Finding their voices. Learning from those who were considered too disabled to talk.

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Short Abstract

Even AAC users' strongest allies can make assumptions, albeit with good intentions, about how people want to be supported. Robust AAC systems are not usually set up to permit people to have control over their life. Nor do they contain vocabulary for the user to discuss their rights and needs. Despite this, AAC users must learn not only how to navigate an AAC system, but also how to navigate a life. People who cannot reliably use spoken words have much to teach us about how this may be achieved.

As the mother of a human who needs AAC, I became passionate about it over 10 years ago. Having completed some extra study in the area, I now manage the Communication and Education Team for Rett UK, work for Microboards Australia, and run my own business consulting with AAC users and facilitating training and support for families and professionals.

I work with people who share their insights through their bodies, AAC devices, spelling, and Talking Mats™ (2023), both commercial and my own versions. I have developed a simplified version of the short Quality-of-Life questionnaire (2004) by the World Health Organisation as a way for people to talk about how they feel things are going in their life.

This talk will discuss what I have learned supporting people to consider what they want and what is important for them. I will share how I have changed my practice, and what these insights might mean for other users and their communication partners.

Long Abstract

Even AAC users' strongest allies can make assumptions, albeit with good intentions, about how people want to be supported. Robust AAC systems are not usually set up to permit people to have control over their life. Nor do they contain vocabulary for the user to discuss their rights and needs. Despite this, AAC users must learn not only how to navigate an AAC system, but also how to navigate a life. People who cannot reliably use spoken words to talk have much to teach us about how this may be achieved.

As the mother of a wonderful human who also has Angelman syndrome, I became passionate about AAC over 10 years ago. Having completed qualifications in the area, I now manage the Communication and Education Team for Rett UK, as well as working as a Microboard's

facilitator for Microboards Australia and running my own business consulting with AAC users and facilitating training and support for families and professionals.

In all my roles, I am fortunate to work with individuals and groups focusing on people who use AAC, both face-to-face and online. My focus is supporting every person to consider what they want and what is important for them. I work with people who share their insights through their bodies, AAC devices, spelling, and Talking Mats™ (2023), both commercial and my own versions.

Through this work it became apparent that a lack of opportunity, confidence and vocabulary for AAC users can make it difficult to discuss how things are going in their life and therefore raise any difficulties. To address this issue, I felt it was important to use a tool that covered the most important aspects of life, allowing people the confidence to know that they were not being influenced to discuss or avoid topics according to other people's perceptions. The Quality-of-Life (QoL) indicators (2004) by the World Health Organisation are both research-based and cross cultural. Both the full 120 question and short 32 question versions cover four main areas:

- Relationships
- Health
- Mental health
- Environment

I first developed a simplified version of the short questionnaire ensuring that all four areas were still covered. Over time I added in questions on communication. Importantly these questions allow individuals to discuss the communication of others as well as reflecting on their own communication. For some the QoL questionnaires are recorded on Microsoft Forms can be completed in as little as 10 minutes by people who are familiar with the questions and the format. Others require further information and find it difficult to concentrate on all aspects at the one time. To help these people address the areas of life that they want to I have developed a Talking Mats™ version. The user should be in control which of the five areas of their life they wish to discuss. By adapting the QoL questionnaires in different ways, it has allowed more people to discuss the good and bad aspects of their life. This is not only reassuring to those around them but can build the individual's confidence about offering feedback on their own life, allowing them an accessible way to share important information.

This talk will discuss what I have learned supporting people to consider what they want and what is important for them. I will share how I have changed my practice, and what these insights might mean for AAC other users and their communication partners.

When AAC users share insights about what is important, it is crucial that we listen. We must use what we learn and add it to the stories and explanations that we then share with others and change our habits, practices and AAC systems accordingly.

References

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