

InterAACt: Communication, Connection and Community

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¹ The Communication Toolbox

Short Abstract

This presentation explores the importance of communication, connection and community for people with Rett syndrome. Supporting women with Rett syndrome to learn to use Augmentative and Alternative Communication (AAC) is crucial for developing communication autonomy. Communication is the pathway towards connection, and the goal of connecting is to understand and be understood.

Creating meaningful opportunities to connect with people is critical –AAC can be effortful and fatiguing, so there needs to be a compelling reason to persist. Creating connections with others and participating in engaging activities can be motivating forces. Connection is a two way street, so support must include ways for individuals to share personally relevant information as well as opportunities to seek information. AAC needs to be customised to include messages that enable the individual to communicate about the topics that interest them, as well as those of familiar communication partners. Signalling that we care about others' interests demonstrates our investment in relationships and fosters closeness.

Being part of a community means you are connected within a network of people who care about you and notice your absence when you are not there. Creating communication-related experiences for women with Rett syndrome can be a powerful way to support people to establish connections in their local area to develop a sense of community. This presentation celebrates the experiences of people with Rett syndrome as they have developed their use of AAC while connecting with others and exploring new experiences.

Long Abstract

Communication, connection and community are important elements of a good life. To “...*have a rich and meaningful life that is purposeful...and includes valued roles and rich relationships with a wide range of people...It is the difference between merely ‘existing’ in life and, instead, thriving.*”[\[1\]](#) This presentation explores the importance of communication, connection and community for people with Rett syndrome. Supporting women with Rett syndrome to learn to use Augmentative and Alternative Communication (AAC) is crucial for developing

communication autonomy. Communication is the pathway towards connection, and the goal of connecting is to understand and be understood.

When we focus on improving communication skills alongside a broader goal of supporting people to establish connections with others, we are supporting people to improve their access to the good things in life. *“One principle should guide families, community service workers, governments and anyone else who cares about people who need some support. That principle is this: the goal of everything done with that person should be to ensure they get access to the good things in life – love and friendship, respect, the chance to develop their abilities.”* [2] Communicating to connect with others is meaningful and motivating and provides a powerful context for speech pathology support. Creating meaningful opportunities to connect with people is crucial – AAC can be effortful and fatiguing, so there needs to be a compelling reason to persist.

Communication support can take a multitude of forms. Supporting people to use AAC to communicate about their interests is integral in helping to identify opportunities where people can engage with others who share their interests. Providing communication support in new environments can be helpful in identifying whether existing AAC strategies will meet the person’s needs in that environment and whether other supports might also be beneficial. Connection is a two way street, so support must include ways for individuals to share personally relevant information as well as opportunities to seek information. AAC needs to be customised to include messages that enable the individual to communicate about the topics that interest them, as well as those of familiar communication partners. Signalling that we care about others’ interests demonstrates our investment in relationships and fosters closeness.

Communication support can help people explore roles and expand their sense of identity. For example, if a person communicates their enjoyment of art, exploring artistic experiences in the community with support could lead to new connections and foster the person’s identity as an artist. Supporting people to explore new experiences that relate to their interests while engaging in speech pathology support can cultivate new friendships and a sense of community. Being part of a community means you are connected within a network of people who care about you and notice your absence when you are not there. *“Studies consistently indicate that relationships and friendships are crucial to the well-being and quality of life of people with disabilities.”* [3] Creating communication-related experiences for women with Rett syndrome can be a powerful way to support people to establish connections in their local area and provide opportunities for people to create relationships outside of home that extend beyond their support team. *“Being part of a community can have a positive effect on mental health and emotional wellbeing. Community involvement provides a sense of belonging and social connectedness. It can also offer extra meaning and purpose to everyday life.”* [4] This presentation celebrates the experiences of people with Rett syndrome as they have developed their use of AAC while connecting with others and exploring new experiences. The women featured in this presentation communicate with purpose to express what is important to them – the people in their lives, their feelings and what is wanted and unwanted. These things are essential elements for living a life with connection, purpose and meaning.

[1] Sherwin, J. (2017). *Good ideas for better lives*. Brisbane: Sherwin & Associates.

[2] Ziegler, H. (2004). *Changing lives, changing communities* Revised edition. Melbourne: Wesley Mission Melbourne.

[3] Kinga, G., Smart, E., Bowman, L., & Pintoa, M. (2023). Social participation interventions targeting relational outcomes for young people with physical and developmental disabilities: an umbrella review and narrative synthesis. *Disability and Rehabilitation*, 45 (13), 2073–2086. doi10.1080/09638288.2022.2085332

[4] Australian Unity in partnership with Deakin University. (2023). Australian Unity Wellbeing Index: Survey 40. The economy, our carers and Australians' wellbeing. Tracking our wellbeing in 2023.. Retrieved from <https://www.headtohealth.gov.au/living-well/connecting-with-others#:~:text=Being%20part%20of%20a%20community%20can%20have%20a,offer%20extra%20meaning%20and%20purpose%20to%20everyday%20life>.

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