 2004 she has held academic and research posts at Manchester Metropolitan University and the University of East Anglia.

Dr Jill Bradshaw, Tizard Centre, University of Kent

Jill is a speech and language therapist and senior lecturer in intellectual and developmental disabilities in the Tizard Centre at the University of Kent. Her research, consultancy and teaching are focused on the communication experiences of people with intellectual and developmental disabilities who have the greatest communication challenges.

Dr Stacey Bissell, University of Birmingham

Stacey is a Cerebra-funded research fellow at the University of Birmingham. Her PhD research co-funded by Cerebra and the Tuberous Sclerosis Association from 2014-2018 explored early developmental profiles, communication and behaviour in young children with tuberous sclerosis complex (TSC). Her current research, as part of the Cerebra Network for Neurodevelopmental Disorders, focuses on sleep and behaviour in TSC and factors underlying poor sleep in children with rare genetic syndromes associated with intellectual disability.

Dr Darren Chadwick, University of Wolverhampton

Darren is a reader in Applied Psychology and has over 20 years of experience of teaching psychology and developing and conducting research that aims to improve the lives of people with intellectual disabilities. Darren's research has concentrated on the health and social wellbeing of people with intellectual disabilities at different life stages and the impact and effectiveness of interventions for people with intellectual disabilities and those who support them. Specific projects have looked at communication, use of social media, eating and drinking safety and enjoyment, physical and oral health, ageing, transition and interpersonal relationships and inclusion.

Dr Debbie Allen, University of Wolverhampton

Debbie is currently a senior lecturer in the School of Psychology at the University of Wolverhampton. Debbie held a postdoctoral research post at the University of Birmingham from 2003-2018. Her research has focused mainly on assessment and interventions for challenging behaviour in children with intellectual disabilities, autism and rare genetic syndromes. She also has clinical experience of working in home-based early behavioural intervention for pre-school children with autism and as a senior practitioner in a community learning disability team.

About the peer reviewer

Professor Chris Oliver

Chris Oliver is Emeritus Professor of Neurodevelopmental Disorders School of Psychology, University of Birmingham and Director of the Cerebra Centre for Neurodevelopmental Disorders. His main research interests are behavioural, cognitive and emotional disorders in people with severe intellectual disability, genetic syndromes and autism spectrum conditions.

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Postal Address

Cerebra

The MacGregor Office Suite

Jolly Tar Lane

Carmarthen

SA31 3LW

Tel: 01267 244200

Freephone: 0800 328 1159

www.cerebra.org.uk

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