

**AUTISM QUEENSLAND RESPONSE TO THE**

**CONSULTATION PAPER: *SUPPORTING YOU TO MAKE YOUR OWN DECISIONS***

**Please note:**

**This submission focuses specifically on Autism Queensland’s development of the *Adolescent Adult Goal Setting Tool* which was purpose-designed to assist for autistic people and those with other neurodivergent conditions to make their own decisions and therefore reduces their reliance on substitute decision making by others.**

1.How can we help people with disability to make decisions for themselves?

At Autism Queensland, we have worked for some years to ensure that the voice of autistic people is heard during the person-centred planning processes. With some investment from the Autism Cooperative Research Centre (CRC), Autism Queensland’s Research and Development Department co-designed and co-produced a tool with and for autistic people, called the ***Adolescent/Adult Goal Setting Tool*** (AAGST) (Ashburner et al., 2019). The AAGST aims to make it easier for autistic people and those with other neurodivergent conditions to be actively engaged in making decisions for themselves and in planning for their future.

As the AAGST involves sorting of cards with pictures, it can be easily used by people who find it difficult to speak or to articulate their needs and preferences. The AAGST is not a standardised tool. Rather, it is a means for facilitating conversations about their aspirations that circumvents social and communication challenges.

The cards are physically sorted and arranged in order of priority - which is far easier than identifying goals - and then listing them verbally or in writing. The user 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 prioritises their goals within the “*Yes, I want to work on this*” pile. In response to feedback from autistic people, we added a self-affirming “*I can already do this*” pile that adds clarity and celebrates their strengths and achievements. Any additional goals not included in the goal cards can be written on a sticky note and added to the “*Something else*” sorting pile.

As they have ownership of their goals, the users are typically highly motivated to work on them. This tool has been successfully used by wide range of autistic people including those with ages ranging from 14 to 60 years, with abilities ranging from those with intellectual disability to those with superior range IQ, and for people with a range of co-occurring conditions.

We have found that if we engage autistic people at a young age in setting their own goals and making decisions about what they would like to do, they develop confidence in their own decisionmaking capacity and are more prepared to speak for themselves. The degree of self-determination of students with disabilities in secondary school has been found to predict successful post-school outcomes in areas such as employment, community access and tertiary education (Chao, Chou & Cheng, 2019; Shogren, Wehmeyer, Palmer, Rifenbark, & Little, 2015).

While not the focus of this submission, Autism Queensland has similarly developed the *Family Goal Setting Tool for Families of Children with Disabilities* (FGST: Disability Version) (Rodger, O’Keefe, Cook, & Jones, 2012). and the *Family Goal Setting Tool: Autism Spectrum Disorder Version* (FGST: ASD Version) (Jones, Rodger, Walpole, & Bobir, 2018) to assist families of young children with disabilities identify and prioritise family-centred goals.

2.Who are the best people help you (or a person with disability) to make decisions? (We call them decision supporters)

Informal decision supporters

An outcome of the AAGST research project was the finding that some informal decision supporters such as **parents and carers** are very accustomed to speaking for the person with a disability after a lifetime of having to advocate on their behalf. Consequently, some tended to jump in and choose the goal cards for the participant or speak for them. We concluded that in many instances it was preferable to allow the autistic person to engage in goal setting without their parent or carer present. This is particularly the case for young people who have goals that they are uncomfortable discussing with their parent present (e.g., goals around dating or use of contraception). However, parents and carers can play key roles in familiarising the person with the cards prior to goal-setting or advising on the removal of goal cards that the person may find distressing.

Formal decision supporters

Our AAGST research also highlighted the importance of the skills and flexibility of the professional practitioners (formal decision supporters)who arefacilitating the goal setting process. First, practitioners need to accommodate any language or cognitive challenges of the person using the AAGST by adapting their own language, by making it clear that it is okay to ask questions, and by clarifying any cards that they appear to be unsure about. Second, practitioners needed to allow sufficient processing time. Lastly, if the user of the AAGST is likely to be overwhelmed by using all the cards, the practitioners select a subset of cards that are likely to be relevant to their lifestyle to make the goal setting process easier.

1. What should they do to help with decision making?

**Informal decision supporters**

In our experience, parents and carers become more comfortable over time to allow the autistic person to speak for themselves. After observing the results of the goal setting process and the willingness of the autistic person to work on goals that they have set for themselves, parents and carers develop a greater appreciation of the autistic person’s capacity for self-determination.

1. How can they get better at helping?

Autism Queensland has developed professional development activities to improve the capacity of our staff to support the decision-making of our clients. This training could be easily rolled out to support NDIS staff and other professional practitioners to develop their capacity in the areas described below.

While the processes involved in using the AAGST are actually very simple, **formal decision supporters** such as planners and therapists need to develop skills in connecting with people with disabilities. For example, they need to develop an understanding of the person’s preferred way of communicating and their strengths and interests. They also need to allow processing time, and to provide clarifications if the person appears to be uncertain.

We found that some people with disabilities benefit from learning about what a goal is. For this reason, the AAGST includes a goal explanation card. Theprofessional practitioners facilitating the goal setting need to explain what goals are using examples that are relevant to the person’s life. For example, they may explain that a goal is something that the person wants to learn to do (e.g., learning to catch a bus), wants to get better at (e.g., getting better at using a computer), wants to do more often (e.g., visiting people more often) or something that the person is planning to do in the future (e.g., planning to move out of the family home).

**Formal decision supporters** need to encourage the person with a disability to express their goals in their own words, and to facilitate the development of a plan to work on the goal in the person’s own words. For example, they need to ask questions about what is happening now in relation to the goal, what success in achieving the goal will look like, their expected time-frame for achieving the goal and about people who can help them to achieve the goal. The answers to these questions can be used to facilitate the person’s formulation of a plan in their own words. Where possible the plan for working on the goal should incorporate the person’s interests and capitalise on their strengths.

**Informal decision supporters** such as family members may need to learn how to take a step back and allow the autistic adult to find his or her own voice so that they can express their goals and preferences.

1. How can we make sure the right people are helping? For example:

• that they are building the capacity of the person with disability, • that they are considering what the person with disability wants.

An essential quality of decision supporters is a willingness to respect the rights of the person with a disability to have agency in the decisions that they make without compulsion or undue influence from others.

1. What is the best way to support people with disability to make decisions about their NDIS plan? This includes decisions about using or changing their plan.

Person-centred planning processes have been found to be challenging for many autistic people, who experience barriers including a reduced confidence in their own decision-making abilities due to history of low expectations of others, and a reduced capacity to communicate their desires due to social and communication challenges (Hagner, May, Kurtz, & Cloutier, 2014). As autistic adults find that impromptu or unstructured dialogue can contribute to their social anxiety, communication supports including mediating objects (such as cards with pictures) can provide a way to initiate and sustain social interactions (Müller, Schuler, & Yates, 2008). We have found that the AAGST enables them to express their preferences and goals using a minimum of spoken words.

1. Are there different things to consider for people with different disabilities or cultural backgrounds?

The AAGST card illustrations were designed to be respectful and inclusive of diversity in terms of ethnicity, gender and sexual orientation.

However, while the goals are likely to be shared by other autistic adolescents and adults and their family members, people from culturally and linguistically diverse backgrounds may have different lifestyles and priorities and may therefore have different perspectives on goals that are important.

Further research is therefore required to explore the applicability of the AAGST goals to people from different cultural backgrounds. There has been some initial exploration into the applicability of the AAGST with people from remote Aboriginal and Torres Strait Islander communities, but further research is needed.

Although the AAGST was designed with autistic people in mind, many of the research participants had many other co-occurring conditions including intellectual disabilities, language disorders, attention deficit disorders and psychiatric conditions (e.g., anxiety disorder, depression, bipolar disorder). We therefore feel that the tool is likely to benefit people with other neurodivergent conditions.

8.How can we help reduce conflict of interest?

***Conflict of interest is when a person or organisation takes advantage of their position for personal or corporate benefit.***

***Undue influence is when a support person makes the person being supported do something they don’t want to do by making them feel scared, by being mean or by threatening or lying to them.***

The AAGST goals include a wide range of potential goals that may be relevant to autistic people in areas such as social relationships, self-care and home living, studying and training, employment, health and fitness, community access and participation, communication, finances, and emotional wellbeing. The user can choose any goal that is personally important and meaningful. The array of possible goals does not align with services typically offered by autism service providers. For example, it may be important to the person to learn to drive a car, to access a vocational education course, or to join a social club in their local area.

As these are not services provided by autism service providers, the aim is to facilitate the person’s access to mainstream services that can enable them to achieve their goal. Potential conflict of interest as regards directing users of the AAGST to use services provided by autism service providers is therefore not typically a concern.

9.Do you have any feedback on our proposed actions in Appendix C of this paper?

**We believe the AAGST and associated professional training could support the following actions proposed by the NDIS:**

* Development of a targeted approach for complex cohorts to provide decision making opportunities. This includes for participants with intellectual disability, cognitive impairment and psychosocial disability.
* Development of a range of materials that describe the support for decision making process.
* Build the NDIS capability and partners to help them to recognise and support decision making opportunities.

REFERENCES

Ashburner, J., Jones, J., Tomkins, V., McLucas, R., Bobir, N., Taylor, J.& Lister, J. (2019). *The development and evaluation of a goal setting tool for adolescents and adults on the spectrum.* Full report. Cooperative Research Centre for Living with Autism, Brisbane. Retrieved from [https://www.autismcrc.com.au/sites/default/files/reports/3-047\_AAGST\_FinalReport\_2019.pdf](https://www.autismcrc.com.au/sites/default/files/reports/3-047_AAGST_Final-Report_2019.pdf)

Chao, P., Chou, Y., & Cheng, S. (2019). Self-determination and transition outcomes of youth with disabilities: Findings from the special need education longitudinal study. *Advances in Neurodevelopment Disorders, 3,* 29–137. https://doi.org/10.1007/s41252-019-00105-1

Hagner, D., May, J., Kurtz, A., & Cloutier, H. (2014). Person-centred planning for transition-aged youth. *Journal of Rehabilitation, 80*(1), 4-10.

Jones, J., Rodger, S., Walpole, A., & Bobir, N. (2018). Holding the cards: Empowering families through an ASD Family Goal Setting Tool. *Topics in Early Childhood Special Education, 39*(2), 117-130. doi:10.1177/0271121418766240

Müller, E., Schuler, A. & Yates, G. B. (2008). Social challenges and supports from the perspective of individuals with Asperger syndrome and other autism spectrum disabilities. *Autism, 12*(2) 173–190; doi: 10.1177/1362361307086664

Rodger, S., O’Keefe, A., Cook, M., & Jones, J. (2012). Parents’ and service providers’ perceptions of the Family Goal Setting Tool: A pilot study. *Journal of Applied Research in Intellectual Disabilities, 25*(4), 360-371.

Shogren, K. A., Wehmeyer, M. L., Palmer, S. B., Rifenbark, G. G. & Little, T. D. (2015). Relationships between self-determination and postschool outcomes for youth with disabilities. *The Journal of Special Education, 48*(4) 256– 267. DOI: 10.1177/0022466913489733

**Support for Decision Making consultation submission**

**Name:** Autism Queensland (QLD)

**Date and time submitted:** 9/10/2021 5:45:00 AM

# **How can we help people with disability make decisions for themselves?**

* Resources: Yes
* Information: Yes
* Decision Guides: Yes
* Having a person help: Yes
* Other: No

# **Who are the best people to help you (or a person with a disability) to make decisions?**

* Family: Yes
* Friends: Yes
* Peer Support Networks: Yes
* Mentors: Yes
* Coordinators: Yes
* LAC: Yes
* NDIA Partners: Yes
* Advocates: Yes
* Service Providers: Yes
* Other: No

# **What should they do to help with decision-making?**

At Autism Queensland, we have worked for some years to ensure that the voice of autistic people is heard during the person-centred planning processes. With some investment from the Autism Cooperative Research Centre (CRC), Autism Queenslandâ€™s Research a

# **How can they get better at helping?**

* Getting to know the participant well: Yes
* Doing some training on decision support: Yes
* By having resources and information about providing decision support: Yes
* Other: No

# **How can we make sure the right people are helping?**

* They are chosen by the NDIS Participant as a decision supporter: No
* They value the rights of people to make decisions with support: Yes
* They are a registered provider: No
* They enable the participant to take risks: Yes
* Other: No

# **What should decision supporters know about so they can better help people with disability make decisions?**

* Guidelines for decision supporters: Yes
* Scenarios or Examples: Yes
* Information Sessions: Yes
* Support Networks: Yes
* Other: No

# **Can you tell us about a time when someone helped you (or a person with disability) to make a big decision?**

Not applicable

## **What worked well?**

No answer recorded

## **What could have been better?**

No answer recorded

# **What is the best way to support people with disability to make decisions about their NDIS plan?**

* Practice: Yes
* Peer Support Networks: Yes
* Information and Resources: Yes
* Guidance Tools: Yes
* Not Sure: No
* Other: No

# **Are there different things to consider for people with different disabilities or cultural backgrounds?**

**An intellectual disability:** Yes, The use of picture-based tools can support people with an intellectual disability in communicating their wishes. Autism Queenslandâ€™s Research and Development Department co-designed and co-produced a picture-based tool with and for autistic people, called the Adolescent/Adult Goal Setting Tool (AAGST) (Ashburner et al., 2019). This tool has been successfully used by wide range of autistic people including those with ages ranging from 14 to 60 years, with abilities ranging from those with intellectual disability to those with superior range IQ.

**A disability that impacts how they think, a cognitive impairment:** No

**A psychosocial disability:** No

**A disability that impacts their ability to communicate:** Yes, As the Adolescent/Adult Goal Setting Tool (AAGST) involves sorting of cards with pictures, it can be easily used by people who find it difficult to speak or to articulate their needs and preferences. The AAGST is not a standardised tool. Rather, it is a m

**From a CALD community:** No

**From an Aboriginal or Torres Strait Islander Community:** No

**From the LGBTIQA community:** No

# **How can we help reduce conflict of interest?**

The Adolescent/Adult Goal Setting Tool (AAGST) includes a wide range of potential goals that may be relevant to autistic people in areas such as social relationships, self-care and home living, studying and training, employment, health and fitness, community access and participation, communication, finances, and emotional wellbeing. The user can choose any goal that is personally important and meaningful. The array of possible goals does not align with services typically offered by autism service providers. For example, it may be important to the person to learn to drive a car, to access a vocational education course, or to join a social club in their local area. As these are not services provided by autism service providers, the aim is to facilitate the personâ€™s access to mainstream services that can enable them to achieve their goal. Potential conflict of interest as regards directing users of the AAGST to use services provided by autism service providers is therefore not typically a concern.

# **How can we help reduce undue influence?**

If decision supporters are reliant on the person with a disability having to describe their goals or decisions verbally or in writing, there is a significant risk that the decision supporter may inadvertently unduly influence a person with a disability, because the person is experiencing difficulties in communicating his or her wishes. The Adolescent/Adult Goal Setting Tool (AAGST) utilizes cards with pictures that can be physically sorted and arranged in order of priority. This is a far easier process for identifying goals and making decisions, than describing them verbally or in writing.

# **What are your concerns (if any) around people with disability being more involved in making decisions for themselves?**

We do not have any concerns about involving people with disability in making decisions for themselves. If people with disabilities are appropriately supported to engage in independent decision-making, they are more likely to have ownership of their goals and are more likely to be motivated to work on them. In our experience, if we engage autistic people at a young age in setting their own goals and making decisions about what they would like to do, they develop confidence in their own decision-making capacity and are more prepared to speak for themselves.

# **What else could we do to help people with disability to make decisions for themselves? Is there anything missing?**

We believe the Adolescent/Adult Goal Setting Tool and associated professional training could support NDIS planners in facilitating genuine self-determination of neuro-divergent people including those on the autism spectrum.

# **Do you have any feedback on our proposed actions in Appendix C of the paper?**

We believe the Adolescent/Adult Goal Setting Tool and associated professional training could support the following actions proposed by the NDIS:

â€¢ Development of a targeted approach for complex cohorts to provide decision making opportunities. This includes for participants with intellectual disability, cognitive impairment and psychosocial disability.

â€¢ Development of a range of materials that describe the support for decision making process.

â€¢ Build the NDIS capability and partners to help them to recognise and support decision making opportunities.