

June 2020

“Scotland’s Augmentative and Alternative Communication Services: still some way from the vision”

Speech and language therapists’ views on the impact of Scotland’s AAC law since it commenced in March 2018

Survey Aims

To support progress towards delivery of the shared vision¹ for people who use augmentative and alternative communication (AAC) to communicate, by:

1. reporting on the impact of the AAC legislation (Part 4 of the Health (Tobacco, Nicotine etc. and Care) (Scotland) Act 2016 – the Provision of Communication Equipment) since commencement in March 2018, from the perspective of SLTs in Scotland; and
2. making recommendations for action by Scottish Government, NHS Boards, local government/authority partners and third sector organisations.

Survey Design

- An online questionnaire and focus group survey between January and March 2020 gathered RCSLT members’ views on the impact of Scotland’s AAC law since it commenced in March 2018.
- Survey questions were generated by RCSLT Scotland staff and Scotland’s SLT AAC Leaders Network and related to the aspects of AAC services set out in the AAC National Core Pathway published by Scottish Government in August 2018².
- This survey ran in parallel with and is reporting at the same time as the related but separate AAC Collaborative³ survey of the ‘AAC user perspective’ on the impact of the law since it commenced.

¹ SG Vision says *“People who have difficulty speaking and who can be assisted by communication equipment have the right to get the equipment and support they need to use it, when they need it, wherever they are and wherever they live in Scotland, enabling them to participate in their communities and be fully included in society.”* See

<https://www.gov.scot/publications/guidance-provision-communication-equipment-support-using-equipment/pages/1/>

² <https://www.gov.scot/publications/national-augmentative-alternative-communication-aac-core-pathway/>

³ The AAC Collaborative is made up of representatives from the Royal College of Speech & Language Therapists; Bobath Scotland; Huntington’s Scotland; Parkinson’s Scotland; Chest Heart & Stroke Scotland; Inclusion Scotland; Camphill Scotland and Speech and Language Therapy Adult Learning Disability Clinical Excellence Network. The work on the survey has the support of MND Scotland and a number of individual AAC users including members of the Scottish Govt. AAC National Advisory Group.

- This report supplements and compliments Scottish Government's own *Progress Report*, published in March 2020, and reflects a number of positive indicators of progress reported therein.

Survey participation

- 13 SLTs participated in 3 focus groups targeting speech and language therapy services in the south east, south west and north of Scotland.
- A smaller version of the survey was given out to a mix of 46 SLTs and educators; 28 were returned (61% response rate).
- 49 SLTs responded to the online survey via the platform Survey Monkey. Numbers of respondents to each survey question varied. Percentages are based on the number of respondents to each question.
- This report combines the findings of the online survey and focus groups.

The SLT respondents to the survey:

- 37% (18/49) work with children and young people, 38% (19/49) work with adults and 24% (12/49) work with mixed age groups.
- 87% (43/49) work for health boards and the remaining 13% (6/49) work in national and regional AAC services or third sector organisations.
- Represent all levels of SLT experience and seniority; however 82% (40/49) are senior and highly experienced clinicians and leaders at Agenda for Change bands 6, 7 or 8.
- All reported they had had AAC training and continuous professional development (CPD) in the field of AAC, although many commented they had not received training in the last few years.

Survey Results

1. Awareness of law

86% (25/29) of respondents reported they were aware of AAC legislation. Only 68% (20/29) were aware of the national AAC Vision, Guidance and AAC Core Pathway.

2. Overall impact of the law on provision of equipment

73% (22/30) feel the legislation has had a little or some impact on provision of equipment – 16% (5/30) believe it has had a big impact. 10% (3/30) believe the law has had no impact.

Encouraging comments:

- *I feel more confident with the law in place that (good service) will continue.*
- *This act has encouraged us to review the process ensuring equity and efficiency of provision of equipment and support for all AAC users.*
- *Parents are more aware of their rights.*

Concerning comments:

- *I still think there is a way to go. With ever reducing budgets, I don't feel like the possibility of provision of equipment is known widely.*
- *Can still take a long time to get equipment for patients. Process of applying for funding*

and decision being made can be lengthy. Patient's needs can change very quickly and this is often not reflected in process of getting equipment.

- *I feel like the money is being taken from one area to fund another.*

3. Overall impact of the law on provision of support to use AAC

69% (20/29) rate the law as having had little or some impact on provision of **support** to use communication equipment, 7% (2/29) thought there had been a big impact and 24% (7/29) thought it had no impact. Overall the impact of the law on provision of support was identified as having a lower impact than on the provision of equipment.

Encouraging comments:

- *The law has required us to review our AAC model from top to bottom and ensure that support is an embedded part of our service model.*
- *Feel there is a slight increase in awareness of the need for support for use of equipment.*
- *I am able to justify using more of my time to provide support in order to increase the chance of successful use.*

Concerning comments:

- *In adult learning difficulties services we have so few SLTs that it is often difficult to give more intensive support over a longer period.*
- *There has been no increase in SLT and challenges in delivering support to children are a result of local authority cuts to SLT Service Level Agreements.*
- *More evidence of loss of support for ASL – direct therapy very rare; once national centre involved local services tend to discharge.*

4. AAC user involvement

28% (4/14) of services have developed ways of gathering the views of AAC service users as they proceed through their AAC journey, but for most these have not been developed.

Concerning comment:

- *During R2S we surveyed those who had been through our AAC service. Since then we have not had the staffing capacity to repeat this.*

5. Leadership

All 14 health board areas have a designated AAC executive lead as well as a designated SLT AAC lead with specific responsibility for developing AAC services in their area.

Encouraging comments:

- *Named individual with responsibility within organisation is improving clarity/consistency of process, budget, staffing etc. This has never been the case previously.*

Concerning comments:

- *Professionals are struggling to be heard, there is a need for more proactive approach.*

Recognition of need, requests for assistance and assessment

6. Recognition that an individual may benefit from AAC

For 52% (12/23) of services the recognition that someone may benefit from AAC services has improved; for the other 48% it stayed the same as it was before the law commenced.

Encouraging comments:

- *I think the profile of AAC has increased and people more likely to request trial of devices.*
- *In our area there have been more appropriate requests and better multi-disciplinary working.*

Concerning comments:

- *I always find CYP who could benefit from AAC but who haven't been identified by local providers. Those that are identified are self-selecting – there isn't a universal approach to identifying CYP.*
- *Outside agencies working with adults do not appear to identify need.*

7. Requests for Assistance (previously called 'referrals')

The system for making AAC related 'Requests for Assistance' and numbers of requests have stayed the same for 86% (19/22) of respondents. 13% (3/22) have seen an increase.

Encouraging comments:

- *Locally we now have an AAC pathway which is almost identical to the national one. We have an AAC champions group which provides SLTs with a local 'expert' in children's services, ALD and adult services to go to if required. We have started an AAC research element to the champions group.*

Concerning comments:

- *It is a very long process and often not quick enough given the fast progression of some conditions.*

8. Waiting for assessment

95% (19/20) of respondents reported that the time people wait to be seen by a local SLT has stayed the same. In one case (5%) it has decreased. Only 16% (2/12) of respondents have developed good practice guidelines on waiting time between the request for assistance and an assessment.

Encouraging comments:

- *“Right to Speak” funding (before the law) supported provision of “AAActionmaker”⁴ Network kits and development of foundation skills for AAC Assessment across the SLT team and therefore improved our waiting times for assessment significantly.*

Concerning comments:

- *Within our service we do not have the capacity to respond as quickly as we would like, currently covering 6500 beds with 1.6 SLTs, this means longer waits for patients.*
- *General increase in waiting times due to reduced staffing resource.*
- *Depends on staffing levels – Dysphagia always takes priority over AAC – waits for assessment more than 12 weeks.*

9. Loan banks

68% (13/19) say that local loan banks are unchanged since the law came into force. 26% (5/19) note an improvement. 5% (1/19) report the loan bank is not as good as it used to be.

Encouraging comments:

- *Funding for updating AAC Assessment loan bank has been provided this year.*
- *With our ring-fenced AAC budget we have been able to update our loan bank.*
- *Fab loan bank following legislation.*

Concerning comments:

- *We are having significant issues within the community sourcing loan equipment for patients.*
- *“Right to speak” ran from 2012 to 2015 and much was used to buy equipment. Any kit bought then is out of date now.*
- *There is very little equipment in the loan bank and it is very difficult to get a hold of appropriate up to date systems; have tried to use it but the equipment is not available, broken or not up to date.*
- *When loan banks were bought under Right to Speak project they have not been updated since – therefore greater reliance on borrowing from national centre.*

10. Equipment provision including waits and funding

The system for securing provision of equipment has shown some improvement for 50% (10/10) of respondents. For the other 50% the system is unchanged.

68% (13/19) report actual provision of equipment has stayed the same. For 32% (6/19) it has increased.

⁴AAActionmakers are SLTs who have developed their skills and take a lead on AAC within their teams. They cascade new resources to their team members, identify CPD opportunities and requirements, promote AAC awareness, provide AAC screenings and reviews and are a link between their community team and Keycomm (Lothian). See <https://keycommaac.wordpress.com/aactionmakers/>

Funding of equipment has stayed the same for 55% (10/18) respondents but there has been an improvement for 45% (8/18) respondents.

64% (9/14) of services had not developed a funding policy at the time of the survey; 34% (5/14) had.

Encouraging comments:

- *We have been reducing waiting times since the AACtionmaker network was launched.*
- *Should be improving with new pathway – faster decision making reducing from 12 to 6 weeks.*
- *With access to a specific budget this has made the provision of equipment more efficient.*
- *We can now validate a request for purchase of equipment from a budget we did not previously have access to.*

Concerning comments:

- *Difficulties with the procurement process and no formal links with IT has meant longer waits for clients to receive equipment.*
- *A lot of equipment put out on loan with expectation that new equipment will be bought if trial successful ...taking a lot of time to procure persons own aid.*
- *Local equipment being provided but still difficulty getting specific apps.*
- *Time from recommendation to purchase – expect 3 months – can be a year.*
- *...there continues to be times where we have difficulties with procurement particularly with more unusual items and their purchase which can incur longer waits.*
- *There have been some changes but it can still take a long time for funding to be approved.*
- *In our area funding from Social Services is non-existent, funding from health board could be more. We have however been given approval to go over (budgeted) funding if required.*
- *We have no formal agreed funding within the health board set aside for AAC and this continues.*

11. Support to use equipment including training of others and long-term support

50% (6/12) of people who commented on the adequacy of available support (in respect of quantity and reach) expressed the view that not enough support to use equipment is available. The other 50% reported either support was adequate or was improving. The system for securing support to use equipment has stayed the same for 65% (13/20) but improved for 35% (7/20) of respondents.

Demand for support has increased for 15% and for 85% (16/19) stayed the same.

84% (16/19) of respondents report no change in actual SLT support available. 16% (3/19) see an improving picture in availability of SLT support.

45% (8/18) of services report developing local AAC support protocols in the last year; 55% (10/18) have not.

40% of training on AAC has been delivered to other SLTs. Of the remaining 60% of training, very little has been provided to other AHPs – with the majority of that provision focused on other non-NHS agencies. Although training is vital for staff in all sectors, it is particularly important for health colleagues.

Most AAC users will have AAC equipment and support needs on and off throughout their lives. However the availability of long-term, life-long support is a weak aspect of SLT service in many areas. Only 18% (2/11) report an improvement in the system for reviewing and providing for long-term AAC support needs. Only 2/9 (22%) services report they have developed long-term support protocols.

Encouraging comments:

- *Still requires improvement but good strides have been made to achieve better support with the development of additional key posts and personnel linked in with the national specialists.*
- *Our education colleagues now have a designated team to support AAC, and more time/focus has been given to training community SLTs.*
- *We are in at the beginning of developing protocols to guide training offered.*
- *We have a robust long term support protocol provided by our staff and local community SLTs.*
- *Long term support works well already within the adult service (acute and progressive neurological conditions predominantly).*

Concerning comments:

- *Our AAC Lead only work 1 day a week and it is next to impossible to arrange joint assessments and follow-ups.*
- *People are being provided the equipment but without support.*
- *ASN support workers are teaching CYP with complex needs without much guidance.*
- *There is not enough support to use equipment. This is just a small part of my job and I don't have the capacity to support families or schools the way they would like/need.*
- *Trials can fail if not adequately supported. This can result in equipment being underused while still on loan.*
- *We have almost no capacity to do long term support.*
- *We are still quite a long way from having the requisite skill mix and confidence across our team to offer support over the long term.*
- *There is poor support outside of SLT for the review of AAC and long term support.*
- *No capacity for long term support, overstretched as it is.*
- *Staff turnover barrier to continuity. Sustainability of support at local level has stayed the same but needs improvement.*

12. Funding for AAC Equipment and Support Services

41% (7/17) of respondents who commented believe funding of AAC equipment and services is adequate. The remaining 59% (10/17) raised questions and concerns regarding variation in partnership funding arrangements; sustainability of funding; time it takes to secure funding; and adequacy of funding overall.

Encouraging comments:

- *We have a good relationship with our social care colleagues in relation to funding*
- *Could be improved further but definitely has improved since 2018.*
- *Adequate for the Adult Service as we have our own dedicated budget.*

Concerning comments:

- *Funding is inadequate, depriving people of opportunities to access AAC.*
- *There is no dedicated time or funding for dedicated SLT, so SLTs have to juggle and fit this in with other priorities.*
- *There is no agreed funding in place from health board - no equipment is purchased jointly with any other agency any more, which used to happen previously (e.g. education, social work). There is no funding put into SLT staffing, or to IT and medical electronics for maintenance or setting up systems.*
- *The amount reserved has been adequate to date however with the increase in requests for high-tech equipment demand is likely to outstrip the existing budget shortly.*
- *I do not think it is a good service. The needs of clients change very quickly and this is not reflected in the funding process. Patients can wait months for equipment but for many it is too long to wait.*

Conclusion and recommended priorities for development

AAC equipment and support provision in Scotland continues on a journey of improvement. The survey reported on here shows some progress has been achieved since the AAC law commenced in March 2018. However, it also shows that there is still much to do to fulfil the recommendations of the 'Right to Speak' Reports of 2012 and 2015 and Scotland's 2018 stated vision for people who use AAC.

RCSLT members and SLT AAC leads identified (79) priorities for AAC service improvement, which, based on real world day-to-day experience, they believe would build on existing AAC services and ensure the vision set out by and for AAC users can be more quickly and universally achieved. These have been grouped into 6 recommendations for national and local level action.

- 1. Improve funding for AAC equipment for assessment, trial, and long-term use by AAC users, as well as AAC regional and national loan banks, with directions on provision of funding and time limits on how long people should wait to get their own bespoke equipment.**

- 2. Act to increase funding for dedicated SLT support for AAC users including directions on waiting times for support and access to life-long support as and when required.**
- 3. Improve availability and access to training for SLTs, families and multi-disciplinary, multi-agency colleagues to ensure that all those involved in supporting AAC users have the necessary knowledge and skills. IPAACKS is an excellent framework to be used as a foundation for a competency-based approach to training and capacity building across professions.**
- 4. Provide support to enable AAC user engagement in co-production of strategic and operational planning and service development across Scotland.**
- 5. Develop protocols on long-term support for AAC users.**
- 6. Explore the benefits of developing a national hub to support local AAC leadership, to strengthen local collaborative working and to help establish excellent, equitable and expert AAC services across Scotland. The already established 'Augmentative Communication in Practice: Scotland' group could contribute valuable insights to this exploration.**

For further information on this report please contact:

Kim Hartley Kean, Head of RCSLT Scotland

kim.hartleykean@rcslt.org

Deborah Jans, Chair of AAC Speech and Language Therapy Leaders Scotland group

deborah.jans@ea.edin.sch.uk