Health (Tobacco, Nicotine etc. and Care) (Scotland) Bill

Stage 2 Amendment on the provision of voice equipment: Call for Views

T Campbell

I am writing in response to your call for views for the above amendment.

My own interest in AAC has come about as I have a child with Angelman Syndrome. One of the main features of the syndrome is a lack of verbal communication. We have dappled with many forms of AAC before settling on the PODD communication system. These include basic noun based communication books, PECS, Makaton. All of these systems have proven to me that a full and robust language system is necessary for proper language development.

I am extremely lucky that the Angelman community is very active in the teaching of AAC and through social media I have access to some of the top experts in the world. I am extremely committed to learning best practice for AAC and as such spend many hours researching the subject. I have also attended training courses and the Communication Matters conference in Leeds.

This experience has led me to be a spokesperson both for the children and parents at my daughter’s school and, in my new role as Communication Consultant for the UK Angelman Syndrome group ASSERT.

I am very much in favour of the Amendment as the ability to communicate is essential to fully participate in life. I cannot express what it means to me each time my daughter is able to share with us her thoughts. Before the intervention of AAC, communication was difficult and frustrating for my daughter and she has progressed significantly since a proper system was introduced it into her life and we got access to training and support for it. (Her very first PODD book was carried back and forward to school and was only used in specific Speech and Language lessons. No one had any training and therefore could not use it with her, needless to say it was a full year of very little progress.)

I think that the right to support of the communication aid is absolutely crucial. We have come a long way on our communication journey but we still have a long way to go. We have not made this progress through support of our local services as there is nothing available currently. In fact, I am in the process of setting up my own communication group for the children of my daughter’s school. The aim of this group is to teach the families how to best support their children at whatever level they may be at.

Whilst the general principal of the amendment is to be applauded there are a few comments which do raise some concerns.

Communication equipment can take the form of pictures, gestures, symbols or photographs as well as high tech support including voice output communication aids.
These are all valid forms of communication and in fact it is extremely important to use lots of different tools to aid communication but, it is simply not good enough to say that pictures or gestures on their own would cover the needs of individuals who cannot communicate through spoken word. The goal for anyone trying to teach AAC should be that the individual is able to communicate autonomously.

This means all individuals should be able to say what they want to say, when they want to say it and to whom they want to say it. The only way that this can happen is to give individuals access to a robust language system.

The language system itself can be high or low tech but must include core vocabulary such as prepositions, verbs, adjectives, adverbs, pronouns, exclamations, conjunctions and determiners as well as the more traditional nouns. Traditional speech and language therapy has focussed very much on nouns but if an individual is always going to have a limited vocabulary then the words that they use should be words that can get a message across in as many situations as possible.

Any language system that contains all of the above has to be a fairly comprehensive system and there are many who would still, wrongly, argue that this is simply beyond some children to learn. If however we look at language acquisition in babies and young children we are encouraged to speak to and around young children, using a diverse and comprehensive vocabulary, as much language as possible so that they can develop as rich a vocabulary as possible. Children with learning difficulties are no different. The primary reason that children with learning difficulties do not learn to communicate effectively is not their disability but rather the lack of this rich language experience.

The Scottish Book Trust has a guide on developing communication skills; the hints and tips contained within it are not difficult and are what a lot of parents do naturally with their children. When it comes to a non-verbal child, however, they very often miss out on this natural language development.

http://www.scottishbooktrust.com/developing-your-child-language-and-communication-skills

It is extremely difficult to provide the same level of language input for an AAC user as it is for someone who will communicate using spoken word. For this reason the support of those using AAC and their families is absolutely crucial.

It is unrealistic to think that every child or adult whom is given a proper language system and has that system modelled to and around them as much as possible will go on to develop full autonomous communication. However, the consequence of this situation is that some time and effort has not been put to best use (mainly on behalf of the families rather than professionals), but conversely, if we never give someone the opportunity and with the right type of support such that they could have become autonomous communicators, then this is a clear denial of basic human rights. This concept is discussed

With all this in mind I would like to see the first summary statement:

Makes the duty to provide or secure provision of voice equipment and associated support explicit within the 1978 Act;

Changed to:

Makes the duty to provide or secure provision of a robust language system (high or low tech) and associated support explicit within the 1978 Act

Or at the very least have the following statement:

Communication equipment can take the form of pictures, gestures, symbols or photographs as well as high tech support including voice output communication aids.

Changed to:

Whilst communication equipment can take the form of pictures, gestures, symbols or photographs as well as high tech support including voice output communication aids, it is necessary that individuals are given access to a full and robust communication system. This can be either low tech as in a book or a high tech speech generating device.

The second part of the amendment that I would like to comment on specifically is regarding the clinical guidelines:

Health Boards currently fund the provision of voice equipment within the 1978 Act (see above) and therefore the Scottish Government does not anticipate significant additional financial implications as a result of this amendment. It is expected that there will be no impact on the number of individuals who require communication equipment as clinical decision making is currently applied and the amendment makes no changes to this.

There are instances, in the case of those with an acquired, temporary lack of speech for example, when it would still be correct to apply guidelines for access to high tech communication aids. However, there are guidelines in place that specifically exclude certain children and adults with disabilities to access to communication and indeed Speech and Language Therapy at all.

In my own health board (Greater Glasgow and Clyde) children (adults with learning difficulties are not as lucky as even this) are expected to meet the following criteria:

i. Follow directions
ii. Make choices
iii. Listen and attend
iv. Make eye contact  
v. Take turns  
vi. Show joint attention  
vii. Understand cause and effect  

before they are allowed access to a communication system.

This system is based on the traditional Candidacy Model of SLT where it was suggested that individuals had to prove that they could use AAC before they got access to it. Not only was this model not based on any conclusive proof (a study of 3 children), it has been outdated since the 1980’s. One such paper is Romski, Mary Ann and Sevcik, Rose A. (1988) ‘Augmentative and alternative communication systems: Considerations for individuals with severe intellectual disabilities’. Augmentative and Alternative Communication, 4:2, 83-93.

There are similar criteria all over Scotland so, unless at least some of the clinical guidelines and the way they are currently applied changes, there will still be many individuals who will not reach the best of their potential. To alleviate any budget concerns, I still think that there will not be much financial impact if these individuals were to be included. It has also been well demonstrated within ‘The Right Speak’ documentation that the costs of teaching communication are minor compared to the lifelong costs of caring for someone with no communication skills.

When considering the costs of the communication system I feel that I should mention the difference that having a second system to model on has made to our family. It encourages my daughter to wear her own talker by helping to normalise wearing a communication device, and it also means that modelling is much easier as you have the system to hand. We had one system (an ipad and the Compass app) provided for us and we had to finance the other one ourselves. In fairness I am not sure how this could be brought into the legislation but it certainly would be a worthwhile inclusion to say that in some instances it is a worthwhile consideration. I am conscious that not all systems come with the price tag of an ipad and an app and a second system would be hugely cost prohibitive.

I am very much in support of the above amendment and hope that there can be legislation that ensures that everyone gets access to a robust language system and they and their families and team get the support to use it.

This amendment could catapult Scotland into one of the front runners for AAC policy. As I understand it only the Australian government are so forward thinking with their views. I think it fits in with other visions the government has such as closing the attainment gap.

T Campbell