



AutismCRC

Goal Setting Tool for Adolescents and Adults

The development and evaluation of a goal setting tool for adolescents and adults on the spectrum

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The Cooperative Research Centre for Living with Autism (Autism CRC)

The Cooperative Research Centre for Living with Autism (Autism CRC) is the world's first national, cooperative research effort focused on autism. Taking a whole-of-life approach to autism focusing on diagnosis, education and adult life, Autism CRC researchers are working with end-users to provide evidence-based outcomes which can be translated into practical solutions for governments, service providers, education and health professionals, families and people on the autism spectrum.

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1. Introduction

People on the autism spectrum (hereafter referred to as people on the spectrum) have goals and aspirations that are similar to people who are not on the spectrum, including a desire to live independently, participate in tertiary education and employment, engage in successful social relationships, find a life partner, and raise a family (Autism Spectrum Australia, 2013; Giarelli, Rutterburg, & Segal, 2013). Adolescents and adults on the spectrum are often asked to participate in the person-centred goal setting processes of organisations such as schools (during post-school transition planning), disability services and the National Disability Insurance Scheme (NDIS). Under the Australia's NDIS program, people on the spectrum are asked to meet with NDIS personal planners to discuss their goals and aspirations, with the aim of turning these goals into specific objectives. NDIS participants need to communicate their goals for a 12-month period, and the support requirements needed to achieve these goals.

Person-centred planning processes have been found to be challenging for many people on the spectrum (Hagner, May, Kurtz, & Cloutier, 2014). Barriers to active participation in person-centred planning for people on the spectrum can include a history of low expectations of self-determined behaviour, and challenges in communicating preferences and desires due to social and communication difficulties, and social anxiety (Hagner et al., 2014). If adolescents and adults on the spectrum have difficulty in articulating their goals and prioritising their support needs, they are likely to experience dissatisfaction with the planning process and the services they receive (Hagner et al., 2014).

A card-sorting process has attributes that make it inherently suitable for people on the spectrum. For example, they have been found to have relative strengths in processing pictures rather than words (Kamio & Toichi, 2000). The cards can be physically held and sorted through, which is an easier process to manage than listing goals verbally or in writing. Information presented in concrete ways (such as cards with pictures) has been observed to be more accessible to people on the spectrum than information presented in more abstract ways (Falk-Ross, Iverson & Gilbert, 2004). Cards with pictures are also more accessible to a broader range of young people on the spectrum including those with cognitive, language or literacy difficulties.

2. Project aims

This project aimed to develop and evaluate the *Adolescent/Adult Goal Setting Tool* (AAGST). The AAGST utilizes a card-sorting process, to assist adolescents and adults on the spectrum to develop, prioritise and communicate their goals in a broad range of areas, including independent

living, and social, community, educational and employment participation. Specifically, the project sought to answer the following research questions:

- Research question 1: Are the goals relevant, important, and sufficiently comprehensive to accommodate the potential goals of a broad range of people on the spectrum?
- Research question 2: Are the wording and images on the cards clear and easily understood by a broad range of people on the spectrum?
- Research question 3: Is the AAGST effective in enabling a broad range of people on the spectrum to identify and prioritise goals that are important to them, and to communicate their goals to others?
- Research question 4: How does the use of the AAGST compare to the use of other goal setting processes that have been used by the participants?

3. Method

Ethics approval was obtained from the University of Queensland Human Research Ethics Committee (Approval Number: 2017000005) and the Queensland Department of Education and Training (DET) (Approval Number: 550/27/1911). Four phases involving cycles of participatory action research phases were used to develop refine and evaluate the AAGST. The research designs used within each of the four phases were as follows:

Phase 1: The AAGST was co-designed by people on the autism spectrum, and teachers and allied professionals with relevant experience.

Phase 2: A survey was distributed to adolescents and adults on the spectrum and their families to evaluate the comprehensiveness, relevance and clarity of the goal cards including the clarity of the images and wording.

Phase 3: The AAGST was refined based on phase 2. A second survey was distributed to a second group of adolescents and adults on the spectrum and their families to evaluate the comprehensiveness, relevance and clarity of the refined set of goal cards.

Phase 4: The AAGST was refined again based on phase 3 and was then used by allied health and educational professionals to facilitate the goal setting of adolescents and adults on the spectrum. A generic qualitative design involving semi-structured interviews for participants on the spectrum and family members, and focus groups with professionals was used to evaluate (a) the comprehensiveness, relevance and clarity of the refined set of goal cards, (b) the effectiveness of the AAGST in enabling people on the spectrum to identify,

prioritise and communicate their goals, and (c) the effectiveness of the AAGST as compared to previously used goal-setting methods. Additionally, the researchers recorded their observations of the duration and location of the goal-setting sessions and the fidelity with which the AAGST was used.

4. Development of the AAGST (Phase 1)

The development of the AAGST (Phase 1) was funded by Autism Queensland prior to commencing the Autism CRC Project to evaluate the AAGST.

Participants: The initial design of the AAGST included 3 ASAN Committee Members, AQ professional staff members including two occupational therapists with 10 years and 40 years of experience respectively, one probational psychologist with three years of experience, one senior special education teacher with over 20 years of experience and one senior speech pathologist with over 30 years of experience.

Procedure: The concepts underpinning the AAGST were derived from Autism Queensland's *Family Goal Setting Tool for Families of Children with Disabilities* (Jones, 2013a), and *Family Goal Setting Tool: Autism Spectrum Disorder Version* (Jones, 2013b). The initial goals including the wording were generated by three researchers based on their clinical experience, and a review of the literature and other person-centred planning tools. Factors that were considered when devising pictures for the goal cards included the need to: (a) make the examples concrete, (b) demonstrate positive nonverbal communication and (c) be respectful and inclusive of diversity in terms of ethnicity, gender and sexual orientation. The goals were sent to our illustrator with the wording and sample images sourced from the internet to assist him in developing the illustrated set of cards.

Results: The initial goals and goal categories consisted of 64 goal items in 12 categories. The professional staff and ASAN committee members suggested a number of additions. By the end of extensive discussion and consultation, there were 72 goal items in 9 categories. They were grouped into nine categories including *Social relationships* (13 cards), *Self-care and home living* (10 cards), *Studying and training* (8 cards), *Employment* (6 cards), *Health and fitness* (4 cards), *Community access and participation* (8 cards), *Communication* (9 cards), *Finances* (4 cards), and *Emotional wellbeing* (10 cards). A draft manual and the base plates on which the cards are sorted, were adapted from the *Family Goal Setting Tool: Autism Spectrum Disorder Version* (Jones, 2013) manual and base plates.

5. Evaluation of comprehensiveness, relevance and clarity of goal cards (Phases 2 and 3)

In order to answer research questions 1 and 2, the comprehensiveness and relevance of the goals, and the clarity of the pictures and words were evaluated through the use of two surveys completed by people on the spectrum and their family members.

Participants: The surveys were distributed to participants who included adolescents and young adults on the spectrum and their family members. Participants on the spectrum who experienced challenges in understanding the survey, were given the option of seeking help from a family member or having a family member complete it on their behalf. In Phase 2, the first survey was completed by 15 people on the spectrum and 11 family members. Participants in Phase 3 included 23 people on the spectrum, 19 of whom completed the survey independently, and 20 family members, 14 of whom completed the survey independently. This discrepancy was due to: (a) some family members completing the survey on behalf of the person on the spectrum or (b) the family member and person on the spectrum completing one survey collaboratively (rather than returning both a survey completed by the person on the spectrum and a survey completed by the family member).

Procedure: Participants (adolescents and adults on the spectrum and their family members) completed an online consent form. The researcher then posted the participants the following materials:

- a demographic information form for the person on the spectrum on their age, gender, ethnicity, autism diagnosis, co-occurring conditions, geographical location, and highest level of education.
- a demographic information form for family members on their age, gender, relationship to the person on the spectrum, their years of education, highest level of education and their geographic location.
- Social Responsiveness Scale, Second Edition (SRS-2) (Constantino & Gruber, 2012) as a measure of the autistic traits of the person on the spectrum.
- The Adaptive Behaviour Assessment System, Third Edition (ABAS-3) (Harrison & Oakland, 2015) as a measure of the adaptive skills of the person on the spectrum.
- A link to the online survey described below.

The aim of collecting the demographic information and the SRS-2 and ABAS-3 assessment data was to: (a) describe the sample, and (b) confirm the inclusion of people on the spectrum with a broad range of abilities and ages to ensure that the goal cards would accommodate a wide range of needs. The online survey involved answering the following questions on the 72 illustrated goal setting cards by ticking one of the following check boxes: “yes”, “no”, or “not sure”.

- Is this goal likely to be important to some people on the autism spectrum?
- Do the words on this goal card help you to understand what this goal is about?
- Does the picture on this goal card help you to understand what this goal is about?

At the end of each category of cards, the participants were asked the following open-ended questions:

- In this category, are there any goals/pictures that you found confusing or that you think need to be changed or simplified? If yes, please let us know which goal/picture and why.
- In this category, are there any goals you think need to be added? If yes, please let us know what they are.

The cards were refined on the basis of the responses to the Phase 2 survey. The phase 3 survey included this refined set of cards. On the basis of responses to the second survey, the cards were refined a second time.

Data analysis: The process of refinement involved three researchers carefully considering the feedback on each card, which included the responses to the open-ended question about whether the goals or pictures were confusing or needed to be changed or simplified, in addition to the ratings of the helpfulness of the images and wording. In most instances, there were no clear suggestions about how to refine the images or wording that respondents reported to be confusing. The researchers therefore discussed possible ways to refine the cards at length, and then came to a consensus about any adjustments that could be made in order to convey the meaning of the goal more clearly.

Results:

- **Participant characteristics:** The SRS-2 results suggested that the participants varied in the degree of autistic traits that they experience with 22 (58%) in the severe range, 12 (32%) in the moderate range, two (5%) in the mild range and two (5%) within normal limits. Their adaptive skills also varied with 18 (47%) in the extremely low range, six (16%) in the low range, six (16%) on the below average range, seven (18%) in the average range and one (3%) in the above average range. As the feedback on the cards is from people with a

broad range of characteristics, they are therefore likely to have an extensive range of life goals, and to vary in their capacity to understand the goal cards.

- **Importance of goals:** The AAGST goals were not expected to be relevant to all individuals on the spectrum, due to wide variations in their individual needs, lifestyles and life stages. At a minimum, the goals needed to be rated as important to some individuals on the spectrum to be retained as part of the AAGST. As each of the 72 goals were rated as important by the majority of respondents in both surveys (between 60 and 100 per cent), all the goals were retained as part of the AAGST.
- **Helpfulness of the wording on the goal cards:** The wording in all the goal cards was rated helpful in aiding comprehension of the goals by the majority of respondents (77 - 100% in Survey 1 and 84 - 100% in Survey 2). The wording on a few cards was altered to reduce the complexity of the language.
- **Helpfulness of pictures:** Ratings of helpfulness of the pictures improved from 50 to 100% in Survey 1 to 63 to 100% in Survey 2. Six images were changed, while minor modifications were made to 30 images to convey the meaning more clearly.
- **Suggested addition of goals:** All suggestions for additional cards were reviewed by three researchers, and in most cases, they were able to be accommodated by adding to the examples provided under the existing goals. The only suggested goal that was not covered by the other goal cards was “*Sex education - Relationship do's and don'ts*”. Consequently, an additional card on “*Learning about sex and relationships*” was added.

6. Evaluation of AAGST content and process (Phase 4)

Phase 4 was designed to address all four research questions, as it evaluated the relevance and comprehensiveness of the goal cards, the clarity of the words and images, and the effectiveness of the AAGST in enabling a broad range of people on the spectrum to identify, prioritise and communicate their goals and to compare its effectiveness to previously used goal-setting methods.

Participants: Phase 4 participants included: (a) seven people on the spectrum (aged 14 to 30 years) who used the AAGST to set their goals, (b) three family members of people who used the

AAGST to set their goals, and (c) eight professionals who had supported 31 people on the spectrum to use the tool.

Procedure:

- ***The semi-structured interviews and focus group questions*** covered the same areas as outlined below:
 - Overall impression of the AAGST
 - Ease of understanding of the cards (words and pictures) and comprehensiveness of cards
 - The effectiveness of the AAGST in enabling people on the spectrum to identify, prioritise and communicate their goals
 - Their preference for either a hard-copy AAGST or a digitised (on-screen) version of the AAGST
 - The effectiveness of using the AAGST as compared to previously-used goal setting methods
- ***Information gathered on the participants:*** The same demographic information was collected for the participants on the spectrum and their family members as was collected in Phase 2 and 3. The SRS-2 was used as a measure of the autistic traits of the participants on the spectrum. The Kaufman Brief Intelligence Test - Second Edition (K-BIT-2) (Kaufman & Kaufman, 2004) was also administered to the participants on the spectrum as a brief measure of IQ.
- ***Observations of the AAGST being used:*** Members of the research team observed the goal setting sessions to gather information on the fidelity with which the professionals facilitated the use of the AAGST for goal-setting, and the duration and location of the goal-setting sessions.

Data analysis:

The qualitative data from the participants on the spectrum, family members and professionals were analysed together, using qualitative content analysis, which is a widely used method of eliciting contextual meaning from text through the development of emergent themes (Bryman, 2001).

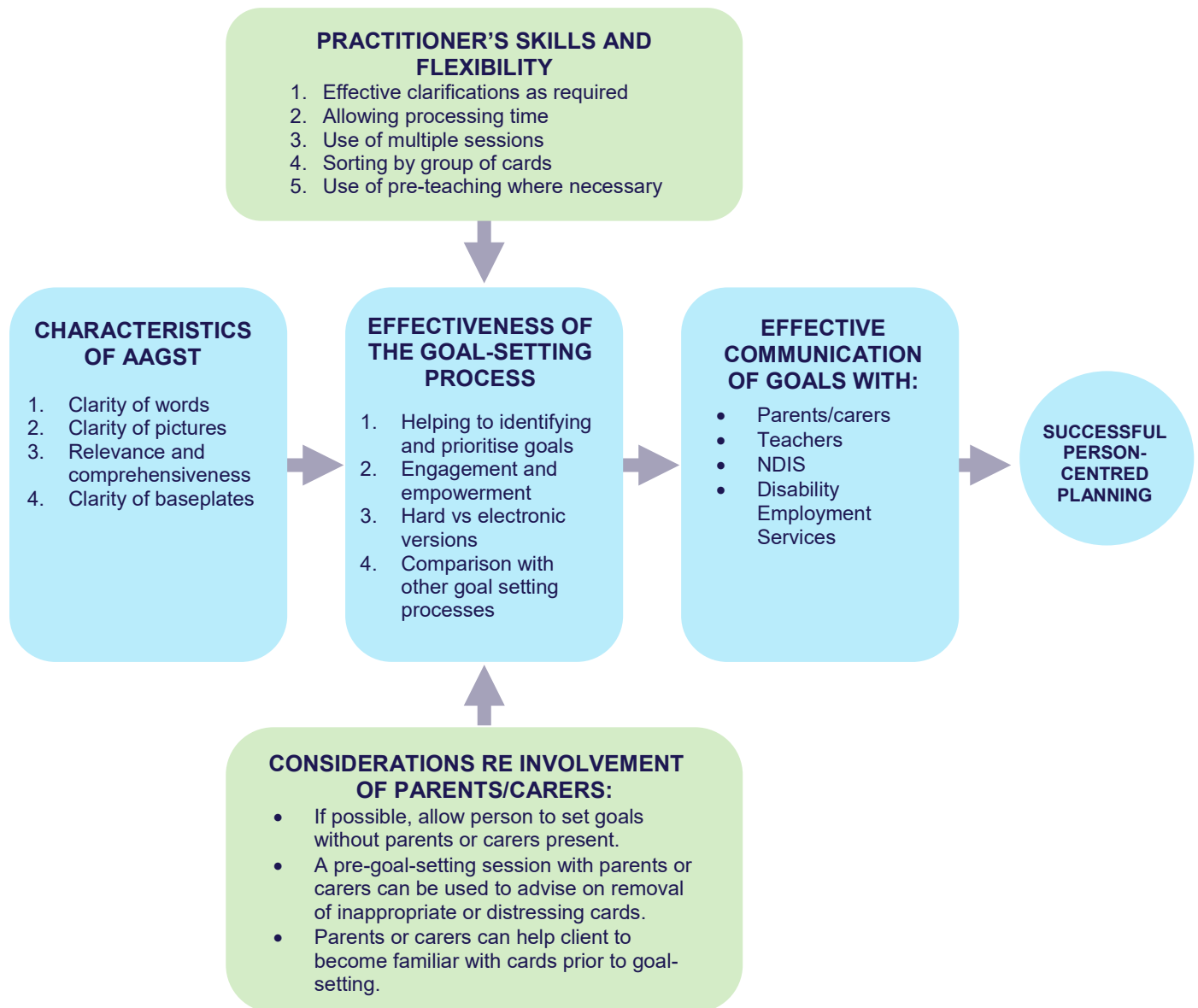
Results:

- ***Characteristics of participants on the autism spectrum:*** Participants on the spectrum who used the AAGST varied widely in terms of: (a) age (14 to 60 years), (b) their estimated

IQ (ranging from mild intellectual disability to high average range), (c) co-occurring conditions and (d) degree of autistic traits. This suggests that the AAGST can be successfully used with people with a range of ages and abilities.

- **Observations of the AAGST being used:** The goal setting sessions of the seven participants ranged from 22 minutes to 2.5 hours in length (M = 54.6 minutes, SD = 44). The goal-setting took place in enclosed rooms, with participants and staff members seated at a table. The essential elements of the AAGST were observed to be completed accurately and consistently by the professional staff on 100% of occasions.
- **Findings from semi-structured interviews and focus groups:** Five themes emerged from the data as being important to the achievement of successful person-centred planning. These included three essential aspects of the planning process: (a) the characteristics of AAGST (b) the effectiveness of the goal-centred process, and (c) effective communication of the goals. Two additional factors, which were observed to impact on goal-setting, included: (a) practitioner skill and flexibility and (b) involvement of parents and carers. These five themes and sub-themes within the themes are illustrated in Figure 1 below. The findings suggest that all the elements represented in the 5 themes combine to contribute to successful person-centred planning.

Figure 1. Summary of the themes and subthemes that emerged in Phase 4



Conclusions

As all the goals were considered important by the majority of participants, they were all retained. While the original set of goal cards was found to be reasonably comprehensive, some additional goals were suggested. However, in most cases, these suggestions could be accommodated by adding to examples to the existing goals. Two additional goal cards were added: (1) *Learning about sex and relationships* (following phase 3), and (2) *Learning about drugs (e.g., cigarettes, alcohol and other drugs)* (following phase 4), as these issues were not covered by the other goal cards. The total number of goal cards therefore increased from 72 to 74 over the course of the

project. In response to feedback, a self-affirming “*I can already do this*” baseplate was added to improve the clarity of the sorting process and to celebrate strengths and achievements. The wording on the cards was considered to be clear and easily understood by people on the spectrum with varied cognitive abilities. Professionals and family members agreed that the images were engaging, and that they aided understanding and reduced processing time. Where necessary, modifications to the images were completed to make the meaning more explicit and less ambiguous. The AAGST was successfully used by individuals with IQs of 52 and above, which suggests that the AAGST is accessible to people with mild intellectual disabilities.

Participants agreed that the AAGST was highly beneficial in enabling people on the spectrum to identify and prioritise their goals. This tool was perceived to be very effective in engaging people on the spectrum, due to its simplicity, user-friendliness and appealing images. The AAGST was preferred by most participants over previously used goal-setting methods because of the ease-of use and the inclusion of a broad range of life goals (most previously used goal-setting processes had focused exclusively on vocational goals). The AAGST also enabled the users to effectively communicate their goals to parents, carers, teachers, NDIS planners and disability employment services. It was therefore perceived to enable successful person-centred planning and genuine self-determination. Two factors that were noted to be important to the effective use of the AAGST were practitioner skills and flexibility, and the consideration of ways to involve parents and carers. In terms of practitioner skills and flexibility, the participants highlighted the need for (a) effective clarifications during the goal-setting process, (b) allowing processing time, (c) use of multiple sessions where necessary, (d) allowing sorting of categories of cards, and (e) pre-teaching of key concepts where necessary. The feedback suggested that it was preferable to allow the person on the spectrum to engage in goal setting without their parent or carer present, to avoid their goals being unduly influenced by others. Nonetheless, parents and carers can play key roles in familiarising the person on the spectrum with the cards prior to goal-setting and advising on the removal of goal cards that may be inappropriate or potentially distressing.

The AAGST gives people on the spectrum a voice when planning their futures. It can be used to enable their active engagement in the person-centred planning processes of many organisations such as the National Disability Insurance Scheme, disability services providers and secondary schools (during post-school transition planning, and disability employment services. In so doing, the AAGST enables people on the spectrum to exercise choice and control over their lives, and therefore has the potential to substantially improve their quality of life.

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