



Autonomy in Decision Making

An introduction and overview of the project

Funding

- This project was funded by a grant received from the Non-Government Centre Support for Non-School (NGCS) Organisations of Western Australia.

Purpose

- The purpose was to look at ways to improve the participation of students in daily decision making.
- Many students have limited opportunities to participate in both large and small decisions in their life because of perceived barriers and lack of access to robust language systems.
- Whilst still advocating for all students to have access to robust language systems, this project aimed to provide schools (and others) with skills and resources which could support all students (regardless of their communication options) to improve their participation in decision making.

Terminology

AAC (Augmentative and Alternative Communication)

An umbrella term used to describe any method of communication which is used to help or instead of speech.

Complex Communication Needs (CCN):

Someone who is “unable to use speech to meet all of their communication requirements, given their age and culture.”

Symbolic Communication:

A symbol is anything someone says or does to send a message that describes objects or ideas.

Symbols can include spoken words, gestures, pictures, sounds, manual signing, and writing.

Example: Pointing to or reaching for a cup to ask, “This one?” or express “I want that cup”

The development of more complex symbolic strategies (like speech) does not mean we stop using less complex strategies (like pointing).

Principle: Article 21 of the Convention on the Rights of Persons with Disabilities (PWD)

“Parties shall take all appropriate measures to ensure that PWD can exercise the right to freedom of expression and opinion, including the freedom to seek, receive and impart information and ideas on an equal basis with others and through all forms of communication of their choice.”

Pressures and Demands

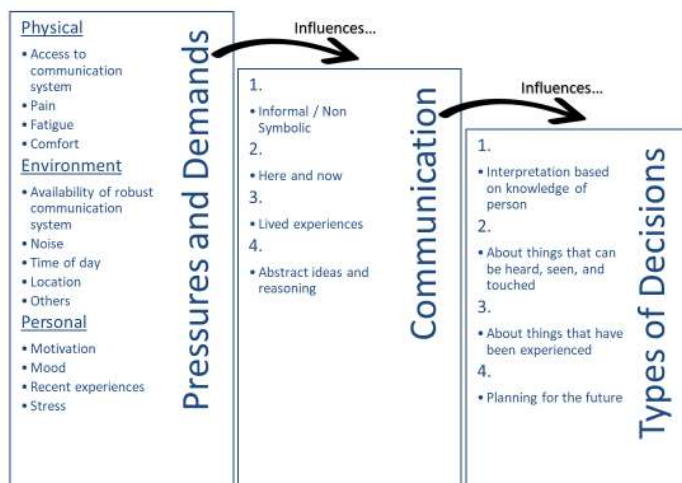
How pressures and demands can influence decisions

Pressures and demands

A variety of physical, environmental, and personal factors can create pressures and demands on an individual. Receptive and expressive communication is affected by these pressures and demands.

Everyone's capacity for making different types of decisions varies depending on their ability to understand the situation and express their opinions.

For individuals with complex communication needs and who use AAC to communicate, these pressures and demands can have an even greater impact on both communication and decision making.



The impact for all

Regardless of someone's communication skills, it is important to consider what pressures and demands are being experienced for appropriate supports and expectations to be in place.

Being prepared and having appropriate supports is essential to effective participation in decision making.

Informal and non symbolic communication

Examples of informal and non-symbolic communication can look like crying, screaming, laughter, reaching, quieting, and movements.

Communication partners typically need to do lots of interpreting of observable behaviour.

Decisions are usually being made about immediate needs and can look like accepting or rejecting, interest or avoidance.

Communication about the here and now

Someone who is communicating about the here and now, usually needs other people to know the setting (context) to understand and might include single or a few concepts.

Decisions at this level may be being made about things external to the individual but might be in the immediate environment.

Communication about lived experiences

Someone communicating at this level does not always require their partner to know or have experienced the same things as them.

Some people may need to have experience with the options to have an informed opinion.

Communication of abstract ideas and reasoning

Discussion of abstract ideas requires access to a robust language system – one that can express a range of unique and varied thoughts.

Decisions at this level could be about the future and potentially about options the individual has not explicitly experienced.

Barriers to Decision Making

Factors which can create barriers to participation in decision making

Perceptions and opportunities

In some instances, people around an individual with CCN may not believe them capable of making decisions and therefore do not provide opportunities; or assume they know the individual well enough to represent their views. This can be the greatest barrier to participation.

Individual

In addition to environmental and perception barriers, there may be individual factors which influence someone's ability to make certain types of decisions at any given time of day.

Understanding how someone is affected by a range of factors is essential to providing the best opportunity to contribute to any decision.

Time factors

It can take more time for individuals with complex communication needs to process and express language.

It is the responsibility of those around them to provide individuals with CCN time to:

- Process incoming information
- Construct and produce messages
- Prepare and contribute to meetings ahead of time

Receptive language

Individuals are regularly presented with information which is inaccessible (content or format).

Understanding how an individual needs to receive information to make certain decisions is essential to creating a space for their contributions.

Expressive language

In some instances, an individual's challenges in contributing an idea is not related to their understanding or thoughts on a topic, but rather their confidence to find or use relevant words to fully express their idea.

It is essential to plan for individuals to have access to and be supported to use communication strategies which facilitate the expression of thoughts and ideas.

Adult AAC user perspective

Bob Williams (fmr USA Commissioner for the Administration of Developmental Disabilities):

"Every person, regardless of the severity of their disability, has the right and ability to communicate with others, express everyday preferences, and exercise at least some control over their daily life.

Each individual, therefore, should be given the chance, training, technology, respect and encouragement to do so."

Melinda Smith (Mentor, public speaker, artist, advocate, communication consultant, advisor):

"Just because you know me doesn't mean you can read my mind or express my words for me".

Resources Pack

Resources pack summary

Assessments

- Independence continuum
 - Establishes insight into current skills and potential target skills which contribute to increasing someone's independence in decision making
- Decision Inventory
 - Provides a snapshot of how much an individual participates in a range of decisions

Individual planning documents

- Decision making profile
 - Establishes a snapshot of current strategies needed to support an individual to make decisions and express opinions
- Communication dictionary
 - Current expressive strategies used by the individual
 - Valuable for individuals at all stages of communication
- Decision planning template
 - Helps prepare for making decisions
- Decision making agreement
 - Used as a record for decisions which are important to the individual

Information handouts

- Preparing for Planning and Workplaces
- Decision making skills – levels 1-5

Communication partner strategies

- Modelling AAC
- Verbal referencing
- Offering choices
- Partner Assisted Scanning
- Descriptive teaching (& planning document)
- Talking Mats (& planning document)

Self-Reflections

- Self-reflection sheets for communication partner strategies
 - Provides communication partners with a breakdown of strategies and a structure to continually assess their own performance.

Visual supports

- Core communication board
- Options book
- Talking mats examples
- Descriptive teaching examples by topic
 - Protective behaviours
 - Planning meetings
 - Emergencies

Resources Pack

References

- Blackstone, S., & Hunt Berg, M. (2003). *Social Networks Inventory: A communication inventory for Individuals with Complex Communication Needs and their Communication Partners*. Monterey: Augmentative Communication Inc.
- Bigby, C., & Douglas, J. (2015). *Support for decision making – a practice framework*. Living with Disability Research Centre, La Trobe University.
- Burkhart, L. Edmister, E., Freed, J., Porter, G., Robinson, S., Staples, A. & Thatcher. E. (2012) *Creating communication communities*. ISAAC conference, Pittsburgh.
www.lburkhart.com/handouts/Communities%20ISAAC%202012%20handout%20C.pdf
- Burkhart, L. & Porter, G. (2006). “Partner-Assisted Communication Strategies for Children Who Face Multiple Challenges” presented at The Biennial International Association of Augmentative and Alternative Communication Conference, Dusseldorf, Germany.
- Douglas, J. & Bigby, C. (2018). Development of an evidence-based practice framework to guide decision making support for people with cognitive impairment due to acquired brain injury or intellectual disability. *Disability and Rehabilitation*, DOI 10.1080/09638288.2018.1498546
- DynaVox, & Dynamic Therapy Associates of Kennesaw GA (2014) *The dynamic AAC goals Grid-2 (DAGG-2)*. DynaVox, Pittsburgh
- Light, J. & Binger, C. (1998) *Building Communicative Competence with individuals who use augmentative and alternative communication*. Baltimore: Paul H Brookes
- Light J, McNaughton D (2012) Supporting the communication, language, and literacy development of children with complex communication needs: state of the science and future research priorities. *Assistive Technology* 24(1):34–44. <https://doi.org/10.1080/10400435.2011.648717>
- Mackay M A & Murphy J. (2012) *Talking Mats and The World Health Organisation (WHO) International Classification of Functioning Disability and Health Children and Youth(ICF-CY): a unique tool for helping adolescents set targets*. Accessed October 29, 2018.Retrieved from <https://www.talkingmats.com/projects/research/>
- Sheldon, E. (Guest). (2019). #031 Using AAC as a tool for self-determination and supported decision making: how to stop guessing what people want. [Podcast Episode]. In G. Stephen (Host), *GoodThingsInLife Podcast*. Retrieved from <https://goodthingsinlife.org/031/>
- Sturum J., Cali K., Nelson N., Staskowski M. (2012). The developmental Writing Scale: A new progress monitoring tool for beginning writers. *Topics in Language Disorders*, 32(4), 297-318
- Witkowski, D., & Baker, B. (2012). Addressing the content vocabulary with core: Theory and practice for non-literate or emerging literate students. *Perspectives on Augmentative and Alternative Communication*, 21, 74-81.