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

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

Gael Gordon

I am writing in response to the Call for Views on the Health (Tobacco, Nicotine etc. and Care) (Scotland) Bill (Stage 2 Amendment on the provision of voice equipment.)

My daughter, who is 10, has Rett Syndrome. Rett Syndrome is a profoundly disabling genetic disorder that is characterized by severe motor impairment, no functional hand use and no speech. As such, my daughter represents one of the very individuals who would directly benefit from this amendment and I welcome it. In particular, I welcome the provision that not only AAC (Augmentative and Alternative Communication) devices and aids, but also support in their use must be provided under this amendment.

I would, however, like to voice a couple of concerns that I have around this legislation and the evidence provided by the government from the perspective of a parent.

1) “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”.

This statement is of concern. By implication, the government is suggesting that under the current system, people are being identified for AAC and it is the pathway to funding that is the biggest barrier to access. In my view and experience this is not the case: it can be time consuming and tortuous but ultimately funding can be found for most devices. The greater barrier is being considered for AAC in the first place. At present, children are often being denied access to AAC because they are said not to meet certain pre-requisites for AAC. As an example, parents, locally, have been told that their child must demonstrate the ability to:

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 can even be considered for a device (and, indeed, any input from speech and language therapy). This is outdated practice (and might even be construed as discrimination eg for individuals with autism who may never achieve good eye contact) but it is nevertheless “clinical decision making” as it is "currently applied". Research indicates that there are in fact no pre-requisites for AAC. This is not even a new idea (eg see 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).

The Scottish Government’s own Right to Speak document makes it clear: “Where a service is unable to identify AAC needs for a child with communication difficulties or to support and make provision for these needs, it is failing to meet these [GIFREC] quality indicators and consequently failing the child. It is difficult to see how any of the above indicators can be met if a child is unable to communicate.” (Scottish Government, 2012).

This Right needs to be codified. For this to happen, the legislation and guidance around it must make absolutely clear that practice must be evidence-based and not merely drawn from a practitioner’s clinical experience.

2) At present, support and training in the use of AAC is very much lacking. This is my own experience (with Greater Glasgow and Clyde): unbelievably, my daughter was issued with a new AAC aid in November the day after receiving a letter suggesting discharge from the service. No training was given or offered. She is not by any means an exceptional case. I know that is an experience that is shared by countless other parents across Scotland. Giving a family a device or aid without adequate instruction is a waste of money and a wasted opportunity for our children. It is not obvious how to use an AAC device with your child. Families need adequate support and instruction. This provision is very welcome but I am concerned that the evidence around the financial implications for Health Boards considers only equipment and not staff time.

Overall, I am delighted that this amendment is being brought forward. This new duty has the potential to be truly life changing for the children, young people and adults who need access to AAC. I sincerely hope that it will be accepted.

Gael Gordon