

Beth presented at ISAAC 2014 and Emma delivered her part of the session through pre-recording her slides as she was unable to travel from Queensland to Lisbon.



Emma and I live at different sides of the world, yet, we have been friends for over 7 years. I live in England. Emma lives in Queensland. Our friendship has been built through using technology, and spending time together, both in England and at ISAAC in Barcelona.

Objectives

- To define “Connectedness”
- To discuss the importance of “Connectedness” in everyday life
- Mainstream research and lessons for young people who use AAC

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Our session was to explore, connectedness. Emma and Beth researched connectedness for young people who use AAC. They considered what connectedness means. Shared some of the ways they had made it happen for them in their everyday lives, referring to academic research throughout.



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Everyone is connected, one way or other. Maybe as a Mother or a Father. We could be a Sister or a Brother or a daughter or a son. Or just a friend to someone, a mentor, a sports coach or an employer. No matter who we are, we are all connected somehow.

Longman Dictionary of English

“connectedness is the **feeling** people have that they are **members** of a group in **society** and that they **share** particular qualities with other members of that group”

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So. What is connectedness? The Longman Dictionary of English defines "connectedness as the feeling people have that they are members of a group in society. And that they share particular qualities with other members of that group".

AAC and connectedness



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Some research implies connectedness is how people are connected by technology. Beth found only a little research around teenage connectedness. And even less on AAC and connectedness there appeared to be nothing about teens and AAC. The research found didn't talk about communication but without communication connectedness couldn't happen.

What is connectedness?

- “It is a **sense of being**
 - a part of something larger than oneself.
 - **belonging**, or a sense of accompaniment.
- It is that feeling in your bones that you are **not alone**.
- Connectedness is a force that urges us to ally, to affiliate, to enter into **mutual relationships**, to take strength and to grow through cooperative behaviour.”

Source: E. Hallowell. Et al. 1993: ‘ Finding the Heart of the Child, Association of Independent Schools in New England, Inc., 1993. 193-209

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Hallowell suggests connectedness is that feeling we have of belonging, or the sense, no matter where we are that we are never alone. This comes from feeling welcomed by others in school, home, work and the wider community. The need for connectedness makes every human being want to make friends and build meaningful relationships.

Karcher (2011)

- Measures teenage connectedness by “their activity in in various places and how we care for people in our social environments”
- This is the **social support** from
 - Peers
 - Friends
 - Adults
 - Media
- And belonging through **social relationships** with
 - Family
 - Close circles of support

Karcher, 2011, The Hemingway Measure of Adolescent Connectedness

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Karcher, used the Hemingway measure of adolescent connectedness, to evaluate the social support teens get from peers, friends, adults and the media. This focuses on achieving a sense of belonging through social inclusion. And attachment, the important safe

childhood relationships to key family members and the close circle of support we all need for mental well being.

Balandin (accessed 2013)

- “satisfying social relationships are important for good physical and mental health”
- Yet People who use AAC
 - Lonely
 - Over reliant on families
 - Have difficulty forming relationships
 - Few work opportunities
 - Poor access

Restricted by ‘gatekeepers’

<http://www.dart-ghg.org/public/anpassningar/Loneliness%20and%20AAC.pdf>

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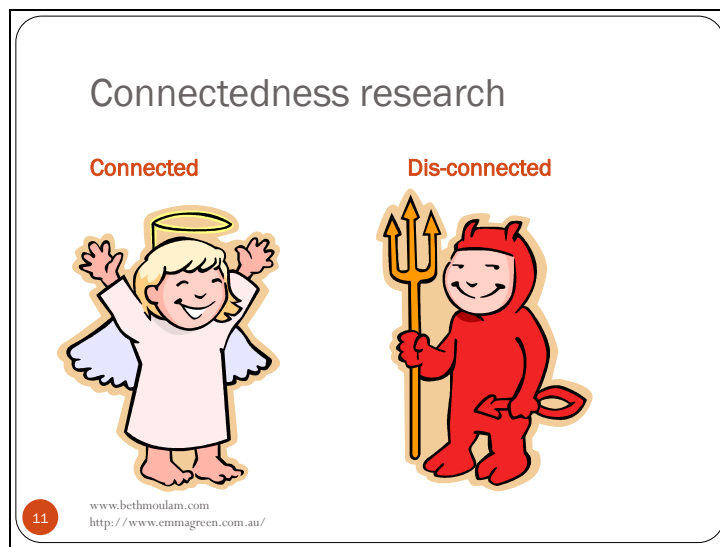
In her research, on loneliness and friendships, with people who use AAC, Balandin suggests younger people who use AAC may feel lonely due to reliance on family. They face difficulty forming relationships inside and outside of school. Their future may be limited by lack of work opportunities. And they may experience poor access to friends, sometimes because of others being unwilling, or unable, to help them meet up with friends, or be in an environment to make friends.

Balandin (2)

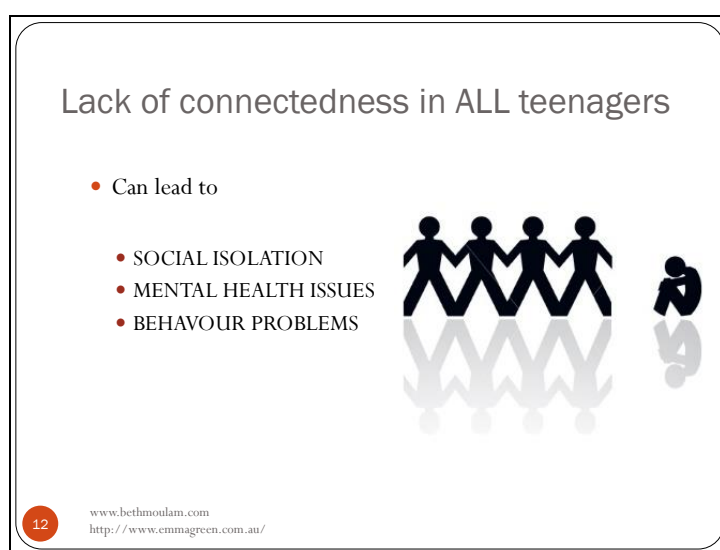
- Barriers to connectedness
 - Over protective families
 - Lack of time and support to train communication partners
 - Not enough support to develop use of effective communication systems
 - Lack of privacy

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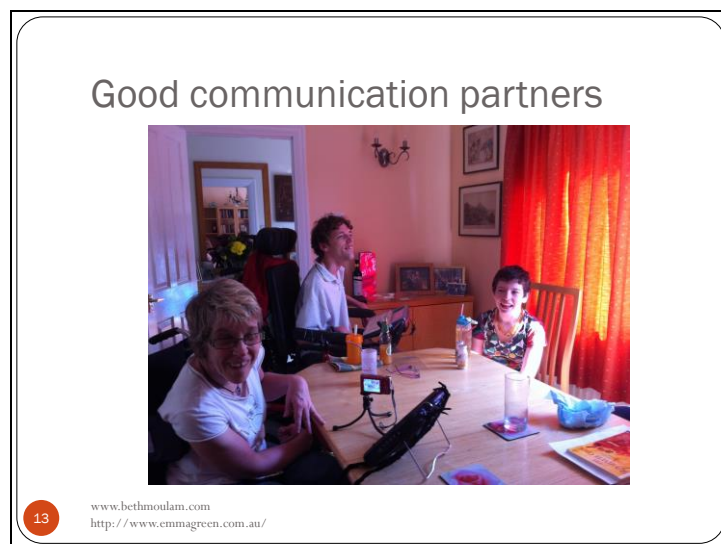
Balandin's work also suggests barriers to connectedness can be over protective families. Communication partners sometimes lack time and skill to help people, who use AAC, to develop relationships. And there may be insufficient support to develop effective use of communication systems ongoing. A further barrier can also be the lack of privacy experienced by those of us with complex needs. We will come back to this later.



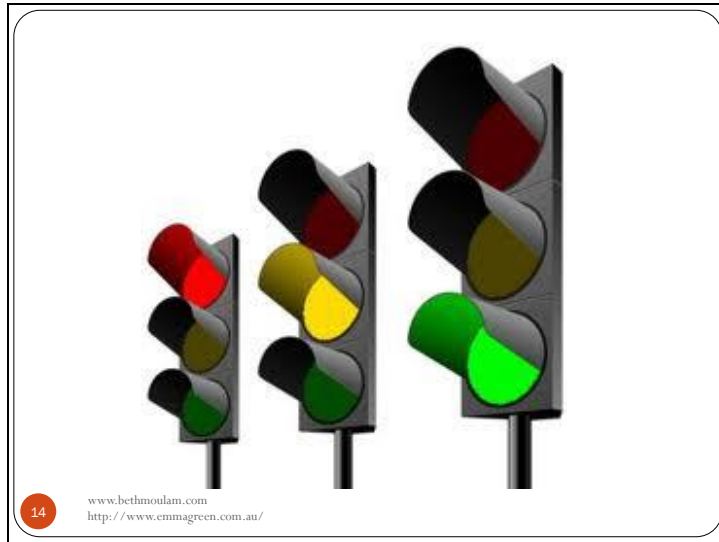
Throughout the research there was proof that all teenagers who are connected at home, at school, socially and to themselves are more engaged, achieve more and stay out of trouble. Without connections all teenagers risk being seen as dysfunctional.



Having little or no natural speech can create huge problems including social isolation, mental issues and behavioral problems. Exactly the same issues when there is a lack of connectedness for all teens. The main difference, for those of us who use AAC, is that it can be more challenging to explain we are lonely. To share when we have things on our mind. And in some cases we may act inappropriately if we can't explain. If we need trusted communication partners to explain our concerns to, we also need trusted and well trained staff to support us to put it right.

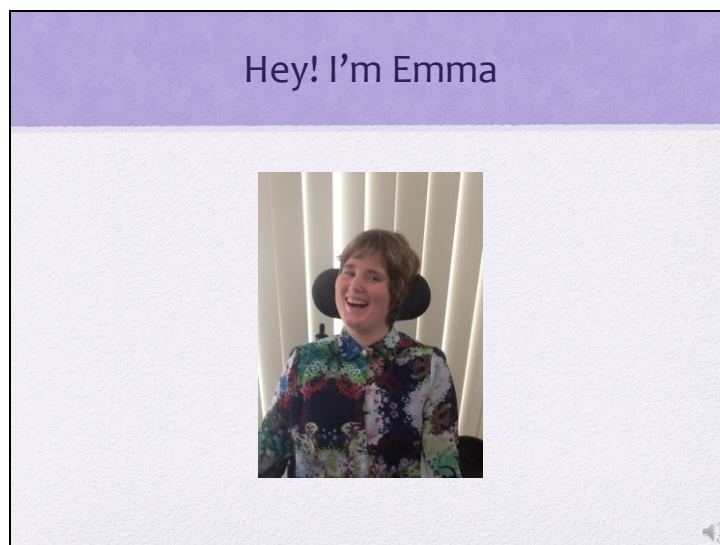


Connectedness is not just about being asked questions and giving answers, we do not want to be passive communicators. It's about meaningful and purposeful conversations. Having a functional dialogue. Providing direction, and the ability to be creative spontaneously. We want to ask questions, and go with the flow. This means we need well trained and supportive communication partners. Clearly there is a theme coming through here, the right communication partners are vital.



Throughout our short lives, both of us have experienced low and high expectations from extended family, professionals, teachers and other staff. Some people have been incredible, others not so. We have met those who would ask a question but couldn't be bothered to wait for a reply. We both know people who made us feel good about ourselves and those who ignored us when we needed or asked for help.

Emma shares her experiences of being connected.



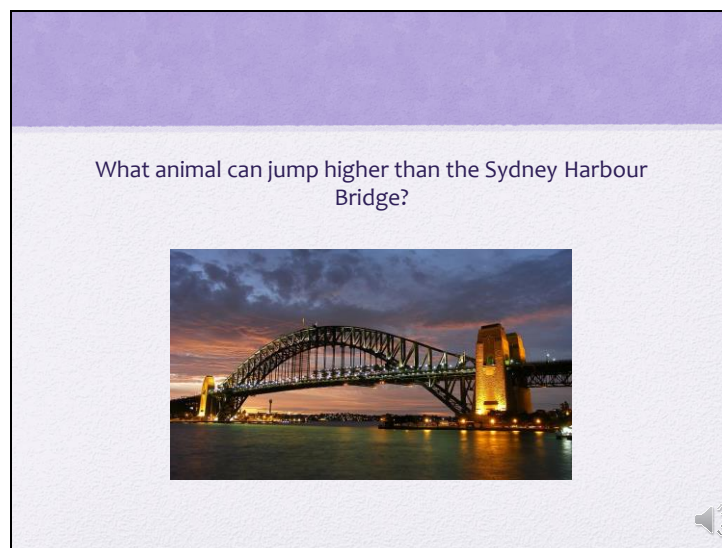
i, my name is Emma.

Even though I can't be with you today, I am excited to have this opportunity to present with my friend Beth.

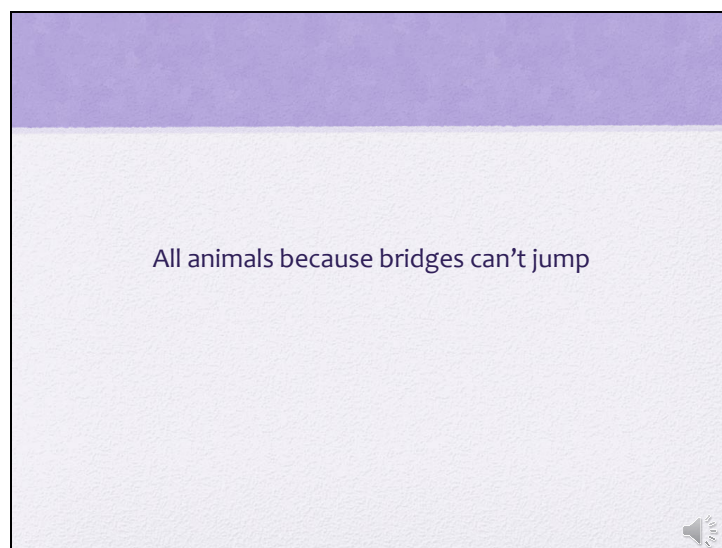
She is a fantastic role model and encourager, and best of all she is my friend.

I am 19 years old, and as you already know, I am from Australia.

As you know, we Aussies love a good joke, so here is one I'd like to share with you.



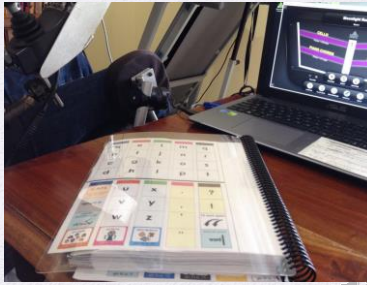
What animal can jump higher than the Sydney Harbour Bridge?



All animals because a bridge can't jump. k, maybe not so funny.

My Multi Modal Communication

- PODD Communication Book
- Tobii with Eye Gaze
- iPad (Tap Speak Sequence)
- Eye pointing
- Facial expressions
- Signs
- Gesture and vocalisations



So here is a little bit of info about me.

I use multi modal communication.

I use a PODD communication book, a Tobii communication device with my eyes, my iPad, facial expressions, signs, gestures and vocalisations.

I can also say a few words but only close family understand my natural speech.

On my Tobii I am learning to send text messages, emails, and use face book.

My Tobii has been a great way to expand my network of friends and to continue to build on my connections.

I am currently studying at home, having my gap year and I am working to get ready for college, which I hope to go to next year.

I hope to go to college and then to university, and eventually be an advocate for those who have no voice.

Being connected is important

- Family
- Friends
- Role Models
- Therapists and educators
- New connections
 - e.g Boccia Team
- Facebook network



Being connected to family, friends, role models, therapists, educators and the other people who are supporting me on my journey is important to me.

I work hard everyday to stay connected.

I use my technology to communicate with people around me and further away.

Some of the great connections I have are my family who are always there for me, and my friends.



I also have some amazing connections with therapists, and some doctors who have known me a long time.

I like making new connections too. I have just started playing Boccia, and now I have a whole new group of people to meet with and communicate with. They are beautiful people who are patient and encouraging with my communication.

I also have my face book network of friends that I am building.

Morgan


- Text messages
- Facebook



**This is my friend Morgan.
She is a good example of one of the friends in my net work.
We send each other text messages, we face book, we go shopping
and to movies and shows.**

Good friends and role models

- Include me
- Inspire me
- Understand me
- Motivate me



**I am so lucky to have good friends and role models in my life.
They include me.
They inspire me.
They understand me.
They motivate me to keep trying.**

Without connections
I feel

- Angry
- Upset
- Annoyed
- Depressed
- Worried
- Lonely
- Disempowered
- Frustrated
- Uncomfortable
- Unmotivated



I have always had to work really hard to communicate and sometimes still communication breaks down, and it can be very frustrating for me, and for the people I'm talking to.

With out strong connections in my network I sometimes feel :

Angry

Upset

Annoyed

Depressed

Worried

Lonely

Dis empowered


Frustrated

Uncomfortable

And unmotivated

Good connections
make me feel

- Safe
- Terrific
- Comfortable
- Empowered
- I have control
- Included
- Sense of belonging



However I am lucky, most of the time I have good connections.

This makes me feel :

Safe

Terrific

Comfortable

Em powered

Like I have some control

Included


And like I belong

I want connections with people and I want to stay connected.

I never forget a strong connection, a bit like an elephant, I never forget.

Some of the challenges

- Credit on sim card to send sms from Tobii
- Facebook won't load
- New PA
- Meeting new people
- It takes time to learn how I communicate
- Frustration
- Emotions
- *Back up is so important



Some things can be hard for me though.

There are challenges to staying connected.

It doesn't always work, but these challenges just make me determined to work harder.

For example, I can't send text messages to my friends if mum doesn't put credit on my sim card for my Tobii, or if face book wont load properly, or when I have a new PA and she doesn't know how a PODD works.

And it is always a challenge meeting new people.

It can take a long time for people to learn how I communicate so that they understand me.

It can be frustrating for everyone.

And there is emotion and medication side effects.


I get so excited, upset or angry sometimes, that I can't communicate as well as I normally do.

Some of this is related to the type of CP I have, and some is related to the medication I have to take that keeps my epilepsy controlled.

Even my yes and no can be hard to read if I am really upset, and if I get really worked up I have trouble even using eye gaze on my Tobii. So it's really important that I have back up methods to communicate.

Hopes, Dreams and Aspirations

- College and University
- Strong connections will help me achieve my dreams
- Over to you Beth!



**I am working hard right now and it is so important that I do.
I want to go to college and one day to uni.
College and uni will be a big challenge and take me longer than most people because I have to write my notes using my PODD book or my communication device, using my eyes.
I also get tired very quickly, and this means I can't work as hard or as fast as other people. I know that I need help with more things than most people, but that wont stop me.
I have hopes, dreams and aspirations. And I need strong connections around me so that I can achieve my dreams.
I would like to hand over to my amazing friend Beth now.**

Thank you Emma. My experiences and feelings are very similar so I am not going to repeat what Emma has said. I do want however to expand with one example of building new connections.

University of York



- Built environment
- Disability support team
- Support Agency
- Academic Staff
- Family and friends in York

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Emma mentioned her dream of going to University. I have finished my first year at The University of York. From the minute I first contacted York, I felt a connection with both the academic and support people I met. The campus is accessible and I have achieved academic success.

Families

- Communication competence and confidence is built around family support
- Connectedness through secure family relationships
- Making time to communicate
- Ensuring the resources needed are always to hand

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Emma and I promised to share with you some of our practical strategies to develop social connectedness, as teenagers who use AAC. First we are both fortunate to be part of supportive families. But, we know that families come under huge pressure with all our constant needs. It could have been easy for our families to stay at home, not to have fought for the resources we need, or not given us the time to express ourselves. Feeling secure at home has helped us to be more confident in the wider world.

Modelling good communication partner skills

- With
 - Extended family
 - Friends
 - Support staff
 - Professionals (outside of SLT)
 - Wider community

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Our families need to model good communication partner support, so when we meet someone else they know how to bond with us. This includes shop keepers, doctors and new personal assistants.

Access to communication resources and communication partners

- Equipment charged and ready to go
- Always on hand
- Kept up to date with changing vocab and software
- New staff trained

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To make sure our equipment is available throughout our lives, we need to make sure it is well maintained, and we need access to the right vocabulary to share our feelings and experiences. This vocabulary needs to grow with us. In school this was supported by staff, in adult life it's our responsibility, and that of our families. Life doesn't stop when we leave school. As we move on it will become the role of paid staff.

Communication partners


- Listen
- Give us eye contact (be on our level)
- Repeat or re-phrase what we say by agreement only
- Ask only one question at a time
- Know when not to speak and how to wait
- Be (and look) interested
- Know how to repair conversations.

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Both of us have access to trusted people, not just family, who know how to listen to our concerns and support us in agreeing a course of action. I also have regular counselling. I find the ability to talk to someone trusted and non-judgmental who is not part of my everyday life essential in making sense of things. Supportive and well trained communication partners are crucial. For us a good communication partner listens and doesn't interrupt. Gives us eye contact by getting down to our level. Repeats or rephrases what we say only by agreement. Knows when to be quiet and how to wait for us to compose what we want whilst remaining engaged. If you start looking around the room we might think you are bored! The list could go on but this is for starters.

Friends and Social Networks

- Create, make and maintain opportunities
- Make it fun for others to be with us
- Join community groups
- Make and maintain social networks using technology

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Like everyone else we need friends. This often doesn't happen naturally. Both of us have had parents who go out of their way, to create situations where we can make, and be with friends. They have helped us to join community groups and develop social networks to keep up with people.

Role Models and Mentors

- Seek out role models (good and bad) in every part of life
 - These don't need to be people who use AAC
- Observe and understand their achievements, expectations and experiences
- Develop mentors with trusted individuals who will answer questions and share experiences freely
 - These don't need to be people who use AAC

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Role models and mentors are vital for everyone. We are both fortunate to have some amazing people in our lives, but none of them live nearby. Technology allows us to create and maintain these. As our relationships have developed with role models some have become mentors, people we can look to for advice and support rather than just observing their communication skills, lifestyle and experiences.

Privacy

- Allow us to have private times
- Create opportunities for support by different people for different activities
 - Going to the doctor versus shopping
- Beware of becoming OVER-CONNECTED
 - Every teenager needs space – WE ARE NO DIFFERENT

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Balandin mentioned in her research the issue of privacy, being self-contained is an important part of connectedness. This is a tough one for people like Emma and myself. We need support 24 hours a day. Whilst being connected is vital there is the risk of being over connected! We can have few secrets, little in our lives is private.

There is a balancing act to agree who supports us, in what type of activities, and when.

Gatekeepers

Whoever you are
please

Before you make a
decision for us –
check what we want



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Balandin also quoted gate keepers as being important in developing friendships. People can unwittingly become barriers to being connected if they are unwilling, or unable, to get us to places we want to go. Or, they make decisions on our behalf without consulting us in what we want. To quote an often used phrase by disabled groups. 'nothing about us, without us'.

Connectedness is essential

- Every human being needs to be connected in time, space and to others
- Research is needed in practical strategies to support people who use AAC to develop connectedness
- Thank you to everyone who we connect with

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These are just our personal views. We would like to see further research in practical strategies in supporting children and young adults facing transition who use AAC to develop connectedness.

In summary, it does not matter where we live, or if we use AAC, we all form connections with others, to places and a feeling of belonging in similar ways. Connectedness is vital for every human being.

Meanwhile, we are grateful for our families and support workers who do an amazing job. And a special thank you to Emma, for being here in voice and spirit if not in person.