The Augmentative and Alternative Communication (AAC) Collaborative includes:

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Euan MacDonald, Euan MacDonald Centre and AAC user
Gavin and Steven Lanigan, AAC user and brother
Jill Clark, AAC user
Craig Stockton, Chief Executive MND Scotland
Communication Matters (ISAAC UK)
Janet Scott MBE, Speech and Language Therapist specialising in AAC
Dr Phillipa Rewaj, Research Speech and Language Therapist, Anne Rowling Regenerative Neurology Clinic
Kim Hartley Kean, Head of RCSLT Scotland Office

The AAC Collaborative is made up of individuals and family members who have used AAC (communication equipment and support) services all their lives or who have started using AAC later in life or who may use AAC in the future, as well as providers of AAC equipment and support services (primarily speech and language therapists - SLTs) to all care groups.

The AAC Collaborative welcomes the introduction of legislation which will establish a duty to provide communication equipment and, as important, essential associated communication support services.

The AAC Collaborative are however very concerned that the draft legislation proposed by Scottish Government will not, as it stands, deliver the quality of AAC equipment provision and comprehensive support needed by individuals to enable them to sustain a good quality of life, learn, work, live independently and enjoy their human rights.

Based on years of experience of needing, accessing or providing AAC equipment and support services the collaborative have set out what they believe legislation must do. See details below. In summary the AAC Collaborative wants the legislation to;

- Ensure the maintenance of capacity to communicate is equally as important as need to maintain physical health.
- Establish a duty to provide all required communication equipment, associated ancillary apparatus and software in a timely manner
- Establish duty to provide essential, comprehensive quality support services in a timely manner at Specialist, Targeted and Universal levels of support.
- Ensure provision of adequate funding for both communication equipment and support services.
• Set out requirement for co-operation and partnership working between agencies at local, regional and national levels
• Set out clear functions for National vs. Regional vs. Local AAC providers and
• Set out accountability and time to comply with Act up to Ministerial level

The AAC Collaborative call on MSPs to ask government how the essential needs of people who do or may need communication equipment and support (as defined in below) will be “guaranteed” through the Bill.

The AAC Collaborative are concerned that within the Financial Impact statement the government says it “does not anticipate significant additional financial implications”. Key providers of communication equipment and support services (such as SLT services) are currently subject to tightening and in many cases severely reducing budgets. Underfunding of AAC services is described as a “main” problem by members of the group. There are unquantified gaps and delays in access to funding for equipment, software and associated ancillary apparatus that is required in order to make the equipment usable e.g. wheelchair mounts or mounting frames, switches etc. Some members of the collaborative are aware of adults who don’t currently get access to public funding for “eye gaze” equipment (which enables people to use eye pointing to control their communication equipment – essential to many people with MND who use communication aids). Another member says “NHS is funding, providing and supporting costly AAC devices (e.g. Eye gaze) … however we do so within a restricted budget and difficult decisions have to be made where they shouldn’t. Further funds are required to provide the support people require”. This variability illustrates the inconsistencies in access to funding and underscores the collaborative concerns regarding the government’s view that they do not anticipate additional financial implications.

Members of the AAC Collaborative disagree with the Scottish Government’s belief that the situation now is that ‘funding is …ultimately found’ for equipment. Some gaps in funding are currently being filled by 3rd sector organisations such as MND Scotland. The statement by government also appears to overlook the costs of the essential communication support services needed by all who use communication equipment.

Although the legislation is welcome it is highly likely to have financial implications in respect of funding for improved communication support services as well as access to guaranteed funds for communication equipment, software and associated ancillary apparatus.

Given the step change in provision of communication equipment and support sought by many the AAC Collaborative are uncomfortable with the government’s statement that ‘The duty imposed by the Bill is intended to encourage Boards to reviews their current AAC service, systems and processes’. The AAC Collaborative believe this needs to be stronger so
rather than ‘encourage’ the duty imposed by the Bill should ‘require’ Boards to review their current AAC service, systems and processes.

The AAC collaborative seek legislation which will –

1. Ensure the maintenance of capacity to communicate is equally as important as need to maintain physical health. Even when people are acutely ill it must not be okay for anyone to say to people that their communication is not important.

2. Establish a duty to provide all required equipment, associated ancillary apparatus and software by which we mean:

- Rapid provision i.e. within 2 weeks of need for equipment and support being confirmed.
- Equitable regardless of where you live, age, why you need AAC
- Person centred - matched to the needs of individual at all ages and stages
- Replacement of equipment that is no longer fit for purpose with modern, up to date equipment when required.
  - Include, where appropriate, software and ancillary apparatus such as adaptations and mountings for the equipment; switches to enable the person to operate the equipment; maintenance, warranties and repair of the equipment and insurance policies relating to the equipment;
  - Incorporate IT and facilitate access to daily living controls and modern communication channels including emails, Facebook, twitter, phone etc.
  - For school pupils and further and higher education students, integrated into educational provisions and incorporate software and facilities to access the curriculum
  - Not be restricted to one “aid” per person. People will require more than one AAC system over the period of their life and may need more than one type of aid for different aspects of life e.g. for work, for home, during sporting activities.
  - Ensure that access to high cost aids is not restricted at all – ensuring selection of communication equipment is solely based on assessed clinical need and efficacy.
- Access to voice banking if they choose.
- Access to high quality text to speech voices if they choose.
- Ensure Health Boards and others are made accountable for quality of provision through use of outcome measures and indicators. Outcomes
might include for example, “100% of people who need and use communication equipment and support report improved ability to communicate and improved quality of life within 3 months of receiving communication equipment and support services”. An indicator of this might be positive report from person on their quality of life. Another outcome measure might be “100% of people receive communication equipment, software and associated ancillary apparatus and are accessing support to use that equipment effectively within 2 weeks of being identified as needing communication equipment and support”. An associated indicator of performance against this outcome would be percentage of people who receive equipment etc. and support within 2 weeks.

3. Establish duty to provide support services by which we mean:

- Timely access to initial and ongoing assessment by communication support services for all who need it. I.e. within 2 weeks of referral.

- Rapid / timely provision of support i.e. within 2 weeks of need for equipment and support being confirmed.

- Equitable regardless of where you live, age, why you need AAC

- Accountability against quality outcome measures and indicators including measure, for example, of improving Quality of Life. (see examples of outcome measures and indicators above)

- Person centred - matched to the needs of the individual at all ages and stages

- Enabling independent living

- Enabling access to the curriculum, for school pupils and further and higher education students.

- IT services which facilitate and enhance AAC provision and use.

- Compliance with nationally agreed quality care pathway including -

Specialist level support on an ongoing basis according to individual needs – to include timely access to standard and, if required, specialist assessment and provision within region; person centred setting of goals / outcomes; opportunity to trial aids and associated tools; expert support to select aid/s; programming of aid for the individual; integration with other Assistive Technology in home, school, education or work environments; training / therapy for individual on how to use their aid and associated “apps” and “add ons” to best effect; training for immediate family and others on how to support use; review of outcomes in terms of needs and goals; on going maintenance, repair, insurance etc. and finally technical support such as wheelchair mountings for aids and switch controls.
Targeted level support: for health, education (nursery to higher education), social care staff and employers to have skills and abilities in supporting people who use AAC.

Universal level support: Awareness across communities and basic ability mainstreamed throughout public services to support people using AAC.

4. Provision of adequate funding by which we mean:
   - Easily accessed and rapidly provided, i.e. within 2 weeks of need for equipment and support being confirmed.
   - Equitable regardless of where you live, age, why you need AAC
   - Person centred - matched to the needs of the individual at every age and stage
   - An established recurring funding pot that can be called upon by providers.

5. Set out requirement for co-operation and partnership working between
   - Health, education and social care service providers
   - Public, 3rd sector and any independent agencies (e.g. communication equipment providers; independent SLTs)
   - Local, regional and national service providers, e.g. NHS Boards and National Services Division.
   - AAC services and national and local public IT planners and operational teams. That is those who develop and implement IT infrastructure and security policy within Scotland’s public services.

6. Set out accountability and time to comply with Act up to Ministerial level – for example to report on quality of AAC provision to Scottish Parliament annually or bi-annually.

7. Set out clear functions for National vs. Regional vs. Local AAC providers.

National services working with a network of regional services could lead on
   - Establishing a national data set
   - National procurement – for equity and economies of scale
   - Virtual national equipment bank – for loans etc.
   - Collection of outcomes data and patient” feedback
   - Universal support activities e.g. communication access in shops etc.
   - Updating online resources developed during the Right to Speak Project
   - Maintaining and updating IPAACKS (a Scot. Govt. commissioned on line CPD tool)
• Lead on research and development
• Lead on the development of training/education opportunities in AAC
• Provide 2nd and expert opinion
• Provide specialist assessment and advice

NB: Some members of the Collaborative also intend to make individual submissions to the committee.

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