INCREASING AAC-CESS TO INFORMATION, CHOICE AND CONTROL FOR NDIS PLANNING: A PROJECT IN CO-DESIGN

Jaquie Mills and Laura Jones

Abstract

This paper shares strategies for including adults with complex communication needs (CCN) who have not had access to robust augmentative or alternative communication tools (AAC) until adulthood in NDIS planning. We found that a lack of resources and strategies for this group means they are often excluded from planning processes and that supporters may need to explicitly model and scaffold planning and planning vocabulary for it to be understood. The emotional needs of AAC users in building trust that planning is meaningful and that their plans will be heard and enacted was also found to be critical for engagement.

Context

Inclusion in planning for the National Disability Insurance Scheme (NDIS), or indeed any planning, for adults with complex communication needs (CCN) who have not had access to robust augmentative or alternative communication tools (AAC) until adulthood can be complex. Merger of Minds is a group of adults with CCN lead by ISAAC award winner Eli Dickenson who meet weekly to explore AAC, literacy and the supports needed to engage in adult life. They were the co-design group for Developmental Disability WA's ILC grant project exploring how to include adults with CCN in their NDIS planning process. This group of men have a label of profound intellectual disability and all require 24/7 support. They all have AAC systems but are in the early stages of use and continue to need support to learn increasingly effective and efficient ways to communicate using their AAC systems.

Process

The group met weekly over 3 months to find out which planning concepts, vocabulary and experiences were needed for them to understand NDIS planning. They engaged in the design of a planning process and resources to support this process by trying things out and giving us feedback, engaging in shared reading and writing, and making and following through plans and reflecting on them.

Challenges

Where adults have not had access to robust AAC they generally also have gaps in their education, and most of the men had limited experience of academic education, with one not having been allowed to attend school until age 12. Consequently there was uncertainty about their understanding of concepts and language related to planning. None of the men are living with their parents and for two of the men high staff turnover is a challenge which impacts the quality of their communication support. However, as a peer group of AAC learners they have been meeting for between 3 and 5 years and have a shared

understanding of their innate capacity as a communicators and growing sense of their rights to self-determination. Four of the men involved have microboards, a formalised network of unpaid supporters committed to supporting their self-determination throughout their lives.

10 Things About Planning

Ten themes emerged about how we approach planning with this group of people. Overall, it was clear that it is important to emphasise with families and services that planning for a person's life should not be lead by NDIS review dates.

1. Don't plan for the NDIS - plan for the person

Genuine person-centred planning means that planning as a concept and practice is part of the AAC learner's regular supports, and that pathways to lay the foundation for, enact and review plans are embedded in daily and weekly support practices. If planning, enacting and reviewing is embedded in this way, when the NDIS review comes around, the role of supporters is to translate the individual's existing, self-determined plans into NDIS goals.

2. Model planning

AAC learners need to see others model how they plan and to model using the language of planning that exists in the AAC learner's AAC system. This needs to reflect the natural ways we plan. NDIS planning is necessary, but not what people typically do and our aim is to create natural rather than bureaucratic planning processes in a person's life. We need to mitigate the risk that planning becomes yet another thing we impose upon AAC learners. We asked supporters to explicitly model the natural and random ways they make plans in their own lives so AAC learners could witness and process what planning is.

3. Don't plan unless there is capacity to follow through

It was found that many plans are made with AAC learners where they have been asked what they like and want in the past but without following through in ways that showed them a relationship between expressing a desire for something and that thing actually happening. For AAC learners exploring what

Eli Dickenson - Host of Merger of Minds

planning is, it was important that there was a timely follow through to make the connection between making a 'plan' and an action happening. Long-term planning was felt to be relatively meaningless at this stage as the time between the plan being made and something happening was too long. When engaging in early planning with this group, plans were made together and on an individual basis which could be followed through, for example a plan to do an activity together, to buy something, or to go somewhere. Where plans are expressed and follow through is not possible, something tangible needs to happen in response, for example putting a photo or drawing on the planning wall for later reference, or deciding a smaller step towards that plan. For planning to work for the AAC learner, trust needs to be built in the process. We are very vulnerable when expressing the desires for ourselves in our own lives, and people need to know and feel they are safe to be able to make and express their plans.

4. Strategies to get a wide range of options on the menu

This group of AAC learners have significant limitations in the options available for them and are dependent on their communication partners to find ways to expand the range of choices. A range of visual supports were used to do this. For example, planning for a holiday, tourism brochures were used and AAC learners browsed through photos of many different places to visit, places to stay and activities to do. Their supporters cut out any photos they expressed an interest in and made a collage which became the foundation for further planning conversations.

5. Support for decision-making

Once AAC learners had identified a number of things they had interest in, a modified talking-mat approach was used to help them identify the things they liked, didn't like or wanted more information about. For planning a holiday we made card sets with the ideas the whole group had come up with to expand the options further. Any interest in activities were followed through right away if possible - for example one AAC learner said he'd like to make damper on a holiday, but when asked if he'd like to try it that week he said yes, and he came back to group the following week to show everyone photos of him making damper at home as a result of the plan made in Merger.

6. Support to understand concepts

There are many visual resources available that explain the NDIS, however resources explaining foundational concepts and language were not found. This group of AAC learners needed support to understand that the NDIS is a funding program, but they didn't necessarily understand what money was, and two of the men had never handled money or handed money over to purchase something. Working with the AAC learners we identified the concepts of money, what the NDIS does, what I can do with the money the NDIS gives me (in practical terms), goals, plans, choices and control all needed explicit opportunities to be learned, understood and used. Consequently the early process included planning to buy things with money and then doing that during the week.

7. Scaffolding planning in AAC systems

All of the AAC learners use PODD books, and one man has PODD for Compass on his iPad. Using Predictable Chart Writing (PCW) turned out to be a valuable way to start planning conversations. A new pragmatic branch was created for planning and different areas of life in which plans could be made were scaffolded using Categories. Communication partners scanned the different categories asking if there was an area in which the AAC learner would like to make a plan, and then having a conversation about that Category with the person. PCW used 'My plan is about (Category). I want to … We discovered that the AAC learners had unexpressed plans which would never have been revealed without an explicit

opportunity to talk about planning. For example, one man, Dan, said he had a plan about Transport. He wanted to go for a drive with Joe. Joe is the friend and housemate of another AAC learner who comes to the group, and had not previously hung out with Dan. As a result of doing the PCW, Joe made a time to go for a drive with Dan, and now this is a regular occurrence and a friendship has resulted.

8. Adding planning vocabulary to the AAC system

Most of the AAC learners did not have words like 'plan', 'choice' or 'goal' in their AAC systems. In addition to adding this vocabulary we created a specific planning pathway under Activities in PODD which scaffolds planning as something you choose to 'do', 'get' or a place you want to 'go'. Developmentally we feel this is the next step to the Categories based scaffolding mentioned previously. Additionally links to 'with' (person) and 'when' are included. Planning so often focusses on the activities, and not on people and relationships, however who we do an activity with can be more important than the activity itself. Excluding planning for relationships from planning generally contributes to the isolation of AAC learners.

9. Embedding planning in weekly schedules

Our conclusion is that unless planning is part of a person's weekly schedule, then it is easily overlooked. It is very difficult for AAC learners, even when supported by committed communication partners, to express plans. Our AAC learners had many plans they wanted to make which their supporters were unaware of prior to this project. The concept of 'planning' as an activity needs to be explicit so AAC learners can let their supporters know they want to make a plan. However this is not enough and we feel that planning should be an innate part of the weekly schedule for AAC learners and properly scaffolded and supported. Follow through on plans made needs to be reviewed and systems need to be in place to honour the plans of AAC learners so they maintain trust in the process of planning and so they can achieve greater self-determination in their lives.

Ideally understanding and practice of planning will happen at school and students who use AAC will be included in their own IEP goal setting process and other curriculum planning using these kinds of strategies. We need to be asking AAC learners if they want to make plans to go somewhere, do something or see somebody regularly.

10. Visual resources for understanding planning

We made a number of readers to understand planning and NDIS planning as part of this project. They were helpful for the AAC learners to process planning vocabulary, concepts and processes. They will be available on the Developmental Disability WA website (ddwa.org.au) from the end of September.

Jaquie Mills

Project manager at
Developmental Disability WA

jaquiemills@gmail.com

Laura Jones

Lecturer (Complex
Communication Needs)
School of Education,
Edith Cowan University

laura.jones@ecu.edu.au