

The attached draft funding proposal was written by Phillipa Cozens from North Bristol NHS Trust. Phillipa is very happy for anyone to use this as a draft to highlight the need for funding in AAC. Obviously some details would have to be changed when using it in different areas.

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Proposal for the Funding of Communication aids for People in Bristol, North Somerset, and South Glos.

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All the examples have been written with the full consent of those involved.

Background

Communication aids can be defined as either low tech or high tech devices or systems that enable someone to communicate their wishes or needs should their speech be impaired. This may be due to impairment from birth, acquired brain injury, neurological diseases (some of them with a rapidly deteriorating progression) or post surgery in head and neck cancer.

They are increasingly being acknowledged as essential aids that enable a person to be more fully involved in decisions about their health and general welfare. The **Mental Capacity Act (2005)** stresses the need for alternative forms of communication to be used, to establish capacity for consent and for a person to assert their wishes. Furthermore, valuable clinical time can be saved with more effective communication, and potential complaints can be avoided. In addition, inability to communicate is rated as a highly significant factor in a person's quality of life, with a strong link with depression.

The Government's 'Integrating Community Equipment Services' document (2001) states:

“ Communication aids for people with speech impairments have been an underdeveloped area in the current provision of equipment services...the Governments intention is that some of the additional funding for equipment services *should be directed to improving provision of communication aids*”

In addition, the need for provision of communication aids or equipment is specifically highlighted in **Quality Requirement 7 in the NSF for Long-term Conditions (2005)**.

The Prime Ministers Strategy Unit Report ‘Improving the Life Chances of Disabled People’ (2005) also reinforces the importance of equipment as it “ increases independence, reduces the need for personal assistance and prevents or reduces health problems”.

Most recently, the UK government has signed up to the new **UN Convention on the Rights of Persons with Disabilities (2007)**, and Augmentative and Alternative communication is specifically mentioned in Article 21 – Freedom of Expression and opinion, and access to information.

Speech and Language Therapists have the training and expertise necessary to provide reliable and cost-effective support to people who may benefit from communication systems as a whole and to advise on suitable strategies and equipment. The kinds of aids that might be required include:

Low technology

- Pen and Paper! (if the person can use a pen and has vision)
- Alphabet charts and systems (This enables the ‘speaker’ to spell out their own words letter by letter, but does require literacy skills) Approx cost 50p-£100
- Individualised communication charts or books (Very useful for everyday care needs but will only give an extremely limited type of communication)
- Amplifiers (Devices that can be worn on the body or incorporated into a telephone to make the speakers voice louder) Approx. cost £85-£500
- Artificial larynges that replace some of the ‘sound’ of someone’s voice

D. had Motor Neurone Disease. His wife rated an ‘E-Tran frame’ (alphabet system, cost £100, originally funded by the local MND

Association branch) as being the single most effective and useful piece of equipment in the last few months of his life. She says, “It enabled him to make end of life choices, and for us to have a real relationship right to the end”

High technology

- Text to speech aids such as a Lightwriter, where the speaker types in a phrase and a synthesized voice says it aloud. (Approx cost £2,300 - £2,600)
- Digital speech recording devices, where the person presses or selects appropriate pre-recorded phrases. (Approx cost £200-£400)
- Personal Computer based aids that have either text or pictures available for selection by the speaker. (Approx cost £2500 +).
- Input devices that enable a speaker to access their aid, if they are unable to use their hands to type. This may be a very simple ‘switch’ or a more sophisticated eye-gaze system for people with no other movement. (Approx cost £20 - £12,000)

The majority of aids are robust, straightforward to maintain and highly re-usable, and can sometimes only be required for a matter of months.

Current provision of aids

Nationally there has always been paucity and inequality of provision of communication equipment. This may be due in part to aids not being viewed as ‘essential’ equipment in the sense that mobility aids, specialist beds and chairs and bathing equipment are. It may also be due to the fact that people with communication difficulties are literally unable to make their voices heard. Those without adequate means to communicate may of course end up with inappropriate and more costly interventions.

A survey of 300 communication aid users in 2000 for SCOPE (‘Speak for yourself’) found that 47% of aids were NOT paid for by a statutory organisation.

In Bristol, South Gloucestershire and North Somerset, funding of aids and equipment for adults is attempted by the following means:

- Funding by local Speech and Language Therapy departments in acute trusts, who have had small specific budgets for this purpose. However, the budget for Weston Area Health Trust was never ring fenced, and is now gone, United Bristol Healthcare Trusts budget has

been severely cut, and the budgets in North Bristol Trust are under threat. It is literally a postcode lottery as to whether or not funding can be found this way, even within some PCTs, as the acute trust boundaries are not coterminous with PCT boundaries. Furthermore, some budgets would be too small to fund even one high tech device.

- Loans from Speech and Language Therapy departments and DART. This works well for some short-term provision of common aids, but when all aids are in use, there may be no immediate means of providing more, i.e. the supply does not meet the demand. This is particularly pertinent for people with rapidly deteriorating conditions who may need equipment very quickly. DART equipment was purchased with 'start up' money, so when equipment eventually needs repairing, replacing or adding to, there are no funds identified to do this. This also does not meet the needs of people who may require equipment that is not in the store.
- Utilisation of a Disabled Students Equipment Grant. This can only be accessed by someone in full time higher education, and is usually quite a limited amount.
- Loans from charities such as the Motor Neurone Disease Association (MNDA). The MNDA aims to provide a timely loan service of Lightwriters for people with MND. However, the charity has decided that they can no longer purchase new aids, and requests have to demonstrate that no other source is available. They emphasize that the loan is short term only. Of course, this loan service does not cover people with other neurological conditions.
- Funding by grants and other charities. This is occasionally possible, but applications are extremely time-consuming, and wastes clinical resources. Funding is usually means tested, which may exclude those with a moderate income. Furthermore, fundraising organisations such as the 'Aidis Trust' state that they will no longer provide assistance for fundraising for communication aids, as their expectation is that funding is the responsibility of statutory services, as set out by the Government in the 2001 ICES document.
- Funding by Individuals. This may be possible for some relatively cheap pieces of equipment for some people, but may not be possible even then, as the need may come at a time when income has dramatically reduced. There is inequity for those people who cannot afford to pay for themselves.

M. has a neurological condition that affects the volume and clarity of her speech. She used an amplifier on loan from DART, and found it immensely helpful in reducing the effort required for speech. It enabled her to continue to work as admin support for her self-employed husband, but she found that particular model too heavy

to wear all day. After an assessment at the Communication Aid Centre, she chose a more expensive but lightweight amplifier costing £500, which she had to purchase herself, there being no funding available in the area in which she lives.

Not all attempts at getting equipment are successful, and those individuals are then left without adequate means of expressing themselves. Many children who have aids funded via education face a lack of equipment as adults when their equipment needs replacing or updating.

This demonstrates the currently piecemeal and fragmented routes followed to obtain equipment. This is inefficient and time-consuming, and local sources of supply are not currently pooled or coordinated to achieve maximum usage.

There is a real possibility that ICES services will be legally challenged in the future, if equipment is refused on the grounds that this type of equipment has never been funded before. There are now several key government documents that will provide evidence for judicial proceedings. At least one communication aid manufacturer has offered funding for legal assistance to mount such challenges.

Long term Proposal

In 2003 Eileen Grist (then the Communication Aid Centre Manager at Frenchay Hospital) produced a document, which set out that all current providers in the Pan-Avon area should ideally be served by a centralised communication aid equipment store, linked to ICES services. The plan was for existing budgets and communication aid equipment stores to be pooled together, with additional funding from all the local ICES services to enable a truly equitable service to develop across the region. This would also allow for maximum efficiency in using, maintaining and tracking equipment. At the time, only South Glos. PCT could offer additional financial resources, and so the idea was not viable. However, this would still be the best long-term solution, and there is still commitment from local Speech and Language Therapy services to make this happen.

A national taskforce organisation called FAST (Foundation for the Advancement of Assistive Technology) comprises of user groups, clinicians and suppliers. Their aim is to raise awareness of communication aid issues, improve standards and design and more recently to develop a business plan for the government to secure on

going funding for communication aids, training and support for adults and children.

K. has MS and has only limited head movement, which she uses to operate an environmental control system, via a switch. She could operate her existing laptop or desktop computer using a switch adaptor (cost £50) and some software (approx £300). This would enable her to communicate effectively via email and use the Internet, and allow her to write her own letters. She declined a place at a day centre once a week, with transport. She feels that her social needs would be well catered for via her computer, and says, “If they are prepared to fund the day centre, why can’t they fund the software? I feel very strongly that this should be provided by statutory authorities”

Medium Term Proposal

If a person needs some equipment, existing resources would be considered first, i.e. local Speech and Language Therapy equipment budgets, loan stores and Disabled Students Grants.

If there is nothing suitable in store, the person is ineligible due to where they live, or the limit of the budgets are reached, I propose that the ICES service for that area consider buying equipment on an individual basis (as a ‘special’), building up the core of equipment available as the equipment is returned. In the medium term, Speech and Language Therapy departments or DART would be well placed to manage and maintain equipment if needs be.

In actual fact, several neighbouring ICES organisations (Swindon, Wiltshire, Somerset) have *already begun* to fund communication aids for individuals in this way, and this is apparently working well.

However, this medium term solution does not address the issue of maximising use of all services and stores, nor does it enable savings through economies of scale.

How much will this cost?

It is difficult to be exact about predicted costs, but to illustrate, the DART store of most regularly used equipment across Bristol, South Glos. and North Somerset from 1999-2006 is

2 Eagle Amplifiers	£170
2 Echo voice Amplifiers	£360

2 E-tran frames	£200
2 Amplifying phones	£100
3 SL35 Lightwriters	£6,900
1 SL86 Scanning Lightwriter	£2,600
1 Lightwriter Printer	£290
2 USB Switch Adaptors	£100
Variety of Switches	£400
Total	£11,120

Of course, DART was commissioned to work with people aged 16-65, with primarily physical impairments, so this does not include children, those over 65 or those with learning difficulties. Some DART clients are seen by acute trust Speech and Language Therapy departments, for which I do not have current figures. However, these DART equipment items have been utilised several times from 1999-2006.

Equipment	Bristol Clients using item	South Glos	N Somerset
Alphabet Charts/Books	19	11	10
Eagle amplifiers	3	2	3
Echo voice amplifiers	3	2	2
E tran Frames	2	2	2
Amplifying phones	2	-	-
SL35 Lightwriters	5	-	1
SL86 Scanning Lightwriter	2	2	2
Printer	1	-	1
USB Switch Adaptors	2	1	-
Total Numbers	39	20	21

Thus £11,000 worth of equipment has helped 80 people over a 7-year period. Many items are currently on loan (including 3 SL35 lightwriters in the Bristol area), and are all in good working order, ready to be used again. We have spent approx £250 over 7 years on repairs and battery replacement.

In the same period, 6 DART clients have been supported with lightwriters loaned from the MNDA, 3 of which are currently in situ by special agreement, and 3 clients in Bristol and North Somerset have purchased their own amplifying equipment. 2 items of equipment have been funded via charities in the Bristol area, but there have been times when equipment has not been provided and the demand could not be met.

Summary

- Communication aids are essential items of equipment, enabling better participation and choice for disabled people,
- The Government always intended that ICES money be used to purchase them, and several key Government documents highlight the need for effective and alternative communication
- There are some local Speech and Language Therapy budgets available, but there is massive inequity across areas, particularly Bristol, and Avon services do not currently link together efficiently.
- Ideally, there should be a pooled central store across local PCT areas, with secured statutory funding.
- In the medium term, ICES services could purchase special items for individuals, which can potentially build up into a useful store, as is already happening in neighbouring PCTs.

The serious consequences of the current situation are that

- some individuals are not accessing the equipment they need, or are not getting them on time
- the range of potential risks arising from inadequate communication includes issues around consent, making choices and concordance with treatment, an increased dependence on care, and waste of clinical time and resources
- there are likely to be legal challenges to the current inequity

References

1. Speak for yourself (2000) SCOPE
2. Integrating Community Equipment Stores, (2001) Department of Health
3. Proposal from the Communication Aid Services to people with Severe Speech Impairments in the Pan Avon Area (2003) Frenchay Communication Aid Centre
4. National Service Framework for Long-term conditions (2005) Department of Health
5. Improving the Life Chances of Disabled People (2005) Department of Health
6. Mental Capacity Act (2005)
7. UN Convention on the Rights of persons with Disabilities (2007) UN