

# Specialised Services Commissioning Policy: CP93

National Alternative and Augmentative Communication (AAC) Specialised Aids

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# **Policy Statement**

Welsh Health Specialised Services Committee (WHSSC) commissions the provision of Complex high tech Alternative Communication (AAC) National Specialised Augmentative for all ages in accordance with the criteria outlined in this document.

In creating this document WHSSC has reviewed the situation for those with a significant speech impairment and the options for its treatment. It has considered the place of Specialised Augmentative and Alternative Communication (AAC) aids in current clinical practice, whether scientific research has shown the treatment to be of benefit to patients, (including how any benefit is balanced against possible risks) and whether its use represents the best use of NHS resources.

#### **Disclaimer**

WHSSC assumes that healthcare professionals will use their clinical judgment, knowledge and expertise when deciding whether it is appropriate to apply this policy.

This policy may not be clinically appropriate for use in all situations and does not override the responsibility of healthcare professionals to make decisions appropriate to the circumstances of the individual patient, in consultation with the patient and/or their carer or guardian.

WHSSC disclaims any responsibility for damages arising out of the use or non-use of this policy.

#### 1. Introduction

This policy has been developed for the planning and delivery of Specialised Augmentative and Alternative Communication (AAC) aids for people of all ages resident in Wales. This service will only be commissioned by the Welsh Specialised Services Committee (WHSSC) and applies to residents of all seven Health Boards in Wales or otherwise the commissioning responsibility of the NHS in Wales.

#### 1.1 Background

Augmentative and Alternative Communication (AAC) covers a wide range of methods and techniques that support or replace spoken communication.

This policy relates to specialised pieces of electronic equipment that require specialist staff to set up and ensure that it continues to meet the needs of the individual.

Those using AAC aids may include people with a disability that has been present from birth (such as cerebral palsy, learning disability or autism), a progressive condition (such as Motor Neurone Disease) or a sudden acquired disability (through a Stroke or brain damage following an injury).

# 1.2 Plain Language Summary

Communication impairment may result from physical, sensory, intellectual, learning or cognitive disabilities. A complex high tech communication aid is a specialist piece of programmable equipment that helps an individual communicate more effectively with those around them.

Complex high tech specialise Augmentative and Alternative Communication (AAC) aids help people communicate as effectively as possible when their speech is impaired. AAC techniques use a person's abilities, to compensate for their difficulties with speech and to make communication as quick, simple and effective as possible when speech is impaired. Specialised techniques include systems powered and computerised devices such as voice output communication aids (VOCAs - High tech systems.).

The provision of Complex high tech AAC aids service is one element of the National Electronic Assistive Technologies (EAT) service based in Cardiff, which provides equipment such as controls that can be activated by direct touch, voice or eye gaze to undertake tasks such as turning on the television or opening a door.

#### 1.3 Aims and Objectives

This policy aims to define the commissioning position of WHSSC on the use of specialised high tech AAC aids for people with communication impairment. The policy describes how the commissioning of specialised AAC

aids is organised with the aim of improving access to these services for all patients both children and adults.

The objectives of this policy are to:

- define the criteria for people with communication impairment to access specialised Augmentative and Alternative Communication (AAC) aids
- improve outcomes for people with communication impairment
- ensure commissioning for the use of Specialised Augmentative and Alternative Communication (AAC) aids is evidence based
- Ensure equitable access to the national AAC service which operates as part of the Electronic Assistive Technology Service.

#### 1.4 Epidemiology

The population includes both those born with a communication impairment (for example and in no order of precedence, those resulting from cerebral palsy, developmental disorders and learning disabilities such as autism) and those who acquire a communication impairment (for example through stroke, cancer, brain and spinal injury and neurological diseases such as Parkinson's, Multiple Sclerosis or Motor Neurone Disease).

From existing models of service in the UK it is anticipated that approximately 300 adults and 90 children would be referred to the dedicated AAC Service each year for specialised high tech AAC aids to address their communication needs. However, due to variance in the surveys conducted, the range is likely to be 200 to 400 adult referrals and 50 to 130 children.

#### 1.5 Current Treatment

This commissioning policy covers adults and children requiring specialised high tech AAC aids.

The specialist hub services based in Wrexham in North Wales and Cardiff in South Wales undertake assessments, trials, and facilitate provision of specialist AAC aids to service users throughout Wales.

Complex high tech AAC aids are one element of the National Electronic Assistive Technology Service based in Rookwood Hospital, Cardiff. The service also provides devices and support for environmental control, access to computers and functional electrical stimulation. The service's assessments and provision of assistive technology covers the individual's needs for both communication and environmental control, recommendations for access to an integrated way to provide the most effective support to individuals and avoid duplication.

The national service also provides training to the local Health Board services and to carers and professionals associated with the service user's care. AAC and Environmental control equipment is provided on loan by the Service and is maintained by the staff either directly or under warranty arrangements.

#### 1.6 What NHS Wales has decided

WHSSC has carefully reviewed the evidence of the provision of Specialised AAC aids for communication impairment. We have concluded that there is enough evidence to fund the use of the provision of Complex high tech AAC aids for communication impairment within the criteria set out in section 2.1.

#### 1.7 Relationship with other documents

This document should be read in conjunction with the following documents:

#### NHS Wales

 All Wales Policy: <u>Making Decisions in Individual Patient Funding</u> <u>requests</u> (IPFR).

# National Institute of Health and Care Excellence (NICE) guidance

 Motor Neurone Disease: assessment and management, NICE guidance [NG42], February 2016

## Relevant NHS England policies

- Guidance for commissioning AAC services and equipment, NHS England, March 2016
- Complex Disability Equipment <u>Communication Aids</u> (Specialised AAC services), D01/S/b, January 2016

#### Other published documents

- Communications Matters, <u>Augmentative and Alternative</u> <u>Communication Services</u>, Quality Standard for Commissioners, September 2011.
- o Mental Health Act (1983): Mental Health Act 1983

# 2. Criteria for Commissioning

The Welsh Health Specialised Services Committee approve funding of specialised high tech Augmentative and Alternative Communication (AAC) aids for people of all ages with a communication impairment in-line with the criteria identified in the policy.

#### 2.1 Inclusion Criteria

- The individual has a complex communication difficulty associated with a range of physical, cognitive, learning, or sensory deficits.
- An individual should be able to understand the purpose of an AAC aid.
- An individual should have developed beyond cause and effect understanding.
- The request for assistance should originate from a registered health or social care professional, using the single point referral form (see Annex i).
- The individual requires a high-tech communication aid.
- The individual requires a Specialist/high-tech communication aid that includes some or all of the following features:
  - o use language packages within AAC software
  - o allow for an extensive range of communication functions
  - use synthesised speech
  - use multiple pages of vocabulary which cannot be replicated in other ways
  - based on a computer platform
  - o require alternative access methods e.g. using switches.

#### 2.2 Exclusion Criteria

The following exclusion criteria apply:

- Individuals have not achieved cause and effect understanding.
- Individuals have impaired cognitive abilities that would prevent retention of information on how to use a Complex high tech AAC aid.

#### 2.3 Continuation of Treatment

If a child's needs are being met or do not require active intervention the setting that they attend and their family may discharge. However, they could be re-referred at anytime if access to specialist help is required.

The individual must continue to be under the active care of the local Speech and Language Therapy Service (SLT), throughout the period of assessment and provision.

Healthcare professionals are expected to review a patient's health at regular intervals to ensure they are demonstrating an improvement in their health and/or wellbeing due to treatment being given.

The local SLT service should discharge a patient if they do not need active intervention once an aid has been provided. However, the patient can be re-referred at any time if further intervention is required.

The local trained and competent SLT team will assess and make appropriate judgement on the piece of equipment needed by the individual and refer as appropriate.

If no improvement to a patient's health or wellbeing has been recorded then clinical judgement on the continuation of treatment must be made by the treating healthcare professional.

#### 2.4 Acceptance Criteria

The service outlined in this specification is for patients ordinarily resident in Wales, or otherwise the commissioning responsibility of the NHS in Wales. This excludes patients who whilst resident in Wales, are registered with a GP practice in England, but includes patients resident in England who are registered with a GP Practice in Wales.

#### 2.5 Patient Pathway

A Healthier Wales: Pathway for the Provision of Communication Equipment and Support in using that Equipment has been produced. This is the pathway for the complex high tech service only, and different to the overall pathway in separate document. A copy of the pathway has been included in annex i.

Further information on the patient pathway can be found on the Cardiff and Vale University Health Board website: <u>Cardiff & Vale University Health</u> Board - CVUHB | The AAC Hub

#### 2.5.1 Request for Assistance form

Referrals requesting assistance are made using the referral form on the Cardiff and Vale University Health Board website. The electronic link to the referral form can be found here:

<u>Cardiff & Vale University Health Board - CVUHB | Referral for Specialist AAC Services</u>

The referral form is an integrated form for the EAT service with a specific section to be completed for referral to the AAC service

Professionals who identify children with complex special needs that would benefit from AAC can complete a referral to local SLT. Increased demand/training requirements placed upon professionals will need to be monitored.

Referrals, on completion of the referral form will be accepted from Health Care Professionals Council registered health professionals.

If additional information on the referral is required from other health, education or social care agencies or the individual's General Practitioner (GP) then further information may be sought.

All referrals will be acknowledged within 10 days of receipt by the service. However, if there is insufficient referral information, this could result in a delay with the referral acceptance and assessment process.

The service will assess all patients fulfilling the acceptance criteria, typically within 6 weeks from the date of acceptance of the referral.

If an inappropriate referral is identified at the time of referral is made, the referral is rejected back to the referrer/local health board with possible recommendations for therapy or low tech AAC.

#### 2.5.2 Assessment for AAC Aids

Individuals referred to the EAT service will be assessed in the most appropriate location (for example their home, place of work, residence, hospital or school).

The assessment will be performed by competent, experienced personnel and in collaboration with other services where necessary.

Ideally the referrer should be present at the initial assessment. If the patient is deemed unsuitable for AAC at the initial assessment, the patient will be discharged from EAT and reviewed by the local service, with a view to implementing recommendations for therapy or low tech AAC.

A complex high tech AAC aid shall only be provided after the assessment of an individual. The assessment recommendations shall be confirmed in writing to the patient, the referrer, the patients GP and other stakeholders as appropriate.

#### 2.5.3 Trial of AAC Aids

A trial of suitable complex high tech AAC aids should be offered to all individuals where an aid is recommended.

A circular trial and review process will be undertaken until the appropriate AAC system can be ascertained. Where appropriate, the last device (successful) system trialled with the patient will remain with the patient as the 'issued' device. This ensures continuity of use and reduced waiting times for provision.

If there is doubt over the patient's motivation or ability to use the equipment then an individual should also be offered a trial of the equipment. The outcome of the trial, either to continue with or to cease provision shall be based on suitable outcome measurement.

#### 2.5.4 Provision of Complex high tech AAC Aid

Provision of a complex high tech aid shall normally be available for use by the patient within 4 weeks of the assessment. Exceptions to this target may occur due to dependencies on other agencies or when the recommended solution involves custom, bespoke or integrated equipment.

Training will be provided to all patients and their support network in the use of the equipment provided. Any necessary information will be given in an appropriate format to patients and their guardian/carers. Additional tuition shall be available as required, taking into consideration the possible cognitive impairment of some users.

Following assessment, children may need time to familiarise themselves with new trial equipment and are often unable to demonstrate a benefit in less than two weeks. If multiple trials are needed a longer time scale is appropriate.

#### 2.5.5 Maintenance of Complex high tech AAC Aids

In response to reported malfunctions of the aids, the service shall ensure that the user is kept up to date of progress and remedial action for critical functions taken within a clinically appropriate time.

Each user of equipment will receive ongoing support in the case of its malfunction. The user will also receive an annual service maintenance visit including statutory testing of equipment and timely review of equipment appropriateness for them.

## 2.5.6 Review of Complex high tech AAC Aids requirement

The frequency of user and equipment review shall be determined on a case by case basis by service personnel with the ability to respond appropriately to changes in clinical conditions (e.g. people with rapidly progressing neurological conditions).

Adjustments, modifications or change of the aid provision shall be provided when indicated following review due to change in patient clinical condition,

functional impairment or circumstances. A full re-assessment of their needs shall also be undertaken when appropriate.

The AAC system issue on loan to the patient will be maintained within the EAT Equipment Management System, using an annual planned preventative maintenance (ppm) schedule. Additionally, where appropriate, individual devices will be maintained under an extended manufacturer's warranty.

#### 2.5.7 Returned Complex high tech AAC Aids

Equipment no longer required by users due to change in their circumstances, shall be reclaimed, decontaminated and refurbished to standards agreed with manufacturers prior to becoming available for reissue.

#### 2.5.8 Re-conditioning of Complex high tech AAC Aids

In addition, the service will undertake (or arrange through subcontractors):

- Re-conditioning of equipment ready for re-use.
- Technical evaluation and management of equipment to ensure it is fit for purpose.
- Development of custom or bespoke or integrated equipment solutions for individual patient's EAT needs when these are identified.

#### 2.6 Designated Centre

The centres for complex high tech Alternative and Augmentative Communication (AAC) specialised aids are:

#### South, Mid and West Wales (Hub)

National Centre for Electronic Assistive Technology 18 Fairwater Rd, Cardiff CF5 2YN

#### North Wales

Artificial Limb and Appliance Centre (ALAC) - (Satellite of Hub) Wrexham Maelor Hospital Croesnewydd Road Wrexham LL13 7TD

#### 2.7 Exceptions

If the patient does not meet the criteria for treatment as outlined in this policy, an Individual Patient Funding Request (IPFR) can be submitted for

consideration in line with the All Wales Policy: Making Decisions on Individual Patient Funding Requests. The request will then be considered by the All Wales IPFR Panel.

If the patient wishes to be referred to a provider outside of the agreed pathway, and IPFR should be submitted.

Further information on making IPFR requests can be found at: Welsh Health Specialised Services Committee (WHSSC) | Individual Patient Funding Requests

# 2.8 Stopping Criteria

If after a suitable trial period there is any doubt over an individual's motivation or ability to use the AAC provided or an alternative aid, for example, due to disease progression, then provision of an AAC aid will cease.

# 2.9 Clinical Outcome and Quality Measures for National Centre's providing Complex high tech AAC

Providers must work to written quality standards and provide monitoring information to the lead commissioner across the age range including children, young people and adults.

Outcome measures such as Psycho-social Impact of Assistive Devices (PIADS) and ACC specific goal setting measures. The Psychosocial Impact of Assistive Devices Scales (PIADS) is a 26-item, self-report questionnaire designed to assess the effects of an assistive device on functional independence, well-being, and quality of life.

Further guidance on the use of outcome measures for AAC services has been issued in the Communication Matters, Augmentative and Alternative Communication Services, Quality Standards for Commissioners Guidance.<sup>1</sup>. Capacity, consent and best interest decisions should also be included.

Specialised AAC services should have mechanisms in place to capture and report the following data on a monthly basis to WHSSC:

- Total number of referrals acknowledged:
  - within 10 days
  - outside of this indicator with reasons why the deadline was not met
- number of referrals to the Specialised service broken down by Health Board

 $<sup>{}^{1}</sup>https://www.communication matters.org.uk/sites/default/files/downloads/standards/aac\ quality\ s\ tandard\ for\ commissioners\ sept\ 2011.pdf$ 

- current waiting times should be reported to that Head of SLT service in each HB on quarterly basis
- number of referrals to the Specialised service, organised by disease category i.e. Motor Neurone Disease
- number of referrals to the Specialised service, organised by Adult and Paediatrics including waiting times for initial assessment, provision of equipment from time of assessment to delivery number of AAC aids issued
- number of AAC aids abandoned i.e. not utilised and the reasons why, which could include deterioration of disease.

The centre should enable the patient's, guardian/carer's and advocate's informed participation and to be able to demonstrate this. Provision should be made for patients with communication difficulties and for children, teenagers, young adults and vulnerable adults.

#### 2.9.1 Annual Symposium

An annual symposium will be held for the clinical community to share experience, develop skills and share learning and innovative developments. Where possible experienced staff from both low tech and high tech provision will share training and development opportunities.

#### 2.10 Training and Development

The National Electronic Assistive Technology Service (EAT) must work with local service providers to support provision of local low tech services, develop staff skills and capability and strong working partnerships. The outcome and experience measures detailed in section 2.9 will be a further measure of the quality of staff development and relationships.

## 2.11 Responsibilities

Referrers should:

- inform the patient that this treatment is not routinely funded outside the criteria in this policy, and
- refer via the agreed pathway.

Clinician considering treatment should:

- discuss all the alternative treatment with the patient;
- advise the patient of any side effects and risks of the potential treatment
- inform the patient that treatment is not routinely funded outside of the criteria in the policy, and
- confirm that there is contractual agreement with WHSSC for the treatment.

In all other circumstances an IPFR must be submitted.

#### 3. Evidence

WHSSC is committed to regularly reviewing and updating all of its commissioning policies based upon the best available evidence of both clinical and cost effectiveness.

#### 3.1 Date of Review

This document is scheduled for review before May 2022, where we will check if any new evidence is available. If no new evidence or intervention is available the review date will be progressed.

If an update is carried out the policy will remain extant until the revised policy is published.

# 4. Equality Impact and Assessment

The Equality Impact Assessment (EQIA) process has been developed to help promote fair and equal treatment in the delivery of health services. It aims to enable Welsh Health Specialised Services Committee to identify and eliminate detrimental treatment caused by the adverse impact of health service policies upon groups and individuals for reasons of race, gender reassignment, disability, sex, sexual orientation, age, religion and belief, marriage and civil partnership, pregnancy and maternity and language (Welsh).

This policy has been subjected to an Equality Impact Assessment.

The Assessment demonstrates the policy is robust and there is no potential for discrimination or adverse impact. All opportunities to promote equality have been taken.

# 5. Putting Things Right: Raising a Concern

#### 5.1 Raising a Concern

Whilst every effort has been made to ensure that decisions made under this policy are robust and appropriate for the patient group, it is acknowledged that there may be occasions when the patient or their representative are not happy with decisions made or the treatment provided.

The patient or their representative should be guided by the clinician, or the member of NHS staff with whom the concern is raised, to the appropriate arrangements for management of their concern.

If a patient or their representative is unhappy with the care provided during the treatment or the clinical decision to withdraw treatment provided under this policy, the patient and/or their representative should be guided to the LHB for <a href="NHS Putting Things Right">NHS Putting Things Right</a>. For services provided outside NHS Wales the patient or their representative should be guided to the <a href="NHS Trust Concerns Procedure">NHS Trust Concerns Procedure</a>, with a copy of the concern being sent to WHSSC.

# 5.2 Individual Patient Funding Request (IPFR)

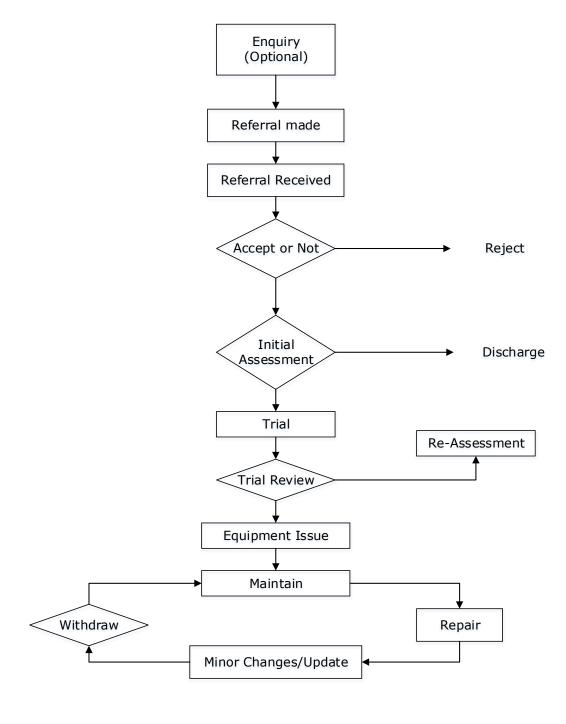
If the patient does not meet the criteria for treatment as outlined in this policy, an Individual Patient Funding Request (IPFR) can be submitted for consideration in line with the All Wales Policy: Making Decisions on Individual Patient Funding Requests. The request will then be considered by the All Wales IPFR Panel.

If an IPFR is declined by the Panel, a patient and/or their NHS clinician has the right to request information about how the decision was reached. If the patient and their NHS clinician feel the process has not been followed in accordance with this policy, arrangements can be made for an independent review of the process to be undertaken by the patient's Local Health Board. The ground for the review, which are detailed in the All Wales Policy: Making Decisions on Individual Patient Funding Requests (IPFR), must be clearly stated

If the patient wishes to be referred to a provider outside of the agreed pathway, and IPFR should be submitted.

Further information on making IPFR requests can be found at: Welsh Health Specialised Services Committee (WHSSC) | Individual Patient Funding Requests

# **Annex i Patient Pathway**



#### Annex ii Checklist

# Interim Specialised Services Policy: National Specialised Alternative and Augmentative Communication Aids (AAC)

The following checklist should be completed for every patient to whom the policy applies:

- Where the patient meet the criteria and the procedure is included in the contract and the referral is received by an agreed centre, the form should be completed and retained by the receiving centre for audit purposes.
- The patient meets the criteria **and** is received at an agreed centre, but the procedure is not included in the contract. The checklist must be completed and submitted to WHSSC for prior approval to treatment.
- The patient meets the criteria but wishes to be referred to a non contracted provider. An Individual Patient Funding Request (IPFR) Form must be completed and submitted to WHSSC for consideration.
- If the patient does not meet the criteria for treatment as outlined in this
  policy, an Individual Patient Funding Request (IPFR) can be submitted
  for consideration in line with the All Wales Policy: Making Decisions on
  Individual Patient Funding Requests. The request will then be considered
  by the All Wales IPFR Panel.