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

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

MND Scotland response

Background

On 16th June 2015, MND Scotland launched its Let me Speak campaign which highlighted the devastating impact of voice loss in people with MND and their urgent need for communications equipment. People with MND struggle to access voice equipment from statutory services and, as a result, MND Scotland has filled this gap becoming the main provider of communications (Augmentative and Alternative Communications /AAC) equipment for people with MND.

Our campaign called on the Scottish Government to:

- Introduce a statutory duty for the provision of AAC services as an urgent priority, so that people who need AAC support across Scotland receive an equitable service.
- Ensure people with MND and other life limiting and rapidly deteriorating illnesses, are a priority for assessment and provision of AAC equipment. By the time some people with MND receive AAC equipment from the NHS, their condition has deteriorated to such a degree they can no longer use it.
- Introduce a recurring fund for the provision of AAC equipment to assist local statutory services to meet the need for AAC equipment.

In response to the campaign, on 1st September 2015, the First Minister announced that the Scottish Government would introduce a statutory right to Communications equipment.

The AAC collaboration

MND Scotland is part of the AAC collaboration; a group of people and organisations who are, or could be, directly impacted by this legislation. The collaboration has submitted a response requesting that the Health and Sport Committee asks the Scottish Government how the following needs will be guaranteed through the Bill:

- Ensure the maintenance of capacity to communicate is equally as important as the need to maintain physical health
- Establish a duty to provide all required equipment, associated ancillary apparatus and software
- Establish a duty to provide support services
- Provision of adequate funding
- Set out requirement for co-operation and partnership working
• Set out accountability and time to comply with Act up to Ministerial level
• Set out clear functions for National vs. Regional vs. Local AAC providers

Key issues for MND Scotland

The amendment to the Bill is a huge step forward and we commend the Scottish Government for addressing the matter so promptly. The detail within the amendment to the Bill addresses some of the issues highlighted in our campaign but, unfortunately, not all.

Our campaign called on the Scottish Government to:

• Introduce a statutory duty for the provision of AAC services as an urgent priority, so that people who need AAC support across Scotland receive an equitable service.
  - The Bill introduces a statutory right to voice equipment and associated support when required. While we are delighted with this progress, a further step is necessary – a statutory duty to provide communications equipment and ancillary apparatus and support. For example, supplying an iPad to a person with MND is not helpful unless it is supplied with a mounting frame for her/his bed or wheelchair. People need to be supplied with the tools to use their equipment effectively. In addition, we wish to ensure that this statutory right to communications equipment includes so-called ‘high end’ equipment such as ‘eye-gaze’. Sophisticated technology like eye-gaze is essential for some people with very disabling illnesses like MND, who find themselves so ‘locked in’ as a result of their paralysis that using more conventional communications equipment is impossible. Finally, what constitutes support should also be clarified and we would hope that it includes the affected person and their family being shown how to use equipment and that all equipment would be maintained and upgraded on an ongoing basis.

• Ensure people with MND and other life limiting and rapidly deteriorating illnesses, are a priority for assessment and provision of AAC equipment. By the time some people with MND receive AAC equipment from the NHS, their condition has deteriorated to such a degree they can no longer use it.
  - People with MND and other rapidly degenerative illnesses must be made a priority for assessment and provision of AAC. We request that this is included in the Bill or a subsequent statutory instrument.

• Introduce a recurring fund for the provision of AAC equipment to assist local statutory services to meet the need for AAC equipment.
The draft amendment states “Health Boards currently fund the provision of voice equipment…and therefore the Scottish Government does not anticipate significant additional financial implications as a result of this amendment.” As health boards currently only have a statutory duty to supply voice equipment to children and young people, the majority of their current budgets are used solely for this. Currently, most health boards have required MND Scotland to supply communications equipment to their adult patients with MND. We believe that whilst a statutory duty is essential, there will be a significant financial implication for health boards. Our campaign highlighted, therefore, the need for the introduction of a recurring fund for the provision of AAC equipment.

About Motor Neurone Disease (MND)

130 people in Scotland are diagnosed with MND each year, yet because of its poor prognosis, just over 400 people have the illness at any one time. From diagnosis, average life expectancy with MND is just 14 months. People with MND will usually quickly become severely disabled with symptoms including losing their ability to walk, write, speak, feed themselves and breathe unaided.

MND Scotland

About MND Scotland

MND Scotland is the only Scottish MND charity that provides care and information as well as funding for research into the illness. We are proud winners of the 2015 Scottish Charity of the Year Award.