Inclusion Ireland
The National Association for People with an Intellectual Disability.

Report on Alternative and Augmentative Communication Seminar

'Communication as a human right: Having your voice heard through Alternative and Augmentative Communication (AAC)

October 19th 2022

IASLT | *The Irish Association of* Speech + Language Therapists

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Section 1: CEO Introduction
Derval McDonagh, CEO, Inclusion Ireland

Inclusion Ireland were proud to host our seminar "AAC as a human right" on the 19th October 2022 in collaboration with the Irish Association of Speech and Language Therapists and with the support of AAC users, Disabled Person's Organisations, families and advocates. It is our belief at Inclusion Ireland that when we are all in a room together, powerful things can happen if we listen and work towards a shared goal and purpose.

Inclusion Ireland's sole purpose is to work towards the full inclusion of people with intellectual disabilities by supporting people to have their voices heard and advocating for rights under the United Nations Convention on the Rights of People with Disabilities (UNCRPD). For many people, having access to a communication system that works for them is the way in which they can access all other rights under the UNCRPD.

The purpose of the event was to :

- Celebrate AAC users and people who communicate in ways other than with speech.
- To develop participant's knowledge around AAC - what it means and where to access support.
- To highlight good practice and examples of where access is working for people.
- To shine a light on where things are not working for people and where access remains a challenge.
- To pull together key recommendations from our participants which can be used by policy makers across health, social care and education so that access to ACC can be significantly improved.

"Today is about honouring people's communication. Acceptance is such a low bar - we need to talk about valuing, respecting and celebrating the ways in which people communicate"

Derval McDonagh, CEO, Inclusion Ireland

We believe that this event can be a catalyst for the wider changes and developments so badly needed if access to AAC is to be recognised as a fundamental human right. Our participants spoke about what AAC enables for them or for their children; access to education, to a healthy family life to relationships and friendships, to fun, to joy, to training and employment. AAC is not a luxury "add on", it is a means to accessing a good life, connected to our community and valued as an equal citizen. Our participants also spoke about the immense challenges in accessing AAC; unclear pathways for funding and a lack of resources, lack of knowledge amongst health social care and education staff, lack of policy, lack of acceptance of anything other than "speech", professionals with outdated knowledge, wider society not understanding or valuing AAC.

We want to thank all of our participants, but particularly those who shared their stories and had the courage to publicly demand better for our fellow citizens. At Inclusion Ireland, we know this was only the first step in coming together. It's what we do with what we heard that is the most important thing. We commit to following up on all of the actions we outline in this report and to continue to work alongside AAC users to advocate for change until every person who needs AAC has access to it, with the support they need to be heard.

Derval McDonagh
CEO, Inclusion Ireland

Section 2: Acknowledgement of our Presenters and Working Group Members

- Aisling Mason, AAC User

- Ms Anne Rabbitte, T.D., Minister for Disability

- Ciara Tuohy, SLT Chairperson of Paediatric Special Interest Group

- Owen McGirr, AAC user

- AAC Users from Prosper Fingal - Suzanne Queenan , Fergal Healy, Gearoid Long, Sorcha McSwiney, Aoife O'Sullivan, Alan Beckett, Luke Byrne, Darren Warren, Daniel Brady Byrne, Gerard McNulty, Stephen Campbell, Stephen Farrell Noone, Philip McCormack, Andrew McCann, Niamh Carolan

- Julia Cummins, Parent and AAC Researcher

- Cír Doyle, Neuropride Ireland DPO Representative and AAC user

- Colina Case, Speech and Language Therapist and the Education Perspective

We would also like to acknowledge the broader working group who brought this seminar together including our team at Inclusion Ireland, members of the IASLT Paediatric Special Interest Group, Members of the IASLT Autism Special Interest Group, members of the Adult Intellectual Disability SLT community.

"My AAC reader lets me live the life I want to live"

Aisling Mason, AAC User

Section 3: Alternative and Augmentative Communication (AAC) definitions and Tips for AAC partners

What is AAC?

A range of communication methods that can be used to enhance or substitute speech (Beukelman and Mirenda, 2013). Any form of communication besides spoken words used with oral speech or instead of oral speech.

Why use AAC?

You might have limited or no speech or it's just easier than speaking for a variety of reasons.

It may help others to understand your speech better.
There might be periods when speech just isn't working for you.
It's simply your preferred method of communicating.

What type of AAC is best ?

There is no one best system or tool that suits everybody – individuals are likely to use different systems and their preference for a system may change over time.
The goal is to establish a successful communication system and enhance participation and independence.

"We need people to be aware of other people's communication needs and how these can change"

Cír Doyle, Neuropride Ireland

AAC myth busters!

AAC does not mean "giving up" on speech – all evidence suggests AAC improves speech and language ability.

It is not a "fix all" – AAC may become part of a person's whole system of communication.

Providing access is just the first step – like learning any language AAC is a skill that takes time and motivation to master.

It is never too late to start and there are no cognitive or skill barriers which means a child or adult cannot access AAC.

"There is no one best system or tool that suits everybody – individuals are likely to use different systems and their preference for systems may change over time."

Ciara Tuohy
Speech and Language Therapist

Tips for AAC communication partners

Honour my communication. When I make an attempt to communicate, acknowledge it even if you don't understand fully yet.

Celebrate AAC. Make sure every way that people communicate is valued and recognised as part of our every day experience.

Believe that we will get there.. Have realistic but high expectations of me. I might need time to get used to things, and so might you. Don't give up easily!

Section 4: Roundtable Discussion Feedback

Question 1: What are the positive stories we want to share?

This question elicited considerable positive feedback. Where people have access to a robust, consistent AAC system, the results are transformative for the person and those who they interact with.

The feedback was broadly themed under the following headings:

1. Supporting autonomy: AAC supports the person to become more independent, developing skills and accessing the world. AAC gives people more agency and control over their lives whether at home, in school, in employment.

2. Supporting wellbeing: Reducing feelings of frustration. Positive impact on mental health.

3. Access to rights: AAC is a means of accessing rights under the UNCRPD. Having your communication understood and validated is a way of having your rights recognised and upheld. AAC can support people to access education and their curriculum.

4. Supports the development of relationships:

- Communication is a two-way process; having a way of communicating opens up relationships within the family including increased interaction and connection with siblings.
- Positive attitudes about AAC encourage collaborative approaches across school and home and fosters better relationships in supporting a child or an adult.
- One participant spoke about the profound and positive affect when they saw their grandchild using AAC to communicate for the first time after previously being afraid of technology.
- An AAC user at the roundtable stated that "AAC opened up my whole world".

5. Supports diversity: Access to AAC supports diversity; not everyone communicates through words and this is something to be supported and celebrated. AAC is becoming slowly more visible, the more visible it is, the more people's perceptions of it will change. An AAC school choir was mentioned as an example of better visibility and support of AAC within a school environment. Whole school approaches to using Lámh were also cited as positive developments. Community based Lámh approaches where shops and businesses use Lámh and AAC regularly is a way of increasing visibility and acceptance.

6. Challenges stereotypes: Access to robust AAC supports the challenging of stereotypes that nonspeaking means "non thinking" or "non-communicating". AAC can show that people learn and communicate in different ways. The "typical" does not have to be the only way.

7. Knowledge Development:

- AAC is rapidly developing. AAC users, Speech and Language Therapists and families are becoming more confident in trying new technology and opening up possibilities for people. Learning from AAC users and people with a lived experience is the best way to understand what works and what doesn't.

- Projects happening with CREATE funding. See page page 11 of this report for more detail on this project.

- Examples of Easy-to-Read in secondary schools. Development of visual support packs for SNAs and Teachers. Using iPads to access.

- Just a Minute (JAM) cards help with transport: ripple impact enabling travel for employment, social connects and activities etc.

- Some organisations have AT/AAC banks

- Schools project in Kildare

Highlighted Project

There are interesting developments happening in the HSE with AAC. This is an example of a project which may support the development of AAC Pathways.

CREATE 2021 or Cooperative Real Engagement for Assistive Technology Enhancement is a digital and assistive technology (DAT) fund which was launched by the HSE National Disability Operations and the National Clinical Programme for People with Disabilities (NCPPD). HSE and HSE funded organisations were eligible to apply for €75,000-€250,000 to finance digital and assistive technology initiatives. Projects had to be aligned with the United Nations Convention of the Rights of Persons with Disability and The National Disability Inclusion Strategy 2017-2021.

Applications had to show evidence of an existing record of accomplishment in working with DAT in a person/family centred way, combined with a willingness to collaborate with service users and others in the sector to co-design systems improvements in the delivery of DAT to enhance people's lives. They also had to develop awareness of the project and show ways which DAT can be introduced and scaled up and provide an outline of how the money was spent, other related activities and evaluation of these.

Taken from: https://www.hse.ie/eng/about/who/cspd/ncps/disability/programme-publications/create-2021.pdf

Feedback from at least two of the ten projects funded was given on the day.

"We should adapt society to meet the needs of everyone equally and partnerships between us all will make it happen"

Ms Anne Rabbitte T.D.,
Minister for Disability

The CREATE grant is currently funding a number of AAC projects.

AT (Assistive Technology) Passport Project

The aim of this project is to develop and pilot a prototype AT Passport System across four participating partner organisations: Enable Ireland, St. John of God Community Services, MS Ireland and Headway Ireland.

People from each partner organisation will participate in co-designing the AT Passport Pilot. The AT Passport is a person-centred digital record (envisaged as an accessible app, linked to a cloud-based AT portal). It places the Assistive Technology user at the heart of the process, with accommodations and resources following the user through life stages, to ensure the provision of AT in a practical, streamlined and efficient manner.

The AT Passport is effectively a record of what AT an individual needs to live their best lives at home, in education, at work and in their communities. In addition, some project funding will enable the participating partner organisations to support 50 adult participants to identify their AT needs and access appropriate Assistive Technology solutions.

Assistive Technology Bank of AAC for Children's Disability Network Teams

The nine Children's Disability Network Teams within Community Healthcare West (Galway, Mayo & Roscommon) applied for funding through the CREATE fund for an assistive technology bank of alternative and augmentative communication (AAC) devices in December 2021. This aimed to support the Children's Disability Network Teams across Galway, Mayo and Roscommon (who support approximately 3504 children and young people) to have access to devices that they could trial with children, young people and their families based on need, not diagnosis, allowing for equity of care within the service. The project received funding of €198,932. To date, team members have received online and in person training. Staff have completed surveys regarding their knowledge and confidence in using AAC. Families within the services have been invited to two engagement sessions to get feedback regarding the set-up of the Assistive Technology banks. A range of Assistive Technology products (ranging from no-tech to voice output devices) have been ordered to develop a bank of Assistive technology for each of the nine teams and are due for delivery in December. The project aims for all nine teams to be able to model and trial use of AAC with families on the team, develop team members experience and comfort with using AAC. The project also aims to measure outcomes for children, young people and their families, track progress and create a template based on evidence gathered which can be duplicated in other parts of the country.

Question 2:
What are the barriers for people in accessing their right to AAC?

Whilst there were some positive examples shared of access to AAC, our participants agreed that there are many challenges and barriers at both individual and systemic levels. These challenges can be broadly themed under the following headings:

1. **Lack of knowledge:**
Some professionals across health, social care and education settings are using outmoded and outdated thinking around AAC.
In many cases children and adults with intellectual disabilities, in particular, are assumed to not have the "competence" to use AAC due to this lack of knowledge.

2. **Lack of training:**
There is a lack of proper up to date AAC training for individuals, families, staff in schools and health and social care settings and for the broader community. Professionals need more training at an undergraduate level and at a continuing professional development level once they are working with disabled children and adults. Thinking is changing rapidly and people need to be completely up to date. What was considered acceptable practice until recently (such as use of PECS) has moved on.

3. **Culture of over valuing speech.**
As a society we tend to over value speech as the "typical" mode of communication. People need to get comfortable with silence. This gives AAC users time to express their message. We don't tend to value other forms of communication as much. AAC partners need to do more to address this and make using AAC a typical part of everyday interactions.

"AAC is part of identity but doesn't define who you are. AAC is your voicebox, nothing more, nothing less"

Owen McGirr, AAC User

4. Ableist systems

Not every person or family has the resources to fight for rights and access. Many of the forms that need to be filled out to access AAC rely on high levels of literacy. There is often advocacy fatigue with little support. The system is so challenging to navigate and often those who need support the most, have the least support.

5. Funding:

There appears to be major challenges in accessing funding for AAC.

- Particular issues were raised around when a device breaks and the length of time it takes to be fixed/get funding to do so.
- There is a lack of transparency around how to access funding. Different pathways in schools and in CDNTS. There needs to be transparency and consistency across the country. Many participants spoke of the "postcode lottery" with different systems across the country depending on what CHO /school the child is in. This is a similar experience for adults.
- The person signing off on the funding may not have met the child or the adult. Decisions are made far from the person or the child. May not have any background/understanding/experience of AT/AAC or even in some locations experience in disability.
- Overly bureaucratic systems leading to paperwork fatigue for individuals, professionals and families. Over and back defending recommendations, appealing decisions, giving more information, repeating information.
- Budget cycle of one year does not allow for planning with a person over their lifetime and can leave the person vulnerable to budget cuts.
- Lack of access to WIFI and other support structures in some settings.

7. Lack of support:

- If a child is on a waiting list for therapy supports, it is extremely challenging to get any advice or help.
- Families rely on each other to figure out what might work for their child. While this is positive in some ways, at times the help of professional support might ensure the child is on the right track. Opportunities can be missed if the person does not have support or guidance in understanding the full breath of choices available to them.
- Lack of access to trials to see what the best fit for the person is.
- Lack of support for therapists; lack of clinical specialisms across SLT and OT to support therapists on the ground to upskill and get the supervision and mentoring they need.

8. Lack of human rights focus:

- AAC needs to be seen as a human right. Examples were shared of AAC devices locked away in schools and in other settings. AAC being used as a "reward" for "good" behaviour, this needs to stop and is the equivalent of taking a person's glasses or wheelchair away.
- People feel undervalued if their right to communication is not acknowledged and respected. This can have devastating consequences for a person's mental health and wellbeing.
- The AAC user should be in the driving seat; too often the person has to "make do" with what is offered rather than having their preferred choice.

9. Lack of collaboration:

In many instances the lack of collaboration across health, social care and education was cited as a major barrier. The person's AAC system needs to be understood in all the environments that they are in.

10. Lack of policy:

There is no policy framework for use of AAC right now in education or health and social care settings. This means that there is a lack of consistency around access and support. Although the UNCRPD highlights accessible communication as a right, this has not been translated into policy.

Question 3:
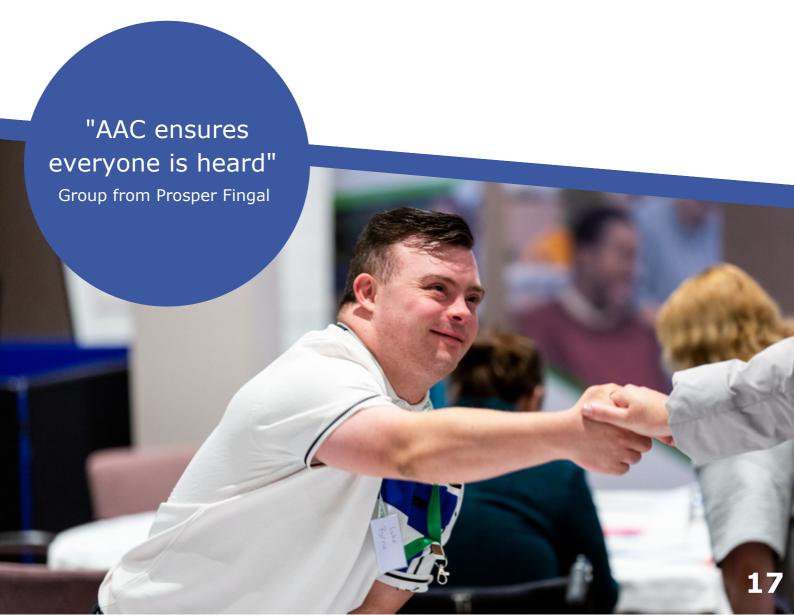# What needs to happen to overcome some of these barriers?

The participants had a range of suggestions and ideas to support better access to AAC from an individual level through to addressing some of the systemic barriers faced by people. These broadly fall into the following themes:

1. Develop neuroaffirmative, best practice policy and guidance across health, social care and education settings.

2. Develop a fair and transparent resource allocation model in health and education settings.

- This may involve a centralised, cross departmental AAC and AT resource allocation model.
- Make the funding process more accessible so that people can access it fairly e.g. review the over reliance on a high level of literacy to apply for funding.
- Multi-annual funding for AAC to ensure that people can be supported as their needs change.

3. Work with the Department of Further and Higher Education, Research Innovation and Science on ensuring that programmes at third level adequately address access to AAC as a core issue in health, social care and education courses.

- Shared modules on AAC at third level across education and health science training
- Ensure thinking is current and neuroaffirmative.

4. Support development of ongoing CPD experiences for people working with AAC users and potential AAC users.

- Make sure that training is up to date and is recommending current practice and thinking, particularly by state agencies such as the NCSE.
- Make sure that any harmful practices are stopped immediately (such as removing an AAC device or using it as a reward)

5. The gaps in access to therapists through the CDNTs and Adult Disability Services need to be addressed through a comprehensive and creative workforce planning strategy; focusing on both recruitment and retention issues in disability services. This should also involve the development of AAC specialist posts.

6. Campaign and advocate for better access to therapy services within education environments.

7. Better support for people who want to try AAC:

- AAC libraries so people can try different things to see if they are suitable.
- Access to an AAC information and support line.
- Access to AAC clinics and drop in sessions with companies and professionals.

8. Campaign for better awareness of the transformative effect of access to AAC. It is not just about accessing education, although this is important, it is about broader access to a person's human rights and a good life.

- More forums and opportunities to share knowledge and experience.
- More challenging of stereotypes and assumptions around AAC users.
- Better representation in the media.
- Recognition and awareness of the right to communicate. Human rights-based approach in all types of policies and systems.
- De-mystify AAC. Use plain English to support people to understand. Come up with a better name than AAC!
- More inclusive research with AAC users to highlight the successes, challenges and barriers.
- Use public sector duty as a way of encouraging public bodies to take their role seriously around supporting AAC use.

9. Take a collaborative approach across all environments where the person uses AAC.

- Department of Education and HSE must work together.
- Establish interagency AAC/AT forums at local level with representation from Health, education and other agencies.

10. Development of AAC advocacy.

- Ensure AAC users are represented by DPOs and supported by advocacy organisations.
- Government needs to listen to people with the lived experience of using AAC to communicate and people who support AAC users, e.g. family members.
- Find, recognise and support AAC champions who will publicly support AAC access.

11. Creation of culturally diverse AAC options.

- Better range of voice options on devices accents/cadence/emotion/inflection etc.
- Support bilingual children to use AAC.

12. Consideration of an Assistive Technology Passport (AT) for each individual as part of a wider 'national AT Ecosystem' - A 2016 discussion paper* co-authored by Enable Ireland and the Disability Federation of Ireland made several recommendations for the design of an effective AT Ecosystem, to support those who need AT to get it in a timely manner. Central to the recommendations is the development of an Assistive Technology Passport.

The AT passport being developed and piloted as part of the CREATE fund would meet this need by ensuring the provision of AT including AAC in a practical, streamlined and efficient manner. The AT passport project, engages the AT user in all stages of their AT journey, while offering the State value for money by reducing the overhead of administration and undue duplication of services which increase the costs of AT service provision.

"AAC ensures everyone is heard"
Group from Prosper Fingal

Recommendations

The following section highlights the key recommendations from the roundtable discussions and the necessary actions needed to ensure better access to AAC for people. It is recognised and acknowledged that resources are an issue. The recommendations are a way of ensuring that limited resources are used in the most effective ways possible.

1. Collaboration across HSE and Education

- At a high level, Inclusion Ireland will facilitate a meeting with the National Council for Special Education (NCSE) and HSE to discuss key recommendations from this report and to support the development of an action plan.
- We need to encourage collaboration between SLTs, teachers, SNAs and working groups developing policies and structures to work together. Positive examples of collaboration to be shared to encourage more of this.

2. Policy and Guidance Development

- Development of AAC Access Policy within schools. This policy needs to be based on current thinking around AAC and neuroaffirmative approaches. AAC should not solely be provided or prescribed for a child to access curriculum, but also be recognised as the way in which children socialise, have a voice and advocate for themselves.
- Development of AAC policy through the clinical programme HSE.
- These policies should align and complement each other.
- The learning from the CREATE Project on development of assistive technology passports should guide the development of AAC Pathways.

3. Resources

- Continue to campaign for a comprehensive and creative workforce planning strategy to ensure there are enough therapists working across health, social care and in schools.

- This strategy needs to address training of additional therapy staff, recruitment of staff and retention of staff.

- Part of this strategy needs to address the development of clinical specialisms to support therapists on the ground in delivering the highest standard of support to children and adults.

4. Funding Pathways

- Wider sharing of guidance for access to AAC funding in education.

- The development of a consistent resource allocation model within the HSE to enable fair and transparent access no matter where a child or adult lives.

- Campaign for funding through budget process for better access to AAC.

- Campaign for multi annual AAC and AT funding for children and adults.

- Reallocate any budget savings towards development of AAC libraries and banks for Children Disability Network Teams

5. Culture and Attitudes

- Development of a two year awareness campaign around AAC to continue through Inclusion Ireland in collaboration with other organisations including DPOs, service providers, IASLT.

- This campaign should raise awareness for family members, special education needs officers, school staff and HSE staff amongst others.

- Use opportunity of roll out of Decision Support Service as a way of highlighting AAC users making decisions.

6. Training and Knowledge

- Link with universities and share recommendations for undergrad training in collaboration with IASLT.

- Highlight need for training of school staff in neuroaffirmative approaches and access to AAC with the NCSE. Support the development of up-to-date training.

- Work with the clinical programme HSE in ensuring that professionals in HSE funded organisations are upskilled in AAC.

- Inclusion Ireland will share information on website and through webinars highlighting and showcasing good practice examples across the country.

- Inclusion Ireland will publish up to date resources on their website.

"Non speaking does not mean non feeling, non thinking, non communicating"

Julia Cummins Parent and AAC Researcher

7. Representation and Visibility

- Encourage and support representation of AAC users in local, regional and national committees.
- Use UNCRPD and Public Sector Duty effectively to champion the rights of people to be represented and to participate.
- Support government agencies and politicians to understand the need to include people who are AAC users.
- Ensure that AAC users have a media presence through campaigns and other work.

Conclusion

Inclusion Ireland were delighted to host this seminar in partnership with the Irish Association of Speech and Language Therapists, Disabled people, Disabled Persons Organisations ,family members, elected representatives and policy makers. We are hopeful that there is a pathway forward to a time when AAC is seen and understood as a human right and where it is valued, honoured and respected.

We commit at Inclusion Ireland to campaigning for the changes so badly needed and to working in partnership with people who can make the changes happen, guided always by the voice of the AAC user