



## Co-Design and Co-Production of a Goal Setting Tool for Autistic Adolescents and Adults

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### Abstract

**Background:** A review of existing tools suggested a need for a goal setting tool for autistic people that (1) addresses the heterogeneity of autistic people to the greatest degree possible; (2) addresses a broad range of goals in areas including self-care and home living, and social, community, educational, and employment participation; (3) incorporates autism-specific adaptations such as visual supports; (4) facilitates the initial identification of goals; and (5) enables the prioritization of goals.

**Aim:** This project aimed to develop a picture-based card-sort goal setting tool with relevant and comprehensible goal cards using a co-design and co-production process.

**Methods:** The first three of four phases of participatory action research (PAR) used to develop the tool are presented, including (1) initial design by autistic people and professional practitioners, and co-production with an autistic graphic designer; (2) survey of 15 autistic people and 11 family members to evaluate and refine the goals, pictures, and wording; (3) second survey of 23 autistic people and 19 family members to re-evaluate and re-refine the goals, pictures, and wording.

**Results:** Responses to open-ended survey questions recommended changing many of the pictures and some of the words on the goal cards. As the majority of respondents rated each of the 72 goals as important, they were all retained. The mean percentage approval of the pictures improved from 78% for survey 1 to 86% for survey 2. The mean percentage approval of the wording improved from 87% for survey 1 to 97% for survey 2.

**Conclusions:** The use of a co-design and co-production methodology over three phases of PAR involving autistic people and their families resulted in many refinements to the goal cards. These iterations in the design process maximized the extent to which the goal cards are easily understood and relevant to the needs of autistic people.

**Keywords:** goal setting, self-determination, co-design, autism, adolescents, adults

### Community Brief

*Why is this an important issue?*

Autistic adolescents and adults are often asked to identify their goals during planning meetings about their support services. However, the goal setting tools that exist often do not provide enough support to autistic people to come up with goals that are important to them and to explain them to others. We developed the *Adolescent Adult Goal Setting Tool* (AAGST) with, and for autistic people to help them set goals that are meaningful and important.

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*What was the purpose of this study?*

We developed a set of cards with pictures that autistic people could sort into piles including a “Yes—now” pile for goals they want to work on, a “No” pile for goals they do not want to work on, or a “Maybe” for goals they are not sure about. The autistic person then chooses between one and six of the most important goals from the “Yes—now” pile and places them in order from most to least important. They are then supported to put their goals into their own words and develop a plan for achieving their goals. The purpose of this study was to gather the opinions of autistic people and their family members on the goals, and the words and pictures on the cards.

*What did the researchers do?*

We wanted to develop a set of goals that are relevant to autistic people, and goal cards with pictures and words that autistic people with a range of ages, skills, and interests can easily understand. Autistic people helped us develop the first set of the cards. We then used a survey to ask 15 autistic people and 11 family members for feedback on the cards. We modified the cards based on their feedback. We used a second survey to gather feedback from a further 23 autistic people and 19 family members. We modified the cards again according to their feedback.

*What were the results of the study?*

Most of the autistic people and their family members rated the 72 goals as important. Based on their feedback, we modified 43 pictures, developed 8 new pictures, and changed the wording on 4 cards. On average, 97% of people who completed the second survey thought that the wording was clear and 86% thought that the pictures were clear.

*What do these findings add to what was already known?*

Extensive feedback from autistic people and their families helped us to develop a goal setting tool to suit autistic people with a range of ages, skills, and interests.

*What are potential weaknesses in the study?*

We do not know if the goal cards are suitable for autistic people who use methods to communicate other than speech (e.g., sign language or symbols) or autistic people from other countries or cultures. Future studies should include these people.

*How will these findings help autistic adults now or in the future?*

The *Adolescent Adult Goal Setting Tool* supports autistic people to express their wishes during planning meetings, giving them more choice and control over their futures.

## Introduction

**A**UTISTIC ADOLESCENTS AND ADULTS often participate in the goal setting processes of organizations, such as schools, disability services, and employment services. Autonomous goal setting enables people to exercise choice and control in their own lives and is therefore an important component of self-determination.<sup>1,2</sup> Evidence suggests that autistic people who are more self-determined have a better quality of life<sup>3</sup> and have more positive life experiences in areas, such as employment status, social participation, advocacy, positive identity, and stress management.<sup>4</sup> This article reports on the development of a picture-based card-sort goal setting tool called the *Adolescent Adult Goal Setting Tool* (AAGST).<sup>5,6</sup> We co-designed and co-produced the AAGST with and for autistic adolescents and adults, with the aim of supporting them to identify and prioritize their goals.

Current autonomous goal setting approaches often do not provide the support that autistic people need to enable them to set personally meaningful goals.<sup>7</sup> A study exploring the

communication experiences of autistic adults highlighted the extent to which anxiety can negatively impact their communication, including during interactions with professional practitioners.<sup>8</sup> Recent research suggests that non-autistic people have as much difficulty understanding autistic people as vice versa (labeled a double empathy problem).<sup>9,10</sup> Crompton et al.<sup>10</sup> found that autistic people can communicate effectively with other autistic people, but communication breakdowns occur more frequently between autistic and non-autistic people.

If autonomous goal setting approaches fail to effectively support communication between autistic people and non-autistic professional practitioners, autistic people are likely to experience dissatisfaction with goal setting and planning processes and the supports they receive.<sup>7</sup> Ineffective goal setting approaches may result in autistic people leaving planning sessions with goals that reflect the ideas of their professional practitioner, carers, or family members, rather than their own ideas. Goal setting processes that facilitate genuine self-determination are therefore essential.

### *Review of current autonomous goal setting approaches*

The *Canadian Occupational Performance Measure* (COPM) is a tool that involves gathering information through a semi-structured interview about activities that the goal-setter needs to do, wants to do, or is or is expected to do, in the areas of self-care, productivity, and leisure.<sup>11</sup> *Putting Feet on My Dreams* (PFD) is a program designed for autistic people without intellectual disability that consists of 10 two-to-three-hour sessions covering knowledge about autism, communication skills, life planning, and goal setting.<sup>12,13</sup> The *Self-Determined Learning Model of Instruction* (SDLMI)<sup>14-16</sup> is designed to enable students to set their own learning goals, make choices and decisions, develop plans to reach goals, and track progress toward goals.<sup>14-16</sup> The SDLMI can be used to support secondary-school-age students with disabilities, including intellectual disability and autism,<sup>14-16</sup> tertiary education students with disabilities,<sup>17</sup> and workers with disabilities.<sup>18</sup> SDLMI is typically implemented during multiple sessions over a period of time.<sup>14-16</sup>

*Transition Assessment and Goal Generator* (TAGG)<sup>19</sup> is an online school-based transition assessment for secondary-aged youth with disabilities, their families, and professionals that aims to identify students' strengths and needs and produce annual transition goals.<sup>19</sup> *myWAY Employability* is a personalized career planner designed for autistic young people without intellectual disability.<sup>20,21</sup> The *Adolescent and Young Adult Activity Card Sort* (AYA-ACS)<sup>22</sup> is a picture-based card-sort tool for adolescents and young adults. McCollum et al. used the AYA-ACS to measure the current participation of young autistic people, without intellectual disability in age-appropriate activities, and to identify new activities in which they would like to participate and barriers to participation.<sup>23</sup>

### *Gaps in current goal setting approaches*

Consistent with the findings of a review by Hodgetts and Park,<sup>24</sup> we identified the need for a goal setting tool that (1) addresses the heterogeneity of autistic people to the greatest degree possible, including those with co-occurring intellectual disability; (2) addresses goals in a broad range of areas including self-care and home living, and social, community, educational, and employment participation; (3) incorporates autism-specific adaptations such as visual supports; (4) facilitates the initial identification of goals; and (5) enables the prioritization of goals, so that the time of autistic people and professional practitioners is used judiciously. Additionally, we identified the need for a tool that is relatively quick and easy to use across a range of practice contexts.

Both TAGG<sup>19</sup> and *myWAY Employability*<sup>20</sup> focus on educational and vocational goals rather than addressing the full gamut of goals that may be important to autistic people. As PFD<sup>12,13</sup> and SDLMI<sup>14-16</sup> are typically implemented during multiple sessions over a period of time, they may not suit services in need of time-efficient goal setting approaches. With regard to visual supports, the AYA-ACS<sup>22</sup> is the only tool that uses a picture-based methodology, making it more accessible to autistic people. Nonetheless, the research underpinning the AYA-ACS,<sup>23</sup> as well as PFD<sup>12</sup> and *myWAY Employability*<sup>21</sup> excluded autistic people with intellectual

disability, and as such, these tools are not appropriate for this cohort. The COPM<sup>11</sup> invites the goal-setter to consider problems that interfere with their occupational performance, but the goal identification process is not facilitated through the use of visual cues, which may limit its accessibility to autistic people.

### *Considerations in designing the AAGST*

The inspiration for the AAGST came from two versions of picture-based card-sort goal setting tools for families of young children, the *Family Goal Setting Tool for Families of Children with Disabilities* (FGST: Disability Version)<sup>25</sup> and the *Family Goal Setting Tool: Autism Spectrum Disorder Version* (FGST: ASD Version).<sup>26</sup> These tools use a goal prioritization process whereby the goal-setter sorts the cards into piles including "Yes, I want to work on this," "No, I don't want to work on this right now," and "I'm not sure about this" and then further prioritizes their goals within the "Yes, I want to work on this" pile. Rodger et al.<sup>27</sup> found that the FGST: Disability Version allowed parents of young children to prioritize what is most important, giving them a place to start when overwhelmed by many possible goals. Similarly, Jones et al. found that the FGST: ASD Version assisted parents to develop and articulate their priorities when overwhelmed by "this huge, big jumble of all the things you want to do."<sup>28(p. 9)</sup>

We aimed to capitalize on the relative strengths of autistic people in processing visual cues.<sup>29</sup> The cards can be physically held and sorted through, which is far easier than listing goals verbally or in writing. Pictures can enhance the accessibility of a tool for autistic people with cognitive or literacy differences, as well as those for whom English is not their first language. Additionally, as autistic adults find that impromptu or unstructured dialogue contributes to their social anxiety, communication supports including mediating objects (such as cards with pictures) can provide a way to initiate and sustain social interactions.<sup>30</sup> The use of pictures may also allow goals that are somewhat abstract, such as social and communication goals, to be presented in more concrete ways to improve accessibility to autistic people. Picture-based card-sort tools support goal-setters with the initial identification of goals by cuing them to reflect on a wide array of goals.<sup>27,28</sup>

This includes goals that the person may not have considered because of assumptions based on previous experiences of goal setting or the scope of a service provider. For example, some young people may assume that they can only set goals in relation to education or employment and may not raise issues of greater personal concern such as learning about sex and relationships, understanding autism, or accessing emotional support. We aimed to design goal cards that would address a broad range of needs, in that the same goal card can have different meanings for different people. For example, "dressing myself appropriately" may be selected for reasons including dressing (1) for a job interview (2) to suit the weather, or (3) to express one's identity. We explain to the goal-setters that goals can be anything that the person wants to change in their life (large or small), including things they want to learn to do (e.g., drive a car), learn to do better (e.g., improve reading skills), do more often (e.g., visit friends), or plans for the future (e.g., find a partner).<sup>3,4</sup>

## Project Aim

This project aimed to design the AAGST to address identified areas of importance including:

- the capacity to be used by a diverse range of autistic people to the greatest degree possible;
- the capacity to address a diverse range of goals relevant to autistic people;
- a process to scaffold the identification and prioritization of goals; and
- the use of visual cues.

The project sought to answer the following research questions in relation to the goal cards:

1. Do autistic people and their family members perceive the goals to be relevant, important, and sufficiently comprehensive to accommodate the potential goals of a broad range of autistic people?
2. Do autistic people and their family members perceive the pictures on the cards to be clear and easily understood?
3. Do autistic people and their family members perceive the wording on the cards to be clear and easily understood?

## Methods

### Ethical considerations

We obtained ethics approval from the University of Queensland Human Research Ethics Committee and the Queensland Department of Education and Training. We provided all participants with participant information sheets, including an “easy-read” version with picture cues, and they all provided informed written consent to participate.

### Research design

#### Participatory approaches

- We used a co-design approach to develop the AAGST. Steen et al.<sup>31</sup> advocate the use of a co-design methodology, as the harnessing of insider knowledge of the people for whom a product is designed ultimately leads to a better fit with their needs. Autistic people with a diversity of ages, abilities, and co-occurring conditions, and their family members, contributed to the AAGST design. We co-produced the tool with the fifth author, an autistic graphic designer who created the card illustrations. The roles of autistic people and their family members as (1) community research partners, (2) core research team members, and (3) research participants are outlined below. The core research team was based at Autism Queensland (AQ), a not-for-profit service provider for autistic people, and included the graphic designer, his mentor (also a graphic designer), two experienced occupational therapists/researchers, and one provisional psychologist/researcher.
- *Initial discussions about the potential value of the AAGST to the autistic community:* The Chair of the Autism Self-Advocacy Network of Australia and New Zealand (ASAN-AUNZ) (*community research partner*) met with the first author. They reviewed the existing FGST: ASD and agreed that a version for autistic adolescents and adults would benefit the autistic community.

- *Review and feedback on the research project plan:* The Chair of ASAN-AUNZ reviewed the research project plan and suggested some changes to the research design, which were implemented by the core research team.
- *Development of initial set of goal cards:* Our graphic designer (*core research team member*) illustrated the initial set of goal cards, drawing on his creativity to translate abstract concepts to concrete images.
- *Review of initial set of 72 goal cards:* The ASAN-AUNZ committee members (*community research partners*) provided an independent review of the goal cards.
- *Completion of Survey 1:* Fifteen autistic people and 11 family members (*research participants*) completed a survey to provide feedback on the 72 goal cards.
- *Refinement of the goal cards following Survey 1:* In response to feedback, our graphic designer (*core research team member*) provided new and revised pictures.
- *Completion of Survey 2:* Twenty-three autistic people and 19 family members (*research participants*) completed a survey to provide feedback on the 72 goal cards.
- *Refinement of the goal cards following Survey 2:* In response to feedback, our graphic designer (*core research team member*) provided new and revised pictures.

**Participatory methods.** This article reports on the first of three of the four cycles of mixed methodologies participatory action research (PAR)<sup>32</sup> (also known as collaborative action research<sup>33</sup>) (Fig. 1) used to develop and refine the AAGST. PAR is recognized as an appropriate methodology for the development or improvement of services or tools, including goal setting tools.<sup>34</sup> It enables refinement of services or tools over time in a progressive manner.<sup>32</sup>

As shown in Figure 1, PAR is a cyclical process with each cycle involving planning, action, observation, and reflection. The first cycle focused on the initial generation of the goal cards by expert panels,<sup>35,36</sup> whereas cycles 2 and 3 focused on refinement of the goal cards from the feedback based on surveys. Cycle 4, which involved a qualitative exploration of perceptions of autistic people, their family members, and professional practitioners of the AAGST goal setting process, is reported elsewhere.<sup>37</sup> Each of these four PAR cycles included multiple “mini” cycles of planning, action, observation, and reflection. The following aspects of the methodology enhance rigor or trustworthiness:

1. Multiple PAR<sup>32</sup> cycles (i.e., four different groups of autistic people and their family members reviewed the AAGST over the four cycles, and professional practitioners reviewed it in the first and fourth cycle).
2. Triangulation by gaining the perspectives of multiple stakeholder groups (autistic people, their family members, and professional practitioners).
3. The use of multiple methodologies including expert panel methodology<sup>35,36</sup> in phase 1, surveys with open and closed questions in phases 2 and 3, and focus groups and semi-structured interviews in phase 4.
4. Purposive sampling to gather the perspectives of a range of stakeholders including autistic people with a diversity of ages and abilities.

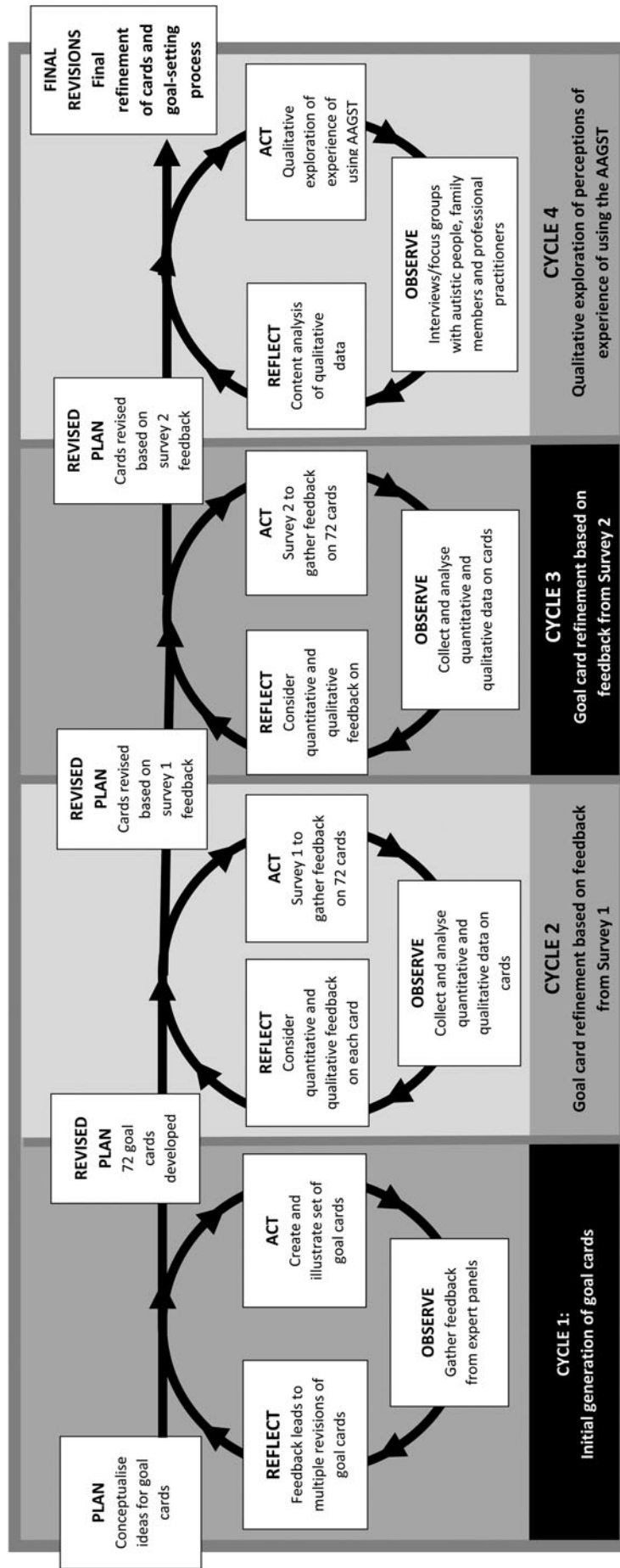


FIG. 1. Participatory action research cycles.

### Cycle 1

**Procedure.** The initial generation and refinement of the goal setting cards involved three panels of experts, and three “mini” PAR cycles. The use of expert panels is a recognized method of consensus decision-making<sup>35,36</sup> often used to develop tools or instruments.<sup>34</sup>

- The first panel of experts, the core research team generated the first drafts of the goals cards. They drew on extensive knowledge of autism, experience in delivering services to autistic people, and a review of the literature and other person-centered planning tools to develop the initial set of cards. The criteria that guided decision-making when designing the goal cards included the need to be: (1) clear, simple, and appealing to adults; (2) respectful and inclusive of diversity in terms of ethnicity, gender, and sexual orientation; (3) sufficiently comprehensive to accommodate a broad range of goals; and (4) sufficiently concise to enable the AAGST to be used in a time-efficient manner. With the aim of balancing the comprehensiveness of the AAGST, and the need to avoid having too many cards in the interests of time efficiency, we considered ways to combine goals where possible (e.g., “managing a bank account” and “budgeting” were combined in one “managing finances” goal). The first draft included 64 cards grouped into 12 categories. The core research team also developed the plates onto which the cards are sorted, the first draft manual, and a draft instructional video.<sup>6</sup>
- We distributed the first drafts of cards to a second panel of experts with expertise in working with autistic adolescents and adults (three speech pathologists, one occupational therapist, and one special education teacher). They responded to the following questions:
  - Are there any items you think need to be added or removed?
  - Do you suggest changing the wording to be more accessible to a range of autistic goal-setters?
  - Do you suggest any changes/additions to categories?
  - Do you suggest any changes regarding cultural considerations?

Their feedback resulted in the addition of some extra goal cards (e.g., “preparing for change”) and amalgamation of some goals (e.g., amalgamation of diet and exercise into “keeping fit and healthy”), bringing the total number to 67 cards. We reduced the number of goal card categories from 12 to 9 to reduce the tool’s complexity (e.g., merging “social,” “relationships/intimacy,” and “caring for others/parenting” into a single category called “social relationships”).

- Our graphic designer illustrated the cards based on sample pictures and wording. We sent the illustrated set of 67 cards to be independently reviewed by a third expert panel, the ASAN-AUNZ committee members who drew on their experiential expertise of autism and advocacy. In addition to the questions provided to the second panel of experts, we asked the third expert panel about the clarity of the pictures. A spokesperson for the ASAN-AUNZ committee contacted the first expert panel (core research team) to discuss the collated feedback of the committee. They suggested five

additional goals that are priorities for autistic people including “disclosure of autistic identity,” “self-advocacy,” and “networking within the autistic community.” They also highlighted the importance of employment for autistic people, which led to the development of two extra employment goals (“applying for a job” and “going for a job interview”). We implemented all recommendations of the ASAN-AUNZ committee. The graphic designer illustrated these additional 5 cards, bringing the total number of goal cards to 72.

- *Draft version of AAGST developed through Cycle 1:* By the end of cycle 1, the AAGST included 72 goal cards grouped into 9 categories: 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 well-being (10 cards). The prioritization process adapted from the FGST (Disability and ASD versions)<sup>31,32</sup> includes sorting the cards on to a “Yes—now” sorting plate for a goal they want to work on, a “No” sorting plate for a goal they do not want to work on, or a “Maybe” sorting plate. We also provide a “Something Else” sorting plate in case the goal-setter identifies additional goals not covered by the goal cards. Any additional goals can be handwritten on a sticky note attached to the “Something Else” sorting plate. We record the goal-setter’s sorting responses on the *Goal Record Sheet*. The goal-setter selects between one and six of the most important goals from the “Yes—now” pile and places them in order of priority (most to least important) on the *My Priority Goals* form (Supplementary Fig. S1). We personalize the goals by writing them in the goal-setter’s own words and record the prioritized goals on *My Goal Tracking Sheet* together with information on what’s happening now, first steps in achieving the goal, and people who can support the goal-setter to achieve the goal (Supplementary Fig. S2). The *My Goal Tracking Sheet* includes a 10-point scale to rate how well the goal-setter feels they are doing with their goal. After working on the goal, the goal-setter reevaluates progress on the 10-point scale.

### Cycles 2 and 3

**Procedure.** We gathered specific feedback about each of the goal cards through two surveys. We chose survey methodology because this was an expedient way to gather feedback on 72 cards. As advocated by Nicolaides et al.,<sup>38</sup> we designed the survey questions to be unambiguous, specific, and concrete to enhance accessibility to a diverse range of autistic people. One autistic adult, and two parents and their autistic sons or daughters, pilot-tested the survey. They found it easy to understand and did not recommend any changes. With the aim of encouraging participation of a range of autistic people (including those with intellectual disability, language disorder, or specific learning disability impacting on reading), we gave autistic participants the option of seeking assistance from a family member to complete the survey.

Some families returned two surveys (one on behalf of the autistic participants, and one on behalf of their family member), whereas other families returned one survey completed collaboratively by the autistic person and their family member. A limitation of this method is that we cannot be sure of the extent to which the comments were the opinions of autistic person or the family member. Nevertheless, we felt that it was important to allow assistance from a family member to include autistic people who benefited from having the questions read to them or from having some words and concepts explained to them. The surveys included the following questions about each goal card:

- Is this goal likely to be important to some autistic people?
- 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?

Possible responses included the following tick boxes: “Yes,” “No,” or “Not sure.” At the end of each goal category (e.g., employment category), we 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.

We refined the goal cards, and, in some cases, replaced the pictures, after survey 1 and survey 2 based on the respondents’ feedback. We distributed the same survey to two different groups of autistic people and their families, with the exception that survey 2 included card pictures and wording that had been revised in response to survey 1. We also collected the following information on the participants to (1) describe the sample and (2) confirm the inclusion of autistic people with a range of abilities, ages, and co-occurring conditions.

- *Demographic information forms.* The autistic participants and their family members provided demographic details, such as age, gender, autism diagnosis, co-occurring conditions, geographical location, and highest level of education, as shown in Table 1.
- *Social Responsiveness Scale, Second Edition (SRS-2).*<sup>39</sup> Either the autistic participants or their family members completed the SRS-2, which is a screening tool to estimate the level of autistic traits (Table 1).
- *Adaptive Behavior Assessment System, Third Edition (ABAS-3).*<sup>40</sup> Family members completed the ABAS-3 as a measure of the adaptive skills of the autistic person.

**Participants**

We recruited participants by advertising the project through AQs networks and social media pages. The eligibility criteria for autistic people included being older than 14 years and having a self-reported autism diagnosis (with and without intellectual disability). There were no specific eligibility criteria for family members. Fifteen autistic people and 11 family members contributed responses to survey 1,

TABLE 1. DEMOGRAPHICS OF PARTICIPANTS

|   | Survey 1:<br>n (%) (n=15)    | Survey 2:<br>n (%) (n=23)    |
|---|------------------------------|------------------------------|
| <i>Autistic participants</i>                    |                              |                              |
| Age   |                              |                              |
| Younger than 20 years                           | 6 (40)                       | 17 (74)                      |
| 20–29 years                                     | 7 (46)                       | 1 (13)                       |
| 30–39 years                                     | 1 (7)                        | 2 (9)                        |
| 40 years and older                              | 1 (7)                        | 1 (4)                        |
| Gender  |                              |                              |
| Male  | 7 (46)                       | 16 (70)                      |
| Female  | 6 (40)                       | 7 (30)                       |
| Nonbinary                                       | 2 (14)                       | 0 (0)                        |
| Highest level of education                      |                              |                              |
| Currently in high school                        | 5 (33)                       | 11 (48)                      |
| Completed year 10                               | 2 (14)                       | 1 (4)                        |
| Completed year 11–12                            | 5 (33)                       | 8 (35)                       |
| Completed 13+ years                             | 3 (20)                       | 3 (13)                       |
| Geographic location                             |                              |                              |
| In a capital city                               | 5 (33)                       | 6 (26)                       |
| In a regional city<br>(population over 20,000)  | 6 (40)                       | 8 (35)                       |
| Within 2 hours of a capital<br>or regional city | 4 (27)                       | 9 (39)                       |
| Type of autism diagnosis                        |                              |                              |
| Autistic disorder                               | 1 (7)                        | 6 (26)                       |
| Asperger’s disorder                             | 9 (60)                       | 10 (43)                      |
| Autism spectrum disorder                        | 5 (33)                       | 7 (30)                       |
| Diagnosed co-occurring conditions               |                              |                              |
| Attention-deficit disorder                      | 3 (20)                       | 10 (43)                      |
| Epilepsy  | 1 (7)                        | 2 (9)                        |
| Intellectual disability                         | 2 (14)                       | 7 (30)                       |
| Anxiety disorder                                | 8 (53)                       | 14 (61)                      |
| Depression                                      | 4 (27)                       | 7 (30)                       |
| SRS-2 level of social impairment                |                              |                              |
| Within normal limits                            | 1 (7)                        | 1 (4)                        |
| Mild  | 2 (13)                       | 0 (0)                        |
| Moderate  | 6 (40)                       | 6 (26)                       |
| Severe  | 6 (40)                       | 16 (70)                      |
| ABAS-3 adaptive skill level                     |                              |                              |
| Above average                                   | 1 (7)                        | 0 (0)                        |
| Average   | 6 (40)                       | 1 (4)                        |
| Below average                                   | 2 (13)                       | 4 (17)                       |
| Low   | 2 (13)                       | 4 (17)                       |
| Extremely low                                   | 4 (27)                       | 14 (61)                      |
| <hr/>   |                              |                              |
|   | Survey 1:<br>n (%)<br>(n=11) | Survey 2:<br>n (%)<br>(n=19) |
| <i>Family member participants</i>               |                              |                              |
| Age   |                              |                              |
| 25–29 years                                     | 0 (0)                        | 1 (5)                        |
| 30–39 years                                     | 1 (9)                        | 0 (0)                        |
| 40–49 years                                     | 7 (64)                       | 9 (45)                       |
| 50–59 years                                     | 1 (9)                        | 8 (40)                       |
| 60 years and older                              | 2 (18)                       | 1 (5)                        |
| Gender  |                              |                              |
| Male  | 2 (18)                       | 2 (11)                       |
| Female  | 9 (82)                       | 17 (89)                      |
| Relationship to autistic person                 |                              |                              |
| Mother  | 9 (82)                       | 16 (80)                      |
| Father  | 1 (9)                        | 1 (5)                        |
| Partner/spouse                                  | 1 (9)                        | 1 (5)                        |
| Grandparent                                     | 0 (0)                        | 1 (5)                        |
| Years of education                              |                              |                              |
| 10  | 1 (9)                        | 4 (20)                       |
| 11–12   | 3 (27)                       | 5 (25)                       |
| 13+   | 7 (64)                       | 10 (50)                      |

ABAS-3, Adaptive Behavior Assessment System, Third Edition; SRS-2, Social Responsiveness Scale, Second Edition.

TABLE 2. SUMMARY OF QUANTITATIVE AND QUALITATIVE RESULTS FOR SURVEYS 1 AND 2

|  | <i>Survey 1 (n=26)</i>  | <i>Survey 2 (n=32)</i>  |
|--|---|---|
| <i>Quantitative data</i>   | <i>Mean of responses to 72 cards</i>  | <i>Mean percentage of responses to 72 cards</i>                                       |
| Is this goal likely to be important to someone on the spectrum?  |   |   |
| “ <i>Yes</i> ”   | 85.9%   | 82.9%   |
| “ <i>No</i> ”  | 6.1%  | 6.7%  |
| “ <i>Not sure</i> ”  | 8%  | 10.4%   |
| Does the picture on this goal card help you to understand what this goal is about?   |   |   |
| “ <i>Yes</i> ”   | 78.4%   | 85.5%   |
| “ <i>No</i> ”  | 13.6%   | 9.3%  |
| “ <i>Not sure</i> ”  | 8%  | 5.5%  |
| Do the words on this goal card help you to understand what this goal is about?   |   |   |
| “ <i>Yes</i> ”   | 87.0%   | 97.1%   |
| “ <i>No</i> ”  | 8.1%  | 1.6%  |
| “ <i>Not sure</i> ”  | 4.9%  | 1.0%  |
| <i>Qualitative data</i>  | <i>Survey 1 (n=26)</i>  | <i>Survey 2 (n=32)</i>  |
| <i>In this category, were 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.</i> | <i>Number and percentage of 72 goal cards with comments coded according to themes</i> | <i>Number and percentage of 72 goal cards with comments coded according to themes</i> |
| Themes related to goals  |   |   |
| Goal has different meanings for different people/not relevant to some people   | 3 (4.2%)  | 5 (6.9%)  |
| Goal applies to everyone—not just autistic people  | 2 (2.8%)  | 0 (0%)  |
| Some participants may not be familiar with goal  | 1 (1.4%)  | 0 (0%)  |
| Suggested different goals  | 1 (1.4%)  | 0 (0%)  |
| Goal not clear   | 1 (1.4%)  | 0 (0%)  |
| Themes related to pictures on goal card  |   |   |
| Meaning of picture is not clear  | 33 (45.8%)  | 19 (26.4%)  |
| Details inappropriate or unnecessary   | 13 (18.1%)  | 7 (9.7%)  |
| Nonverbal behaviors do not reflect meaning   | 11 (15.2%)  | 8 (11.1%)   |
| Alternative picture suggested  | 3 (4.2%)  | 1 (1.4%)  |
| Additional detail suggested  | 2 (2.8%)  | 10 (13.9%)  |
| Themes related to words on goal card   |   |   |
| Wording is not clear   | 1 (1.4%)  | 2 (2.8%)  |

and 23 autistic people and 19 family members contributed responses to survey 2. The survey 1 respondents returned 26 surveys, including 15 on behalf of an autistic participant and 11 on behalf of a family member.

The survey 2 respondents returned 32 surveys, including 7 on behalf of an autistic participant, 7 on behalf of a family member, and 18 completed collaboratively by the autistic person and their family member. Table 1 shows the demographics of the autistic people and their family members and the number and percentage of autistic participants with varying levels of autistic traits according to the SRS-2, and with varying levels of adaptive skills according to the ABAS-3.

#### Data analysis

As shown in Supplementary Tables S1 and S2, there was a “mini” cycle of action, observation, reflection, and revised

plan for each of the 72 cards in cycles 2 and 3. In this study, the “Action” describes the version of the goal card developed in cycle 1. “Observe (collect and analyze data)” details the quantitative and qualitative data collected through surveys 1 and 2. “Reflect” details the core research team’s reflections on both the quantitative and qualitative data. “Revised plan” details the core research team’s reasoning behind the goal card revision. We analyzed the quantitative data using descriptive statistics (number and percentage of respondents who responded “Yes,” “No,” or “Not sure” to the questions about the relevance and importance of the goal, and the clarity of the pictures and wording).

We also calculated the mean percentage of responses for the 72 cards for surveys 1 and 2 (Table 2). To measure changes in responses to surveys 1 and 2 associated with the revisions to the card pictures and wording (there were no revisions to the goals), we compared the mean percentages of



“Yes” responses in surveys 1 and 2 using the Wilcoxon signed-rank test (a nonparametric method was used as the Shapiro–Wilk test indicated non-normal distribution of data). We analyzed the qualitative data using thematic content analysis.<sup>41</sup> We refined the initial set of preliminary descriptive themes until they adequately captured the full breadth of the data. Two coders independently reviewed a subset of the findings to ensure reliability of the coding and resolved any discrepancies through discussion.<sup>42</sup>

There was no established *a priori* percentage of people who rated the goal as important or rated the pictures or words as clear, that triggered card revisions. Rather the core research team’s reflections on both the quantitative data and qualitative themes informed a revised plan (whether to add a new card, retain, or revise the card, and if so how to revise the card). Where both the qualitative and quantitative data indicated that the goal cards were unclear, the core research team discussed many possible ways to change the card. In some instances, there were no clear suggestions about how to refine the pictures. For example, the picture illustrating “Visiting people/having someone over,” showed someone being welcomed at the front door. Although one responder interpreted the picture as “A person walking through a door indicates walking into a room,” the team was unable to think of a clearer way to illustrate the act of visiting people. For example, a picture showing people sharing a meal with their guests would likely have been misinterpreted as depicting a goal about mealtimes.

## Results

As indicated above, the detailed results of the surveys can be viewed in Supplementary Tables S1 and S2. A summary of quantitative and qualitative results for surveys 1 and 2 is also provided in Table 2. This includes the mean percentages of “Yes,” “No,” or “Not sure” responses for the 72 cards to the questions about the relevance and importance of the goal, and the clarity of the pictures and wording. Table 2 also includes the themes that emerged from the qualitative data (the number and percentage of goal cards with comments coded according to each of the themes).

### *Feedback and changes made to goals*

The AAGST goals were not expected to be relevant to all autistic people, due to variations in their individual needs, lifestyles, and life stages. For example, although one participant indicated that the goal on “Exploring spiritual needs” was unnecessary as he does not believe in God, the card was retained as spirituality is important to some people. At a minimum, the goals only needed to be rated as important to some autistic people to be retained as part of the AAGST. The percentage of people who rated the goal as important was not established *a priori*, as restricting the range of goals would have rendered the AAGST less inclusive of the interests of a diversity of goal-setters. As each of the 72 goals was rated as important by the majority of respondents in both surveys, all goals were retained.

As shown in Table 2, the mean percentage of “yes” responses (the goal is important) for all 72 goal cards was 85.9% for survey 1 and 82.9% for survey 2. Relatively few responses to the open-ended survey question (qualitative data) related to the goals (Table 2). We reviewed all sug-

gestions for additional cards, and in most cases, they were able to be accommodated by adding to the examples provided under the existing goals. We considered this preferable to developing new goal cards, due to a concern that too many cards would render the AAGST too time-consuming to use. For example, one respondent suggested an additional goal card for “washing clothes or not wearing clothes too long so that they get stinky.” “Wearing clean clothes” was added as an example to “Dressing myself appropriately (e.g., depending on event or weather, wearing clean clothes).” One suggested goal not covered by the other goal cards on “Learning about sex and relationships” was added, bringing the total number of goal cards to 73.

### *Feedback and changes made to pictures on cards*

The respondents expressed many more concerns about the pictures, than the goals or the wording on the cards. As shown in Table 2, the mean percentage of “yes” responses (the picture aids clarity) for all 72 goal cards was 78.4% for survey 1 and 85.5% for survey 2. The Wilcoxon signed-rank test indicated that the mean percentage of “yes” responses for survey 2 was significantly higher than the mean percentage of “yes” responses for survey 1 ( $Z=5.08$ ,  $p<0.001$ ), which suggested that the survey 2 respondents perceived the pictures to be clearer than the survey 1 respondents. However, these results could also be attributed to sampling differences (e.g., the survey 2 respondents had lower levels of adaptive skills on average than the survey 1 respondents).

With respect to the qualitative themes, 26.4% of the survey 2 respondents made comments suggesting that the picture was unclear compared with 45.8% of the survey 1 respondents, suggesting some improvements in the picture clarity. Compared with the survey 1 respondents, the survey 2 respondents had fewer concerns about the details of pictures but made more comments about the need for additional details. Our graphic designer produced 5 new pictures and revised 29 pictures following survey 1 and produced 3 new pictures and revised 14 pictures following survey 2.



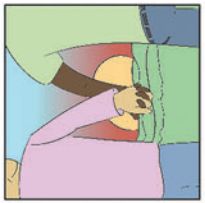
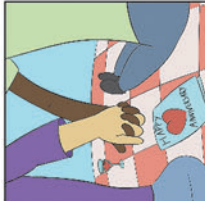
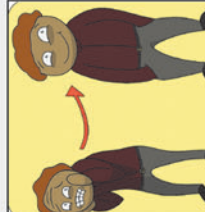
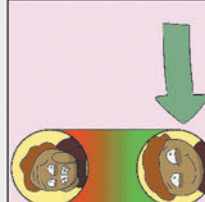





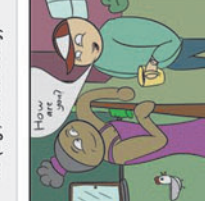
As shown in Figure 2, he used a number of strategies to make the meaning of the pictures clearer. This included adding explicit cues (e.g., “Happy anniversary” card to enhance the meaning of the picture depicting a long-term relationship). He changed the way that nonverbal behaviors were illustrated to enhance meaning (e.g., depicting people smiling at each other to illustrate a friendly social gathering). He also added speech bubbles to convey communication goals more clearly (e.g., a speech bubble saying, “What I need is ...” to the card on “Letting others know my needs/feelings/what’s important to me.”)

### *Feedback and changes made to wording on cards*

Overall, there were fewer concerns about the wording than the pictures. As shown in Table 2, the mean percentage of “yes” responses (the wording aids clarity) for all 72 goal cards was 87.0% for survey 1 and 97.2% for survey 2. The Wilcoxon signed-rank test indicated that the mean percentage of “yes” responses for survey 2 was significantly higher than the mean percentage of “yes” responses for survey 1 ( $Z=7.36$ ,  $p<0.001$ ), which could suggest improvement. However, as we made relatively few changes to the wording, this finding should be interpreted with caution. These results

| Original picture   | Comment   | Changed picture  | Type of change   | Original picture  | Comment   | Changed picture   | Type of change  |
|--|---|--|--|---|---|---|---|
|  <p>Dating/finding a partner</p>  | <p>"I think the dating/finding a partner one just looks like people in a restaurant in general"</p>                   |  <p>Dating/finding a partner</p>  | <p><b>Explicit cues added:</b> Love hearts</p>   |  <p>Making friends/being a friend (face-to-face or online)</p>                                     | <p>"Not sure if friends should be hugging due to ASD tendency to move into other's personal space."</p>                 |  <p>Making friends/being a friend (face-to-face or online)</p>                                     | <p><b>Non-verbal behaviour change:</b><br/>No hugging</p> <p><b>Explicit cues added:</b><br/>Best friends forever T shirts</p>                              |
|  <p>Visiting people/having someone over</p>   | <p>"The visitor's body language is extreme. If someone came up to me like that, I would feel startled and scared"</p> |  <p>Visiting people/having someone over</p>   | <p><b>Non-verbal behaviour change:</b><br/>Visitor's arms down</p>                                 |  <p>Hosting or attending social gatherings/events (e.g., birthdays, Christmas, dinner parties)</p> | <p>"Display relaxed cheerful characters who are modelling the preferred behaviour"</p> <p>"Could be about anything"</p> |  <p>Hosting or attending social gatherings/events (e.g., birthdays, Christmas, dinner parties)</p> | <p><b>Non-verbal behaviour change:</b><br/>People smiling and looking at person in the cap</p> <p><b>Explicit cues added:</b><br/>Banner saying "party"</p> |
|  <p>Understanding contracts (e.g., phone providers, insurance, loans, credit cards, lease)</p> | <p>"Could be redrawn to show one contract ...and someone holding a pen to sign it"</p>                                |  <p>Understanding contracts (e.g., phone providers, insurance, loans, credit cards, lease)</p> | <p><b>Picture redrawn to convey meaning more clearly:</b><br/>Picture of contract being signed</p> |  <p>Relaxing</p>  | <p>"Relaxing looks very stimulating with loud music."</p>   |  <p>Relaxing</p>  | <p><b>Minor changes to enhance meaning:</b><br/>Music removed, and grass added to depict relaxing garden setting</p>  |

FIG. 2. Examples of picture changes.

|   |  |   |   |   |   |  |   |
|---|--|---|---|---|---|--|---|
|  <p><b>Getting emotional support</b></p>     | <p><i>"Looks like how to deal with overly friendly people"</i></p>   |  <p><b>Getting emotional support</b></p>     | <p><b>Non-verbal behaviour change:</b><br/>No hand on shoulder and people are seated facing each other</p> <p><b>Explicit cues added:</b> Cup of tea and box of tissues</p> |  <p><b>Being in a long-term relationship</b></p>  | <p><i>"The concept of long-term needs to be concrete i.e., use of numbers, calendar etc."</i></p> |  <p><b>Being in a long-term relationship</b></p>  | <p><b>Explicit cues added:</b><br/>'Happy anniversary' card</p> <p><b>Minor changes to enhance meaning:</b><br/>Figures more androgynous to broaden relevance</p> |
|  <p><b>Staying calm</b></p>                  | <p><i>"Staying calm looks like two people in uniform, one scared of the other."</i></p>  |  <p><b>Staying calm</b></p>                  | <p><b>Explicit cues added:</b> Stress scale with arrow pointing to 'calm'</p>   |  <p><b>Letting others know</b><br/>my needs/feelings/what's important to me (e.g., self-advocacy)</p> | <p><i>"Perhaps speech bubbles for people talking."</i></p>  |  <p><b>Letting others know</b><br/>my needs/feelings/what's important to me (e.g., self-advocacy)</p> | <p><b>Use of a speech bubble:</b> "What I need is..."</p>   |
|  <p><b>Planning and preparing meals</b></p> | <p><i>"What are the little boxes? Having the word 'meal plan' and a calendar makes the card look like it is about 'schedules' rather than 'cooking'"</i></p> |  <p><b>Planning and preparing meals</b></p> | <p><b>Picture redrawn to convey meaning more clearly:</b><br/>Multiple pictures incorporated into a single kitchen scene to provide context</p>                             |  <p><b>Getting along with others</b><br/>(e.g., being polite and kind)</p>                           | <p><i>"All I see is people sitting down... talking to friends/people"</i></p>                     |  <p><b>Getting along with others</b><br/>(e.g., being polite and kind)</p>                           | <p><b>Picture redrawn to convey meaning more clearly:</b><br/>Greeting a neighbour in a friendly way</p> <p><b>Use of a speech bubble:</b> "How are you?"</p>     |

**FIG. 2.** (Continued).

could also be attributed to sampling differences between the survey 1 and survey 2 respondents. Participant feedback resulted in some changes of wording to reduce the language complexity on four cards (e.g., “Making purchases” was changed to “Buying things” and “Contraceptives” was changed to “Birth control/safe sex” [e.g., avoiding disease and unwanted pregnancy]).

## Discussion

The first research question aimed to determine whether autistic people and their families perceived the goals to be relevant, important, and sufficiently comprehensive to accommodate the potential goals of a broad range of autistic people. The majority of the autistic people and their families perceived each of the 72 goals to be relevant and important. While they suggested some additional goals, in most cases, these suggestions could be accommodated by adding examples to the existing goal cards.

We gathered feedback on the goal cards from a diversity of autistic participants with ages ranging from 14 to older than 40 years, co-occurring conditions including intellectual disability, attention-deficit disorder, anxiety disorder, and depression, and a range of adaptive skills and autistic traits. The aim of gathering feedback from a range of participants was to maximize the potential of the AAGST to accommodate the heterogeneity of autistic people to the greatest extent possible. However, we recognize that there are likely to be some autistic people with intellectual disability whose receptive language means that some of the concepts and wording of the AAGST may not be accessible to them. Additional research into goal setting approaches that effectively accommodate this cohort of autistic people is a priority.

The nature of goals addressed by the AAGST differs from other reviewed goal setting tools, which often focus exclusively on goals related to daily occupations or activities. For example, the study on which the AYA-ACS is based, explored participation in age-appropriate activities of neurotypical young people.<sup>22</sup> Similarly, the COPM focuses on daily occupations in the areas of self-care, productivity, and leisure.<sup>11</sup> While the AAGST does include goals related to daily occupations or activities (e.g., dressing, grooming, finding a job), the co-design process led to the inclusion of goals unrelated to daily occupations that are important to autistic people, such as coping with sensory challenges, understanding autism, and connecting with the autism community.<sup>5,6</sup> The AAGST also includes goals that focus on emotional well-being such as staying calm, and getting emotional support, which may reflect the need to address mental health concerns that can be experienced by some autistic people.

The second research question sought to determine whether autistic people and their families perceived the pictures on the goal cards to be clear and easily understood. We made many refinements to improve the clarity of the pictures. The pictures were more likely to be rated as unclear for goals that were more abstract in nature, such as the social relationships, communication, and emotional well-being goals. For example, rather than interpreting a couple sharing a meal as a “date” in the “Dating/finding a partner” goal card, this picture was perceived as “just looks like people in a restaurant in general.” From a “double empathy” perspective,<sup>11,12</sup>

the feedback of autistic participants was invaluable in identifying instances in which they perceived the depiction of social scenarios to be ambiguous.

The third research question sought to determine whether autistic people and their families perceived the wording on the goal cards to be clear and easily understood. As most autistic people and their family members perceived the wording to be clear, we made changes to four cards only. The capacity to read is not a requirement for AAGST goal-setters, as the professional practitioner facilitating the goal setting process can read the words to the goal-setter. Nevertheless, because it would be preferable for the goal-setter to access this information autonomously, the research team is currently seeking additional funding to develop an online AAGST, which would enable the goal-setter to click on text and have it read aloud (i.e., text-to-speech function).

## Limitations and future research

Although other autistic people and their family members are likely to share the perspectives reported here, we recommend caution if transferring the findings to people from other sociocultural backgrounds.<sup>43</sup> For example, people from culturally and linguistically diverse backgrounds may have different lifestyles and priorities and may therefore have different perspectives on goals that are important. In clinical practice, we have successfully used the AAGST with Australian First Nations peoples, but formal research in this area is required. Although we gathered feedback from autistic people with an intellectual disability and their families, we did not specifically examine the accessibility of the AAGST goal cards to people who use augmentative and alternative communication (AAC) devices to communicate.

Further research into different ways of using the tool with AAC users is a priority, as is the need to explore goal setting with people whose receptive language means that some of the concepts and wording of the AAGST may not be accessible to them. As only 2 of the 72 cards specifically related to autism, it is possible that the AAGST may be useful to people with other conditions. Research with people with other conditions such as intellectual disability or mental health conditions may therefore be warranted.

## Conclusions

The AAGST aims to give voice to the aspirations of autistic people, thereby putting them in the “driver’s seat” of their own life. The design of cards that communicate the goals they represent in an unambiguous way was critical to the success of this tool. The use of a co-design and co-production methodology over three phases of PAR resulted in many refinements to the goal cards. These iterations maximized the extent to which the goal cards are easily understood and relevant to the needs of autistic people.

## Authorship Confirmation Statement

All persons who meet the authorship criteria are listed as authors, and all authors certify that they have participated sufficiently in the work to take public responsibility for the content, including participation in the concept, design, analysis, writing, or revision of the article.



### Author Disclosure Statement

The Cooperative Research Centre for Living with Autism owns the project Intellectual property (IP) of the Adolescent Adult Goal Setting Tool (AAGST) and Autism Queensland owns the background IP. The authors are employed by Autism Queensland. The authors receive no personal remuneration for the sale of the AAGST.

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### Supplementary Material

Supplementary Figure S1  
Supplementary Figure S2  
Supplementary Table S1  
Supplementary Table S2

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