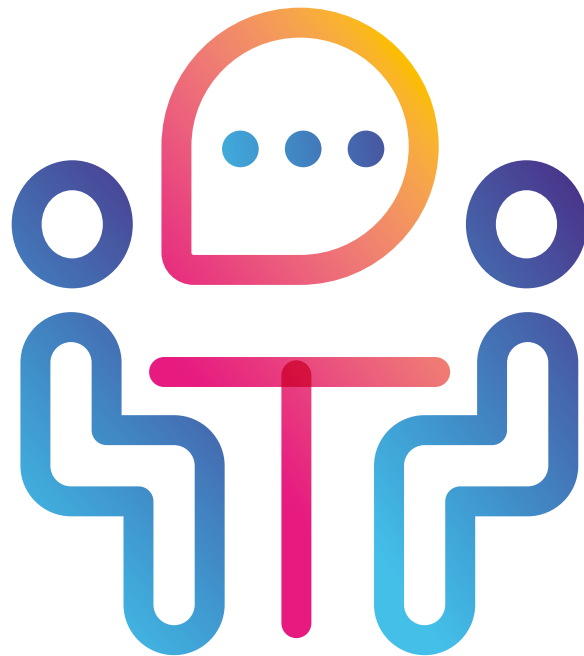


Guidance on the importance of autistic voices and meaningful consultation



Guidance

Preface

Consultation with autistic individuals is a fundamental aspect of good practice as recognised by Autism Accreditation. This process ensures that services and support genuinely reflect the needs and preferences of those they aim to assist. This guidance has been developed to provide practical suggestions and ideas on resources for schools and services seeking to obtain meaningful feedback from autistic individuals.

We begin with an introduction, followed by an article authored by two members of the National Autistic Society's specialist speech and language team, which explores how communication works. Next, we offer an overview of Augmentative and Alternative Communication (AAC) and observation as effective tools for seeking feedback from autistic individuals with limited speech. Finally, we present a list of AAC resources and approaches that we hope you find useful.

Christine Flintoft-Smith,
Head of Autism Accreditation

Introduction



Importance of autistic voices and meaningful consultation and collaboration

Engaging autistic individuals in the development and evaluation of services fosters a deeper understanding of autism from the perspective of those who experience it. This collaborative approach enhances the quality of support provided and promotes inclusivity and empowerment (Autism Education Trust, 2021). By prioritising this consultation, schools and services registered with our quality assurance programme demonstrate their commitment to delivering effective, person-centred care that aligns with the principles of respect and dignity for all autistic individuals.

Unfortunately, autistic individuals can often be excluded from decisions that impact their lives, particularly young people, children and those with learning disabilities or limited spoken communication (Health and Social Care Committee, 2022). Communication barriers may prevent meaningful dialogue, and even when these barriers are overcome, individuals may not be perceived as capable of expressing their views or providing feedback (NHS England, 2022). Common misconceptions, such as “they don’t speak, so I can’t ask them their views”, “they don’t understand what I’m saying, so there’s no point”, or “I understand them very well – I know what they want” (Johnson et al., 2022), can further marginalise autistic voices. This can result in autistic individuals having little say in what is important to them and how they wish to lead their lives.

From capturing feedback to effecting change

There are several effective ways to capture feedback from autistic individuals to enhance service delivery. Surveys, questionnaires and anonymous feedback boxes can be designed with simple, clear language and visual aids to facilitate understanding (Babalola et al., 2024). One-on-one interviews, whether verbal or using Augmentative and Alternative Communication (AAC), allow for personalised feedback, while focus groups provide a supportive environment for group discussions (Walsh et al., 2021). Observing behaviours in various settings can yield valuable insights, and visual feedback tools, such as picture cards or emoji scales, enable individuals to express their feelings (Nicolaidis et al., 2014). An increasing range of digital platforms and apps tailored for feedback collection can cater to diverse communication styles (Mason et al., 2019). Gathering input from family members and support staff can provide additional context. By combining these methods, services can ensure they capture comprehensive and meaningful feedback.

Introduction



However, this is only part of the story. Accreditation expects that once feedback is obtained, it is collated and thoroughly analysed to identify patterns, strengths and areas for improvement at both individual and service levels (Health and Social Care Committee, 2022).

This analysis can reveal valuable insights into how services are perceived and experienced by autistic individuals, guiding adjustments to support plans. For instance, if feedback consistently highlights a need for more sensory-friendly environments, services can proactively address this concern (Johnson et al., 2022).

It is essential to document all feedback and the subsequent actions taken in a structured and accessible manner. This documentation should be available to all relevant stakeholders, including families, staff, external professionals and quality assurance assessors, including Autism Accreditation and statutory inspectors (National Autistic Society, 2021).

Incorporating feedback into service delivery not only enhances the quality of support provided but also empowers autistic individuals by validating their voices and experiences. By prioritising their input, services can create a more inclusive and responsive environment that truly meets the needs of those they serve.

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Communication



When people think of communication and what this means, many may think of verbal communication, but this is just one aspect of communication. There are various methods of communication including non-verbal communication, written communication and visual communication. An environment which uses a total communication approach values all means of communication equally. The aim for individuals who have communication difficulties or differences is to communicate in whichever way they choose. This may include facial expression, body language, gesture, sign, objects of reference, photographs, pictures, symbols, written word and electronic devices.

The right **communication environment** is crucial for autistic people to assist with their understanding. Good communication practice may include:

- ensuring the environment is quiet and distraction-free
- listening and responding to communication immediately and consistently.
- using the person's name first to gain their attention.
- keeping language clear, simple and relevant.
- avoiding confusing language. Long, complex and abstract concepts can be difficult to process and understand. Say what you mean and mean what you say.
- considering that some autistic people take language very literally and do not always understand humour and sarcasm.
- accompanying your spoken language with gestures and signs if appropriate
- using visual supports to aid understanding. These are understood by a developmental hierarchy - objects of reference, photographs, pictures, symbols and the written word. Symbols should always be presented alongside the written word.

Use of visual supports

- People who can read tend to represent things visually in writing. People who are unable to read may require a method more suited to their specific needs.
- There is a range of representation - objects, photos, picture symbols, more abstract symbols and writing.
- An object of reference is used by people who require concrete objects to represent things to them. Eg cup = drink.
- For some people, using photos as a main means of representation is a stepping stone to using symbols.
- Symbols can be used in a range of ways to aid people's understanding on a daily basis. They are used in the environment, in methods of assisting transition, in information and social stories and they are also used in a wide range of communication aids.

Communication



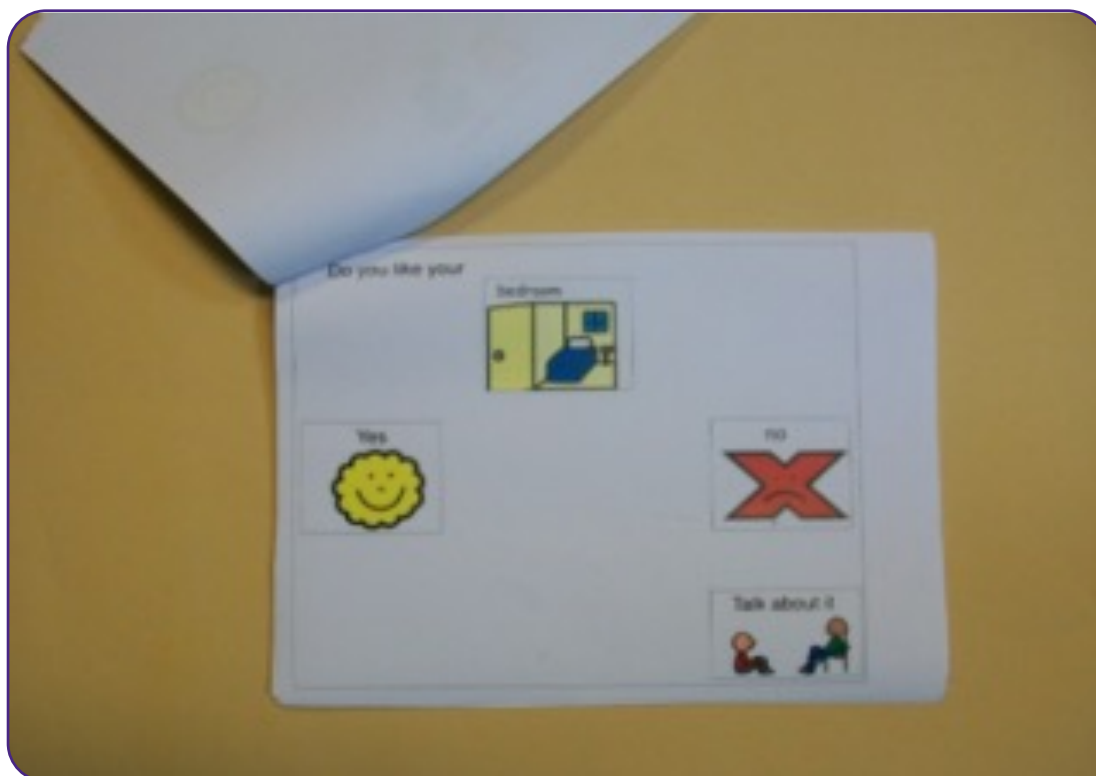
Gaining views by signalling like and dislike using symbols

Some people can signal clearly that they like or don't like things. Some people can do this clearly by their speech. Some people, who do not speak, may use their general demeanour. They may use their sounds, facial expressions, gestures, body movements or behavioural responses in a consistent way, allowing interpretation by others.

Individuals who can use pictures or symbols may use these to signal like and dislike, yes and no or more and finish.

A range of pointing boards and choice boards can assist when people are asked directly.

Other methods involve putting symbols of items in question next to symbols indicating like and dislike or yes/no.



Communication



Talking Mats

This is a highly successful method of gaining people's views using pictures or symbols. It uses a top line of feelings symbols and other symbols are related to these.

To use Talking Mats, people must first learn to clearly understand the like/dislike top line symbols and then reliably be able to relate a picture/ symbol to these. It is important that the person's understanding of how to use this system is clearly assessed before starting to use it.



Yes/no

The use of Yes/No should be modelled throughout the day. This assists in understanding the function of the symbols and can be done verbally, by nodding and shaking of a head, by sign or by pointing or exchanging appropriate pictures /symbols.

It is important to give people a positive and communicative way of saying that they don't want something.



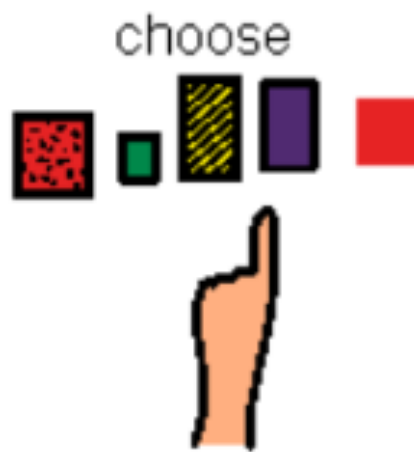
Communication



Making choices

Before making any choice, people need to be informed of the options they can choose.

When offering choices, it's important to remember that this needs to be personalised to the individual and may require the use of objects, photos, symbols or the written word.



How can views be captured?

Views can be captured using a range of resources matched to a person's developmental / cognitive ability. It's important to provide the means, reasons and opportunities for a person to communicate their thoughts and opinions.

Views may be sought using:

- photographs/symbols
- simple questions
- Talking Mats
- simplified language
- a consistent adult who knows the person extremely well.

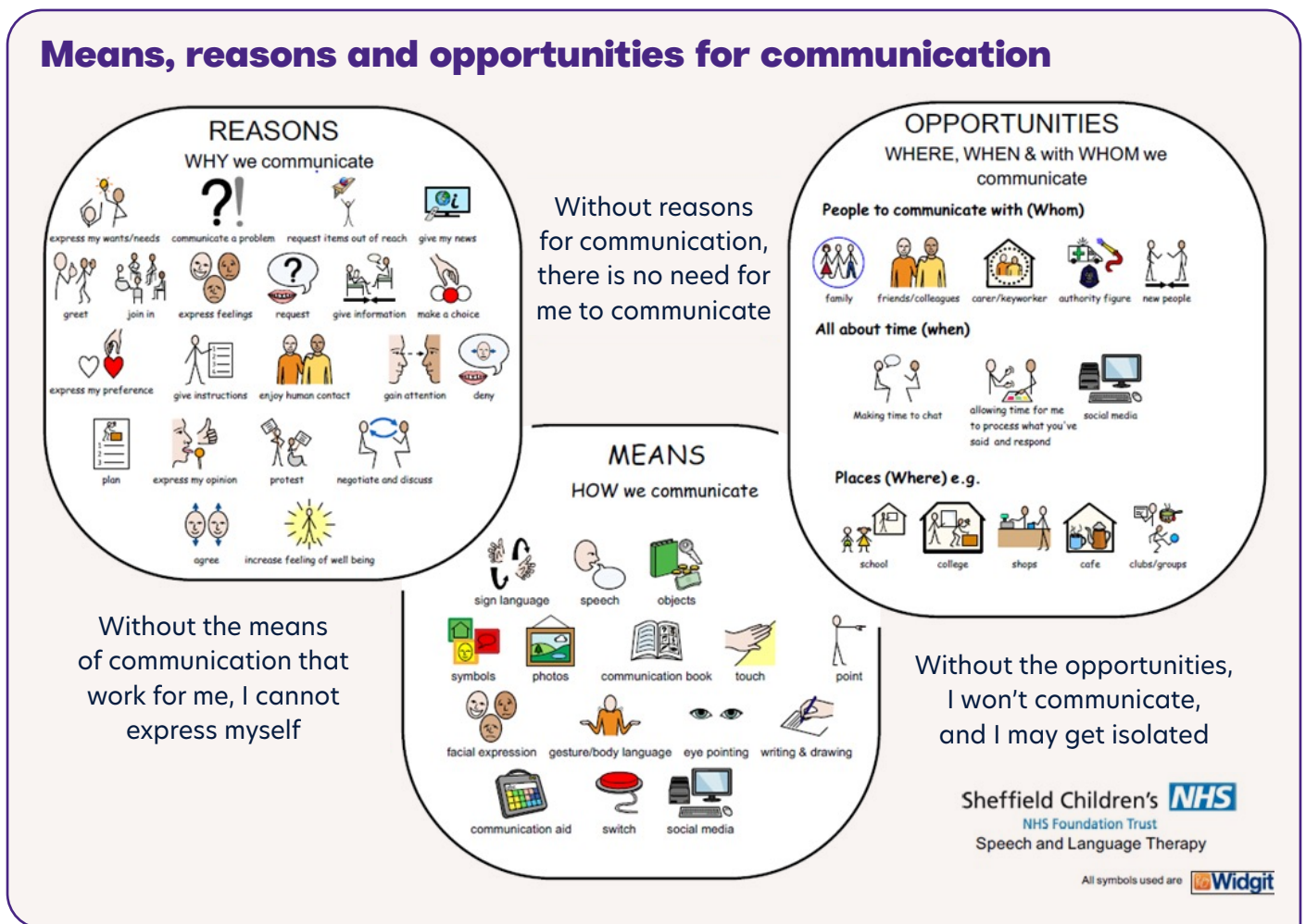
Communication



Reflections

The use of questionnaires for gathering views, thoughts, opinions and feelings needs to be meaningful. Written questionnaires are only accessible to those who can read and understand what is being asked of them.

Views and thoughts can be easily captured through using a variety of mediums. A personalised approach is essential.



Joanne Neill Smith,
NAS Clinical Lead/Principal Speech & Language Therapist

Karen Shirkie,
Highly Specialist Speech & Language Therapist

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Using Augmentative and Alternative Communication and observations to obtain feedback



Augmentative and Alternative Communication (AAC)

AAC describes a range of tools to help people with limited speech to express their needs and wants, likes and dislikes, what makes them feel happy and secure and also what they do not like, what makes them feel unhappy and insecure.

AAC devices may be simple letter or picture boards or more sophisticated computer-based systems. AAC helps someone to communicate as effectively as possible, in as many situations as possible.

Low-tech communication aids

Low-tech communication aids:

- do not need a battery
- are often paper-based
- Common types include:
 - picture cards, photos or communication symbols made by companies
 - signing, such as Makaton and Signalong
 - picture or symbol communication books, such as from Boardmaker and Widgit.

High-tech communication aids

A high-tech communication aid needs a battery or another type of power to work. They run on devices like computers, tablets, phones or specialist communication devices.

You do not need specific skills to use a high-tech aid. A healthcare professional, such as an occupational therapist or speech and language therapist, will be able to advise on a suitable access method.

Access methods

You can access aids in several ways, depending on what you need. There are lots of types of pointer tools. For example:

- touching the screen with your fingers
- using a pointer tool, like a head mouse
- tracking where your eyes are looking with an eye gaze camera
- using a switch like a big mac or jellybean switch
- using a joystick.

Using Augmentative and Alternative Communication and observations to obtain feedback



Tips to help someone use a communication aid

Specialist Speech and Language Therapist, Amie Woghiren (Scope), has these tips:

- **Be patient and supportive** - Using AAC takes a lot more time than speaking. If someone has not replied yet, they may still be thinking. Wait and then wait a bit longer.
- **Familiarise yourself with the device** - Get to know the vocabulary, phrases and tools on the device so that you can solve problems together. This will also mean that you can plan for new words. These could be names of new staff, or vocabulary for a new topic at school.
- **Model using the device** - If you're working with someone new to AAC, it's like learning a new language. Asking lots of questions is unhelpful if you do not know the answers. Once you're familiar with what's on the device, you can show where to find the words and phrases the person needs.
- **Take it everywhere** - Unless there's a safety reason (like being near water), there's no limit to where an AAC device can be useful.
- **Vary language** - AAC is useful for expressing choices, but there is more to life than 'I want'. You can use AAC to make jokes, express feelings, make speeches and deepen friendships. The possibilities are endless.

The role of observation in obtaining feedback from autistic individuals

Observation is essential for understanding and supporting autistic individuals, especially those with limited speech. In educational and social care settings, effective observation can bridge communication gaps and provide valuable insights into their needs, preferences and experiences. By carefully interpreting non-verbal signals, caregivers and educators can better understand an individual's emotional responses to various activities and environments.

It is crucial to observe individuals over time and across different contexts, as an autistic person's gestures or facial expressions may not always align with typical emotional associations. For instance, staff may learn that a smile can indicate stress rather than happiness. This nuanced understanding is vital for accurate interpretation of their feelings.

Moreover, effective observation fosters trust between autistic individuals and their supporters. When individuals feel understood and their needs are acknowledged, they are more likely to engage and communicate, even if their speech is limited. Building this rapport is essential for creating a safe and supportive environment where autistic individuals can thrive (Hughes et al., 2020).

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Appendix 1: Approaches and resources



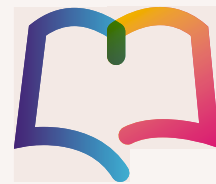
The following lists are by no means exhaustive, and their purpose is purely to guide what approaches and resources are available.

It is important to note that listing any approach or resource does not constitute an endorsement. There is no single approach that is universally suitable for all autistic people, as each individual has unique challenges, skills and preferences. We encourage professionals to conduct their own research and consider the specific context and requirements of each person. Tailoring support to the individual is essential for effective communication and understanding.

Approaches to support the development of communication

Name of approach	What is it?	Where can I find out more?
Attention Autism	A learning approach that aims to develop natural and spontaneous communication skills in autistic people using visually-based and highly motivating activities.	https://www.youtube.com/@ginadaviesautismcentre
Blank Levels	The Blank Levels of Questioning, sometimes known as the Language of Learning Model, was developed by Blank, Rose and Berlin in 1978. It aims to develop children's verbal reasoning and abstract language capabilities.	https://childspeechbedfordshire.nhs.uk-Introduction-to-Blank-levels
Colourful Semantics	A method of teaching individuals how to understand and build sentences.	https://www.structural-learning.com/post/colourful-semantics-a-teachers-guide https://www.amazon.co.uk/Colourful-Semantics-Resource-Developing-Childrens/dp/0367210509

Appendix 1: Approaches and resources



Name of approach	What is it?	Where can I find out more?
Gestalt Language Processing	A form of language development that starts with whole memorised phrases and moves to single words. It begins with the person imitating phrases he or she previously heard (delayed echolalia). A person then breaks down the phrase as he or she learns the meaning of the individual words. The person uses those individual words to build other, novel phrases and sentences to communicate.	https://kidtherapy.org/helpful-articles/what-is-gestalt-language-learning/
Intensive Interaction	A learning approach that aims to develop natural and spontaneous communication skills in autistic people using visually-based and highly motivating activities.	https://www.intensiveinteraction.org/
Lego Therapy	A social development programme that uses LEGO activities to support the development of social skills in a group setting.	https://www.autism.org.uk/advice-and-guidance/professional-practice/lego-pilot
SCERTS (Social Communication, Emotional Regulation and Transactional Support)	A framework for developing communication and social emotional skills in autistic people.	https://scerts.com/the-scerts-model/
smiLE Therapy	A programme which teaches social communication skills to support everyday short interactions with people in the mainstream community.	https://www.smiletherapytraining.com/about-smile-therapy
Speech and Language Therapy	Support for children and adults who have difficulties with communication.	https://www.autism.org.uk/advice-and-guidance/professional-practice/speech-therapy

Appendix 1: AAC resources



Low-tech resources

Name of resource	What is it?	Where can I find out more?
Boardmaker	A symbol-based language system used to create custom-based teaching materials such as choice boards and classroom timetables.	https://goboardmaker.com
Body language and gestures	Body language and gestures is a type of nonverbal communication in which physical behaviors, as opposed to words, are used to express or convey information.	https://www.helpguide.org/relationships/communication/nonverbal-communication
Colourful Semantics	A method of teaching individuals how to understand and build sentences.	https://www.structural-learning.com/post/colourful-semantics-a-teachers-guide
Comic Strip Conversations	Simple visual representations of what people said and thought in a social interaction to help an autistic person understand different people's perspectives.	https://www.autismwestmidlands.org.uk/autism-information/visual-resources/
Communication Boards	A sheet of symbols, pictures or photos that a person will learn to point to, to communicate with those around them.	https://www.leicspart.nhs.uk/wp-content/uploads/2019/02/Communication-Boards.pdf
Communication in Print	A desktop publishing program for creating symbol-supported resources for printing.	https://www.widgit.com
Minimal Speech Approach	Using simple speech consisting of one or two words paired with a picture, object or gesture.	https://www.icommunicatetherapy.com/child-speech-language/autism-minimal-speech-approach/
Objects of Reference	Using an object to represent an activity, person or place.	https://www.leicspart.nhs.uk/wp-content/uploads/2019/02/Objects-of-Reference.pdf
Talking Mats	A visual communication framework which supports people with limited communication to express their feelings and views.	https://www.talkingmats.com/

Appendix 1: AAC resources



Low-tech resources

Name of resource	What is it?	Where can I find out more?
Picture Exchange Communication System (PECS)	A system in which visual symbols are exchanged to develop functional communication skills.	https://pecs-unitedkingdom.com/pecs/
PODD (Pragmatic Organisation Dynamic Display)	A book or device containing symbols and words to support communication between people with complex communication needs and their communication partners.	https://www.assistiveware.com/blog/what-is-podd
Signing systems (Makaton; Signalong)	Systems based around the use of signs to communicate.	https://signalong.org.uk/about https://makaton.org/About-Makaton/Helpwithautismand-communication
Social scripts	Scripts aim to teach an autistic person what to say in social situations.	https://www.twinkl.co.uk/teaching-wiki/scripting
Social Stories	Stories that share social information with an autistic child or adult in an accessible way, respectful of their different perspective and interpretation of the social world.	What is a Social Story? - Carol Gray Social Stories.pdf (www.autism-westmidlands.org.uk)
The Engagement Model	An assessment tool to help schools support pupils who are working below the level of the national curriculum and not engaged in subject-specific study. It can also be used to identify how autistic people with limited speech feel about the activities being offered to them in any setting.	https://www.youtube.com/watch?v=vYYnkJ4XyIM
Total Communication Approach	Involves encouraging and accepting all types of communication, not just speech, equally. This includes facial expression, body language, gesture, sign, sounds, symbols, written language, pictures and objects of reference.	https://www.hpft.nhs.uk/media/ybuovikk/total-communication-approach.pdf

Appendix 1: AAC resources



Low-tech resources

Name of resource	What is it?	Where can I find out more?
Visual supports	Communication tools that use photographs, pictures, symbols or written words to support autistic people in their communication and to help reinforce routines and schedules.	https://www.autismwestmidlands.org.uk/autism-information/visual-resources/
Widget symbols	A symbol-based language used predominantly for people with learning disabilities. It uses pictorial symbols, either as an alternative to text or to accompany it.	https://www.widgit.com/

High-tech approaches

Name of resource	What is it?	Where can I find out more?
Go Talk	GoTalk communicators use recorded messages, any messages the user will likely need, in any language, dialect or accent, and the user can use them to communicate with the press of a button.	https://www.spectronics.com.au/product/gotalk-communication-device-series
Grid	Grid is used by children and adults with communication difficulties, to have a voice and live more independently, available on Windows and iPad.	https://thinksmartbox.com/grid/
Proloquo2Go	Proloquo2Go uses a visual vocabulary of symbols and pictures to represent words and concepts, and allows users to communicate by selecting and arranging the symbols in a way that forms a message.	https://www.assistiveware.com/products/proloquo2go

Appendix 1: AAC resources



Name of resource	What is it?	Where can I find out more?
Sonoflex	Sonoflex enables users to combine core and topic-based vocabulary with over 11,000 symbols and over 50 preset phrases. It comes with over 800 words and phrases used in daily conversation, encouraging more independence for the user and less support from teachers and other support workers.	https://us.tobiidynavox.com/products/sono-flex
TouchChat	TouchChat uses a visual vocabulary of symbols and pictures to represent words and concepts, and allows users to communicate by selecting and arranging the symbols in a way that forms a message.	https://touchchatapp.com/
LAMP	LAMP uses the Language Acquisition through Motor Planning methodology to grow vocabulary and communication skills.	https://lampwflapp.com/
LetMe Talk	LetMe Talk is a free AAC talker app that enables you to line up images and then read this row of images as a sentence.	https://www.iaccessibility.com/apps/speech/
LITTLEmack	A very basic device with a switch that speaks a recorded message when pressed. You can record a new message over the old; for example, a parent/carer can record a message for a child to take to school, and they can bring home a message recorded by a teacher.	https://www.ablenetinc.com/littlemack/

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