

United Nations Convention Rights of Disabled People

<https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/convention-on-the-rights-of-persons-with-disabilities-2.html>

Access to all forms of a communication is a precondition for equal enjoyment of all civil, political and economic, social and cultural rights, including but not limited to:

Freedom of expression and opinion. Equal rights. Living independently and being part of the community. Education. Health

United Nations Convention Rights of Children

https://downloads.unicef.org.uk/wp-content/uploads/2010/05/UNCRC_united_nations_convention_on_the_rights_of_the_child.pdf?_ga=2.48460898.51759018.1537632597-1303041821.1537454913

Article 23 (children with a disability)

A child with a disability has the right to live a full and decent life with dignity and, as far as possible, independence and to play an active part in the community. Governments must do all they can to support disabled children and their families.

All children have a right to life, survival and development. Freedom of expression, thoughts and beliefs, and their views should be heard. The best possible health and treatment of care, an education that develops their personality, talents and abilities to the full. Their best interests are a top priority in all decisions and actions relating to them.

Implication: Quote from Mum re social contract?

UK Policy

The policies of each home country draw on the UK legislation introduced in 2014 (the Family and Children's Act)

UK Government (2014) *The Family and Children's Act (2014)*
http://www.legislation.gov.uk/ukpga/2014/6/pdfs/ukpga_20140006_en.pdf

England Policy

Department of Education and Department of Health (2014) Special Educational Needs and Disability Code of Practice (2014)

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/398815/SEND_Code_of_Practice_January_2015.pdf

The Special Educational Needs and Disability Code of Practice (SEND CoP) provides statutory guidance, which means they **MUST**, to:

Local authorities; all types of school, academies and colleges, early years providers

the national health commissioning board, clinical commissioning groups, NHS Trusts, NHS Foundation Trusts, Local Health boards

Covers all children 0-25 years with special educational needs and disabilities.

Parents, children and young people must be consulted and participate in decisions made both at an individual and strategic level. **Their views, wishes and feelings MUST be heard**, they must be facilitated to participate. Having a proxy for a child or young person's view is not good enough.

Children and young people must be central to the assessment and planning processes, and have control over decisions about their support. This is a **person centred approach**.

Children from a young age should be enabled to make choices for themselves, to make friends and stay healthy, to achieve educationally and prepare them for adulthood.

Strong **focus on high aspirations and improving outcomes** for children and young people with greater numbers going onto higher education and employment, living independently and participating in society.

Provides guidance on joint planning and commissioning of services to ensure close co-operation between education, health and social care. This includes **joint commissioning specialist support and services such as speech and language therapy and assistive technology**. Where low incidence high cost specialist items are needed such as AAC then these are commissioned centrally by NHS England.

Local authorities should adopt a key working approach. The key worker might be from a statutory service, or the voluntary, community, private or independent sector.

The educational focus is on 7 key areas of learning:

communication and learning (CoP explicitly notes every child is different and needs change over time)

physical development

personal, social and emotional development

literacy

mathematics

understanding the world

expressive arts and design

At age 2 and 3 years the focus is on communication and learning, physical development and personal, social and emotional development.

The ability to communicate impacts on all 7 key areas of learning.

Both visual and hearing impairments and multi-sensory impairment require specialist support and equipment, as does physical disability. This is not specifically mentioned for speech, language and communication impairment.

Data Sets

HI and VI are recognised as part of the data sets for disability collected by schools, SLCN and particularly need for AAC is not.

Data-sets include but are not restricted to:

- use of out-of-area placements for those with low-incidence needs
- local data on disabled children from the register of disabled children in their area (including those with impaired hearing and vision) which local authorities are required to keep under Schedule 2 of the Children Act 1989. Local authorities should ensure that registers of disabled children and young people, and particularly details of those with a vision or hearing impairment, are kept accurate and up to date, as such low-incidence needs are particularly difficult to plan for from national data sets.

Specialist staff should be qualified whether the cause is HI, VI, Multi-sensory impairments or physical disability.

Specialist teachers and support service

Schools should work closely with the local authority and other providers to agree the range of local services and clear arrangements for making appropriate requests. This might include schools commissioning specialist services directly. Such specialist services include, but are not limited to:

specialist teachers or support services, including specialist teachers with a mandatory qualification for children with hearing and vision impairment, including multi-sensory impairment, and for those with a physical disability. (Those teaching classes of children with sensory impairment **must** hold an appropriate qualification approved by the Secretary of State. Teachers working in an advisory role to support such pupils should also hold the appropriate qualification.)

Implication:

There are teachers of HI, VI and PSS employed by education. For communication impairments reliance of health partnerships.

Gaining AAC qualifications to teach or work in a school is rare. Mainly SLTs who undertake post-graduate AAC studies as CPD.

If the child or young person is either vision or hearing impaired, or both, the educational advice and information **must** be given after consultation with a person who is qualified to teach pupils or students with these impairments.

Implications:

For a child who needs AAC there is no requirement to consult a specialist teacher (if one exists) about learning language and literacy through the medium of AT

Preparing for adulthood should start from the earliest stage, emphasis on year 9 (age 14) for formal planning. EHC plans must be maintained until fully transitioned into adult services and a new plan is in place. Everything done in school supports future independence and community life.

Scotland

March 2018 saw the commencement of the Health (Tobacco, Nicotine etc. and Care) (Scotland) Act 2016. This states the National Health Service (Scotland) has a Duty to provide or secure communication equipment and the support needed in using that equipment, to any person who has lost their voice or has difficulty speaking.

The 2018 Guidance on provision and use of equipment is clear, concise and explicit to avoid misunderstanding about types of AAC, that the aim is to allow all those with communication impairment to realise their communication potential with dignity and respect, compassion and being included in their assessments to ensure equipment is appropriate, efficient and safe for them. The stated outcome of provision is improving their daily lives and being part of their community. That the care and support they need is responsive with them being given the opportunity to develop the skills to use AAC and maximise their language and communication potential. This includes supporting their families, carers and friends to learn how to communicate with someone who needs AAC, set up and maintain systems and how to develop the communication skills of an AAC user. For the professionals the training is more comprehensive and should include:

- Strategies for communicating with people who use communication equipment.
- Preparing, adapting and updating communication equipment.
- Developing language and communication competence via the use of communication equipment.
- Identifying and creating opportunities for the person to use their equipment to communicate independently.
- Managing and maintaining the communication equipment.

People who need/use AAC and their extended network of support will be supplied with universal, targeted and specialist support to facilitate skill development. Universal support is awareness raising eg through a workforce, targeted support if for the workforce who are working directly with the person using AAC (multi-agency) and specialist support is from a local and specialist team who are interacting with the person using AAC eg speech and language therapy, teachers etc. This team should be qualified/competent assessed using IPAACKS.

Intervention and support may also take place within differing environments e.g. home, school/college, work, leisure, day care, hospital and any other community settings during everyday activities to allow the person to practice using the communication equipment functionally, in real life situations.

The Scottish Government (2018) *Guidance on the Provision of Communication Equipment and Support in using that Equipment - Our Vision, Principles and Definitions of Communication Equipment and Support*. Available at <https://www.gov.scot/Publications/2018/05/8091>

There is a clear National AAC Core Pathway which encompasses 6 steps: recognised need, assessment period, provision of equipment, support of user, family and professionals, review of progress, and finally going forward. This is by far the most comprehensive of the home countries approaches.

The Scottish Government (2018) *The National Augmentative and Alternative Communication (AAC) Core Pathway*. Available at <https://www.gov.scot/Publications/2018/08/7472>

The views of children, young people and parents must be heard and guidance is clear on this and how to achieve it.

Detailed statutory guidance on education supports assessment and provision of AAC, whilst not specifically named (that I can find) the introduction of the new 2018 legislation now underpins this. Cost should not be the primary consideration in determining what provision is to be made.

Children with a coordinated support plan should be provided by education with a co-ordinator (sounds like a keyworker).

The Scottish Government (2017) *Additional support for learning: statutory guidance 2017* Available at <https://beta.gov.scot/publications/supporting-childrens-learning-statutory-guidance-education-additional-support-learning-scotland/pages/8/>

Wales

The Additional Learning Needs and Education Tribunal (Wales) Bill was passed by the National Assembly for Wales on 12 December 2017 and became an Act on 24 January 2018 after receiving Royal Assent. This will be launched as a Code of Practice in 2019.

The existing AT guidance for teachers (2015) specifically mentions some children will need help with using augmentative and alternative means of communication and notes a wide range of support required for those with communication impairments may be needed.

Current demand for AAC outstrips funding and staffing, however, the Electronic Assistive Technology Service are working with the Wales Government to develop of robust business plan for the Service.

Welsh Assembly (2018) *Additional Learning Needs transformation programme*

<https://beta.gov.wales/sites/default/files/publications/2018-09/additional-learning-needs-aln-transformation-programme-v2.pdf>

Welsh government (2015) *Assistive technology guidance for teaching practitioners supporting learners with specific learning difficulty* <https://beta.gov.wales/assistive-technology-guidance-teaching-practitioners-support-learners-specific-learning>

Welsh Assembly Government (2004) *Special Educational Needs Code of Practice for Wales*

<https://beta.gov.wales/sites/default/files/publications/2018-03/special-educational-needs-code-of-practice-for-wales.pdf>

Northern Ireland

The current code of practice is now 20 years old, updated in an addendum in 2005. Recent legislation has been passed under the Special Educational Needs and Disability Act (Northern Ireland) 2016 which is due to be introduced in 2019. At the present time the emphasis is on schools working with parents.

Meanwhile following consultation the Public Health Board and the Health and Social Care Board announced on 1/8/18 immediate funding to reshape the current pathway for AAC services delivered within Health and Social Care Trust based services and more centralised procurement and provision. The new model should be introduced in April 2019.

Department for Education (2005) *Code of practice on the identification and assessment of special educational needs*
<https://www.education-ni.gov.uk/publications/code-practice-identification-and-assessment-special-educational-needs>

Department for Education (2016) *Special Educational Needs and Disability Act (Northern Ireland) 2016 (SEND Act)*
<https://www.education-ni.gov.uk/articles/review-special-educational-needs-and-inclusion>

Other care pathways

Hearing impairment

Around 50,000 children and young people aged 0-25 years in the UK have a hearing impairment.

By the age of 16 then 0.2% of the population might have cochlear implants. Cost of a single implant £14,660 (often 2 provided). Diagnosis, care and rehabilitation support is through a multi-disciplinary team and includes ongoing the following resources:

- On-going sound processor programming and assessment dependent on individual need
- After the first year following implant surgery, the patient will be offered regular audiological review, typically annually. Flexibility for additional appointments will be available if required to adequately meet the needs of the patient
- Recognised & validated developmental age appropriate audiological and speech perception measures will be performed on at least two occasions in the first year.
- Sound awareness training in adults and development of listening skills in children.
- Communication skills training in adults and development in children.
- Listening and language skills development training and / or support on an individual patient needs basis.
- Training provided at the centre and as outreach where appropriate. Advice to patient (and carers if appropriate) on care and use of the implant
- Advice to other organisations e.g. trouble shooting advice for local staff (for children)
- On-going support and maintenance – including a comprehensive spares and repairs service.
- Medical – access to the implant medical / surgical team as required
- Upgrade or provision of new sound processors on average at 5 yearly intervals, where available, in order to ensure patient access to up to date technology to maximise their hearing performance and subsequently outcome from the intervention.

<https://eput.nhs.uk/wp-content/uploads/2017/01/Care-pathway-for-HI.pdf>