



# ADACAS

A D V O C A C Y

Response to  
National Disability Insurance Scheme  
Consultation Paper:  
Supporting you to make your own  
decisions

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## Acknowledgement of Country

ADACAS acknowledges the many language groups and the Traditional Owners of the lands on which we work: the Ngunnawal, Yuin and Dharawal peoples of the Canberra and NSW South Coast regions. We pay our respects to their Elders past, present and emerging, and to all Aboriginal and Torres Strait Islander peoples across our communities.

Always was, always will be Aboriginal land: sovereignty never ceded.

## Executive Summary

Given the pivotal role of the National Disability Insurance Scheme (NDIS) in meeting Australia's international obligations as a signatory to the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), it is imperative that the NDIS upholds the decision-making rights of people with disability and maximise person's decision-making about things that affect them/their life to the greatest degree possible, including through ensuring availability of supported decision-making supports and processes as needed.

Decision-making processes and providing support for decision-making needs to be a much more flexible, person-centred process than that outlined in the proposed policy. It is imperative that the proposed policy be significantly updated to better capture the need to meet individual needs (in all their diversity and intersectionality), as in its current form, the policy risks excluding people, and impacting negatively on their human rights. We additionally encourage further work with Aboriginal and Torres Strait Islander communities to ensure that any policy being considered is culturally appropriate and recognises the diversity of approaches to decision-making. Similarly, we encourage further work also with Culturally and Linguistically diverse communities, to seek to ensure that inclusive approaches are progressed.

Having access to skilled independent decision-supporters can be very important. ADACAS emphasises the importance that formal support for decision-making be funded in a number of ways – that advocacy agencies be block funded (such that independent support is available), however that there also be NDIS funding categories that allow for support coordinators, and other paid support staff to provide decision support when the person with disability wants or needs this to occur.

Good practice in supported decision-making requires knowledge of rights, reflective approaches, and skill. It is not enough to have a policy alone. There needs to be ongoing education/training/skill building/expert mentoring and support available, and work to address barriers to decision-making to ensure that all people with disability and anyone else present in the lives of people with disability, who might find themselves in positions of influence, and/or in the role of decision-supporter, whether formal/informal) are aware of the rights of people with disability including around decision-making. It is important that people are skilled in offering support for decision-making should this be wanted. There must also be concerted

efforts to ensure that people with disability get opportunities to build and continue to engage with their decision-making rights throughout their entire lives.

The NDIS was designed as a way of upholding the human rights (including the decision-making rights) of people with disability. Supported decision-making, which seeks to enable people to maximise their participation in decision-making, engage with dignity of risk, and exercise choice and control, aligns perfectly with the values of what so many campaigned for. We welcome the NDIA's focus in improving access to support for decision-making accordingly.

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## 1. About ADACAS

The ACT Disability Aged and Carer Advocacy Service (ADACAS) is an independent advocacy service, funded to provide advocacy by the Australian and ACT Governments. ADACAS is based in Canberra and ADACAS staff works with clients in the ACT and set zones in the Shoalhaven and Eurobodalla areas of NSW. ADACAS has been operating in the ACT for 30 years.

The primary focus for ADACAS is individual advocacy – we provide human-rights focussed individual advocacy for and with people with disability, older people, people with mental health issues and carers. ADACAS advocates are frequently working with people with lived experience of “falling through the cracks” in current service systems. ADACAS offers issues-based advocacy, and the topics of advocacy are multiple and varied, ranging from housing, to access to justice, to psychiatric treatment order hearings, to quality-of-service issues, to child protection processes, to restrictive practice/ restraint/ seclusion, to substitute decision-making, the Disability Royal Commission, the National Redress Scheme, to aged care service issues, to NDIS and NDIS appeals etc. ADACAS is a member of DANA, the Disabled Persons Advocacy Network, and OPAN, the Older Persons Advocacy Network. Aside from advocacy, ADACAS has a separate team offering Support Coordination to some NDIS participants within the ACT.

ADACAS also has a respected research and projects capability. Over the past decade we have specialised in Supported Decision Making (SDM) and have received funding through ACT and Commonwealth grants. ADACAS conducted the Respect, Know, Act Project which aimed to explore how health care systems can respect the rights of all people, know how to respond to situations where rights are not upheld and act in a way that supports decision making rights (Ramcharan, et al., 2013). ADACAS developed a supported decision making tool: the [My Decision Making Toolkit](#) (ADACAS, 2019) and has delivered education sessions on SDM and rights to people with disability, families/carers, and the disability and aged care sectors. ADACAS were funded by the Older Persons Advocacy Network (OPAN) to explore how SDM and individual advocacy can be used together to support older people at risk of or experiencing abuse. Advocacy organisations use the Strengths Based Network Activation Model© and other ADACAS resources (including an android app) to support people to participate in decisions which affect their lives. ADACAS continues to be recognised for our expertise in SDM and our innovative approaches towards positive change.

## 2. Introduction

As a disability advocacy organisation, ADACAS is attuned to the need for reform in support of the human rights of people with disability, including in relation to experiences of decision-making. It is imperative that in developing policy around support for decision-making, that the NDIA takes an approach which upholds Australia's UNCRPD obligations, to provide people with disability with the support they require to exercise their legal capacity on an equal basis with others (Article 12.3 of the UNCRPD) (UN General Assembly, 2007). Australia's National Disability Insurance Scheme (NDIS) was designed with people with disability with the intent that people with disability would be at the centre of decision-making (Australian Government, 2013), with all the choice, control, dignity, and autonomy that this implies.

Supported decision making (SDM) approaches enable people with a disability who require this support, to exercise choice and control, to take risks to pursue their goals and engage with others in the decisions that affect their lives (National Disability Insurance Scheme, 2021). We emphasise the need to ensure that the decision-making rights of people with disabilities are respected and that the decision-making rights of people with disability is maximised through decision-making processes (including via the provision of support for decision-making as needed) (UN General Assembly, 2007).

We underline also concepts of dignity of risk – that there needs to be much broader awareness that people with disability, like people without disability, are entitled to make decisions (with or without support), take reasonable risks, build decision-making skills throughout life and to learn from decision-making experiences.

ADACAS endorses the list of issues that the NDIA has heard from the community (as listed on pages 7-8 of the Support for Decision-making consultation paper) and welcome this opportunity to provide comment on the proposed NDIA Support for Decision-Making policy.

### 3. Supported Decision Making

#### i. Concepts of supported decision-making

In the NDIA papers provided as part of the consultation, the distinction is drawn between supported decision-making (SDM) and support for decision-making, naming SDM as a process, and support for decision-making as the supports provided to enable that process to occur.

In ADACAS' view - supported decision making (SDM) can be processes, happening as a decision is being made. They are flexible processes of support directed by an individual whose supporter/s can support in explaining issues, assist with understanding of options and impacts and take account of the decision makers responses and preferences, whilst at the same time supporting the individual decision-maker to utilise their decision-making skills. These human rights focussed processes can support informed approaches around balancing dignity of risk (and when needed, risk mitigation in support of the person's decisions). Supported decision-making processes need to be strengths based, proactive and person centred. The approach and process of supporting someone to make a decision looks different for each person, each time a decision is made, and in relation to each different decision. In this sense SDM is a process to enable people to exercise their legal capacity and thus greater autonomy and self-determination (Ramcharan, et al., 2013).

SDM can be an approach that recognises the process of supporting another person with their decision making and therefore an alternative legal route to substitute decision making. Therefore, SDM can be seen as a process and an end as there is legal recognition of the process of supporting someone to make a decision and the legal outcome of the decision made as a result of the process (Browing, Bigby, & Douglas, 2014).

SDM can also be understood as a set of tools for access, inclusion, and participation. It builds the capacity of individuals and the community at large to seek and give support when and where it is needed. The capability of the person needing the support to make a decision 'to exercise legal agency is dependent on the integrity, quality and appropriateness of support available' (Australian Law Reform Commission, 2014). Please refer to the discussions around capacity and capability later in this paper.

As put forward by ADACAS (2013), finally SDM is also a means to which substitute decision making, formal or informal, can be grounded in the will and preference of the person. SDM

increases the participation of people with disability in decision making and to be central to the decision making in their own lives.

The term capacity is a legal term with varying definitions in substitute decision-making laws. As a term and concept, it has also over time been used in ways that dismiss, and preclude the participation of people with disability in decision-making rather than to uphold their decision-making rights. ADACAS endorses the choice of the NDIA to use the term capability in this policy, and encourages all efforts to uphold the decision-making rights of people with disability and to maximise participation of people with disability in the decisions that affect their lives.

At the present time, much of the literature around disability and decision-making and support for decision-making uses western concepts of disability and approaches via an individualist mindset/view of the world. The support offered to the decision maker needs to be sensitive to intersectional needs. We emphasise the importance of working together with Aboriginal and Torres Strait Islander communities to ensure that the NDIA's policy approaches are updated in culturally sensitive and inclusive ways. Aboriginal and Torres Strait Islander people should have access to culturally safe support if they would prefer.

ADACAS also acknowledges that there are many other culturally and linguistically diverse groups and communities that approach decision-making in different ways (including via collectivist approaches). A person's identity also needs to be considered when using SDM principles. An individual's construction of self-concept impacts on their participation in decision making. A decision supporter needs to be considerate of this too. We encourage taking account of and learning from many ways of viewing disability and decision-making and SDM in working towards a final version of this policy.

**Pablo's story:**

Pablo\* and his family are from a Culturally, Ethnically and Linguistically Diverse background and all decisions are made as a group. Pablo wants to buy a car and modify it so that he can drive it, but even though this is something he really wants, he has explained he will only do so with the agreement of his parents and grandparents. How do we incorporate into the NDIS decisions that are less individualistic yet respond to the needs of the person? A car to Pablo means independence and less reliance on others and could open more employment opportunities as he is able to drive further to go for different jobs. However, if assisted to buy a car without his family's support, it will cause conflict and it may mean that no one in his family

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may help him in the future with anything that related to the car and might be a source of disagreement for years to come.

\*Names and identifying details have been changed

## ii. Importance of trusted relationships in supported decision-making

The quality of the relationship is important to enabling good support for decision making. Trust is a crucial basis of the relationship where the supporters view the decision maker as capable of making a decision, having a positive approach towards risk, understand the importance of choice and control and a commitment to upholding human rights (Browing, Bigby, & Douglas, 2014).

It is the quality of the relationship between decision maker and supporter, rather than the type or length of the relationship that makes the difference. The closeness of the relationship influences the response of the supporter to the expression of the person's will (Browing, Bigby, & Douglas, 2014).

Trust in the decision-making relationship allows for people with disability to feel more comfortable in communicating their wishes, and allows supporters to assist if needed in expanding awareness of choices and consequences in conversations about preferences, but also gives confidence that supporters will respect the preferences if they choose to reject the new opportunities. Being able to suspend judgment and become neutral and nonjudgmental as a supporter is key (Ramcharan, et al., 2013).

It is important for supporters to know the person such that they can enable the support to be tailored to the preferences of the individual. For example: knowing how a person's cognitive impairment impacts for them, can allow the supporter to adjust communication and presentation of information. Knowing how a person has made decisions in the past and understanding how a person might present at other times could be important in a situation where the person might be nervous or shy. If the decision supporter does not know the person well, they may misinterpret responses, which means they might receive less support in their plan or different types of support to what they need. We reiterate the importance of the quality of the relationship and of trust in decision-making relationships.



Support looks different for every person and for every decision therefore a one directional continuum is not the right way to show this. The level of support an individual might need is dependent on many factors. Including a two way arrow shows that decision making capability can move from either end of the spectrum depending on the circumstances including those highlighted earlier such as previous experience making decisions, the choices, life stage and environment/contextual factors etc.

The Australian Law Reform Commission report on Equity, Capacity and Disability in Commonwealth Laws (2014), acknowledges the concept of a spectrum for decision-making (Australian Law Reform Commission, 2014). At one end of this spectrum lies autonomous decision making, at the other is substitute decision making. A spectrum of decision-making capacity lies within these two extremes, and decision support can be given according to where each person is at that moment on this spectrum. ADACAS highlights that whilst a person may need a large amount of support in one decision making domain for a particular decision, they may be able to make an autonomous decision in another domain. For example, at a given time a person may need considerable support to make treatment decisions but need little or no support to make a decision about care or recovery (Victorian Law Reform Commission, 2012).

### *b. Life stages*

Whilst we recognise and appreciate the intent to offer clear diagrams: in our view, presenting a “Life Stages Framework” as “contained boxes” with ages against each category is inaccurate, rigid, and inappropriate. Not all individuals experience increases and decreases in exposure to decision-making responsibility at age-bound phases of life (or at those particular ages). This figure ignores individual circumstances and the influence of family, culture, attitude, socioeconomic status, geographical location. Imposing life stage “expectations” could lead to significantly incorrect predictions and in labelling the decision-making as “typical” it also excludes people with different experiences. People cannot and should not be categorised into these boxed stages. A graphic that links ageing explicitly with the potential for decrease of capacity also risks promoting and reinforcing harmful ageist stereotypes, taking away from what should be there – a presumption of capacity, and endeavours to ensure that when anyone needs support with decision-making, that support is available and present.

As emphasised above - the framework you have proposed does not recognise fluctuations in life stages or even movements back and forward across different experiences (perhaps in

different domains of life. Understanding what kind of supports an individual needs across life stages and working to build their capacity involves a combination of efforts from the individual, decision supporters and NDIA planners and funders. We recommend that this graphic be removed, and ways of thinking about different phases of decision-making be re-envisioned in more inclusive, flexible ways.

#### *c. Exposure to Choice*

Whilst we absolutely agree with the importance with all decision-makers (inclusive of people with disability) being exposed to choice (and all the choices, beyond those typically considered), in practice our experience is that decision-making for most people is nowhere near as linear as described, and may involve gradual flexible processes of considering options, changing minds, re-considering, getting further advice etc. We would suggest the policy also be updated to recognise the recurrent nature of decision support with decisions often needing to be shaped and reshaped before a conclusive decision can be made.

#### *d. Context/Environment*

Figure 1 of the Decision Making Capability framework at present in our view has omitted an important factor highlighted in the literature - the environment and context of decision making (Weid, Knebel, Tesky, & Haberstroh, 2019) The extent to which a person's decision-making capability is be maximised can depend on environmental factors such as the time of day, location, noise or who is present (and the nature of the relationship/s with that person/that person's views and beliefs). It can also be affected by personal stress or health factors including but not limited to anxiety levels, infection, and whether the person is affected by medicines, drugs, or alcohol.

The setting in which the decision is being made can be important to the way the individual can actively participate. For example, a calm and undisturbed atmosphere may be required to enable informed consent to occur. The cognitive fluctuations in a person with disability need to be considered and how this may influence their understanding of and response to a decision to be made. We suggest that environment be added as part of the circumstance section of the figure.

#### *e. Timing/Speed*

Another factor that is not adequately included in Figure 1, is the timing and speed with which the decision needs to or is being made. This could refer to time of day, but also the amount of

stress or duress that a person is experiencing about their decision and the effect that all of this has on whether the person's ability to participate in decision making is being maximised.

#### *f. Capacity / Support-needs in relation to decision-making*

We also highlight concerns that including the word "capacity" in Figure 1 is problematic, in that the term capacity it is so often used to dismiss or curtail rights, rather than a way to open conversation about the level of support that is needed. We would suggest that this be changed and that the box instead focus on *supports needed to maximise participation in decision-making*.

#### *g. Decision Supporters*

Whilst decision supporters are important – this model (Figure 1) does not take adequate account of people who are **not** supportive of the person participating to the maximum extent possible with decision-making/decisions, and the impact that this can have (in terms a person's decision-making impacts). There is also insufficient allowance for the scenario of other people having vested interests (and seeking to unduly influence a person with disability's decision-making accordingly).

ADACAS highlights also that the array of formal/ informal decision supporters can by necessity vary per decision (it is not static). With some decisions, a person with disability might want to include their support coordinator and a family member as part of their decision support network. For other decisions, they might use their GP and a friend to support them with decision-making. In our view, this flexibility/nuance needs to be more explicitly highlighted in the proposed decision-making capability framework. It can be beneficial for a person to have more than one person as their decision supporters and for supporters to work together with the person with disability to seek to strengthen their decision support network, actively seeking out other decision supporters.

#### *h. Decision Factors*

The three segments related to decision in model 1: type, level, and impact, are all important. Whilst importance is acknowledged in the text, it is not adequately captured in Model 1.

## **5. Decision Making processes**

As a person centred, strengths-based approach, supported decision making is a relationship between supporter and decision maker based upon trust. It relies upon information and

appropriate communication of information. Be able to access, explain, and weigh up information is all a part of this process. Being aware of and examining risk, taking this risk safely. The supporter/s needs to work with the decision maker to consider the safeguards of the decision-making process which may be needed. Supports for the individual should be time specific and take into consideration community and cultural contexts. Showing an awareness of bias and vested interest is also important.

For the NDIS to truly give the opportunity for participants to exercise choice and control the person with a disability needs to be given the opportunity for self-determination. People desire to make choices and to change things if they change their mind or the results of the decision are not favourable. Flexibility is also a key factor in facilitating supported decision making. An example of this may be if a participant makes a supported decision to go with a particular service provider. The service needs to be able to adapt to the person's needs and they change, or their goals differ. As mentioned earlier - supporting a participant to decide does not make it concrete and does not mean that the person might not decide to refine or review their decision and want further support with this accordingly.

ADACAS staff developed a model which has been used effectively in our advocacy practice known as the Strengths Based Network Activation Model© , a model which: "assumes different roles for already existent members of a person's network; provides training to this group and the person; and activates the relevant network role where necessary" (Ramcharan P, 2018). This model is useful when working with an individual to establish their support network and visualise who might be available for different decisions should the individual need this support. Understanding networks, documenting preferences re networks is an important aspect of supported-decision-making processes. Some people may need assistance to build or strengthen their networks such that there are people who can be called upon according to their expertise/approach.

For example, the following NDIS participant built a successful network of supporters based on the supporter's areas of expertise:

#### **Matteo's story**

Matteo\* lives independently in the community and has an intellectual disability and he counts on his network of support people like his bus driver whom he trust to give him information about the bus number he needs to catch if going somewhere unfamiliar; the bank teller at his

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local bank branch that will help him to withdraw money from his account and remind him of a safe amount to carry in his wallet; his cleaner that he trust to help him keep his home tidy and presentable because that is the way he likes to keep it; his mother whom he prefers to speak about financial matters because she enjoys as much as he does buying things online; and his aunt that he goes to if he wants to do something different because she always says yes and is supportive and will help him to convince others.

\*Names and identifying details have been changed

Some of the SDM skills and techniques which decision supporters, including NDIA planners and partners need to be aware of and trained in to deliver and use appropriately and when applicable as part of supported decision-making processes, include (but are not limited to):

- To avoid miscommunication and indicate the need for a decision, it is also important to highlight the start of the decision-making process by raising and defining a decision topic and discussing goals (Groen-van de Ven, et al., 2017).
- Supporters need to ensure that decision-makers have access to all the information in ways that suit for decision-makers, so that decision-makers know what their options are. A lack of adequate information could result in a poor outcome or consequence of the decision, and this could lead to less confidence in making future decisions.
- Some people with a disability may be able to express their wishes, preferences, and decisions verbally, in Auslan or in writing. Others may use communication aids, body movements or other technologies to communicate. As part of decision-support processes, supporters, including NDIA staff need to learn and understand how each participant communicates and how they prefer and can be best supported to do so.
- For those who may have impaired memory, using simple and clear language, consistency of expression, using appropriate nonverbal communication techniques as well as employing visual aids, props could help to compensate and to support their understanding (Fetherstonhaugh et al., 2016; Smebye et al., 2012; Tyrrell et al., 2006).

### Marcina's story:

Marcina\* loves socialising and walking through her community. She also has a mild intellectual disability with a severe memory impairment. Marcina inherited a large sum of money and would like to buy her own apartment, however, she forgets from one day to the next what information she has received in relation to buying property. Over a period of twelve months that ADACAS worked with her, whilst she had ongoing memory problems, Marcina's goal and clear decision that she wanted to buy an apartment never changed. Due to the impacts of memory difficulties, she was however having ongoing difficulties with progressing on this goal (enacting this decision) – i.e. remembering the complex details and progressing on the steps involved in purchasing a property. ADACAS' supported decision-making staff worked with Marcina over a period of time, mapping her decision to buy an apartment, supporting her to build her support network, access expert assistance and navigate the various guardianship and legal processes involved to allow her to progress in a safeguarded way towards this goal.

\*Names and identifying details have been changed

### Michael's story

Risk is a fact of life and despite the obligations under the CRPD - in the Australian disability sector, there has been a tendency to be risk averse. ADACAS has strongly advocated for the right of people to choose, and to experience the dignity of risk. ADACAS' supported decision making staff help people to manage risk by making risk less significant. For instance, Michael\* wants to expend all his fortnightly income buying the latest Xbox. ADACAS assisted him to weigh up the risks of spending all of his money and not buying food for the fortnight, with the benefits an Xbox would bring. We worked together with Michael to assist him to put together a plan in relation to his needs for the fortnight that he would not be able to afford any food: he prepared to eat the food he had in the pantry and as a back-up he bought 5 minutes noodles. He also obtained the address and telephone number of the food relief pantry near him, as a backup in case of emergency. Michael then proceeded and bought and was very happy to have an Xbox. Michael advised us afterwards that he had learnt that it was not a very good idea not to have money for food because he did not like eating noodles that much and missed eating fresh fruit. This situation involved reducing risks and managing them rather than the eliminating all risks.

\*Names and identifying details have been changed

ADACAS notes the importance of processes of supported decision-making being individually, flexibly, and adequately safeguarded. In our experience - when the processes are safeguarded appropriately (individually, in ways that suit for the specific participant), it can be conducive to people with disability having better decision-making experiences and engaging with risk positively. Having skilled independent people (such as advocates) document a person's values, options, and priorities (and supported decision-making approaches/processes) can be an important part of the supported decision-making process. We discuss safeguarding in more detail later in this paper.

## 6. Opportunities for Change

The Support for Decision Making Policy offers the opportunity to increase the participation and engagement of people with a disability in decision making about decisions which affect their lives. Offering people with disabilities more involvement in their own lives through preference and choice making is vitally important to their quality of life (Jenkinson, 2007).

Identifying decision support needs for all participants before they turn 18 is important, however the identification of these needs must be done progressively over time. As individual's needs change over time the support they will require must grow with them. As participants practice their decision-making skills and experience new things there may be the need for increased decision support. If the decision support is not offered, it could result in substitute decision making or the appointment of a guardian for the participant.

### i. Funding for decision support

In terms of formal decision-supports – ADACAS recommends that DSS block fund independent advocacy agencies to provide decision-support such that they can maintain independence from decision-making that is occurring, and also such that they can work with NDIS participants regardless of the current adequacy of their NDIS status or NDIS funding levels.

Of recent times, DSS has been funding a decision-support pilot also for people with disability who do not have (and are unlikely to be able to immediately build) adequate decision support/informal support networks. ADACAS further recommends that this funding be continued and expanded.

## **ii. Improving NDIS processes**

There are a number of steps that the NDIS can continue to take to make it easier for NDIS participants to engage with NDIS processes and make NDIS related decisions. One of the areas where there has been significant work, but continued work is needed, is in relation to communications. We strongly endorse the proposal to use plain English in the Operational Guidelines, as it will ensure that more participants can understand these. It would also be great to see an expansion of the documents available in easy English, and expansions in the scope/range of materials that have been translated into an array of other languages. We welcome the work the NDIA has been doing in starting to develop further information specifically also for Aboriginal and Torres Strait Islander communities and would encourage continued co-design with those communities as further information is developed.

## **iii. Nominees**

It will be useful to update the Operational Guidelines to improve how nominees are appointed. The SDM framework should be used by the nominee as the decision supporter which in turn supports the National SDM principles. This safeguards against risk of abuse of relationship or any conflict of interest which may occur.

## **iv. Training/education/culture change around rights and SDM**

To achieve widescale changes in the way that supported decision making is envisaged and how people experience it in person, and for the Support to make Decision policy to be effective it is important for staff and partners to receive further training and education about human rights, supported decision-making and build their skills in how practically to facilitate decision support. The need to educate about SDM was also recognised as part of the Victorian Law Reform Commission's Final Report (Victorian Law Reform Commission, 2012).

Achieving good practice in supported decision requires both knowledge around human rights and SDM, and practical skills in how to support decision makers appropriately and flexibly. Education and training initiatives should be codesigned with people with a disability, their families/carers, service providers as well as with advocacy/representative organisations and experts in SDM. Education/training should be available to people with disability, their families/carers/supporters, service providers and offered widely to others with whom the person with disability might come into contact. Ongoing support needs should be provided to decision-supporters, and disability and related sectors to ensure continued improvements are

made to SDM knowledge and practice. Building decision-making skills and experience should be part of each child and young person's experience (both at home, and in school settings) – but as for all in our communities, skill building and experience should continue to occur in an ongoing way throughout the lifespan. Additionally, disability awareness, human rights and SDM training should be embedded systematically within tertiary and vocational education programs for health and other disciplines who may in future work with people with disability.

The training of guardians and enduring powers of attorney is also needed to ensure the rights, will and preference of individuals comes at the forefront of decisions being made. There is an urgent need to ensure that all service providers, NDIA staff, and community partners are well-versed in human rights and SDM.

#### **v. NDIS processes and the role of NDIS staff in relation to SDM:**

As mentioned above - ADACAS recommends that SDM funding in participants plans be implemented in ways that allow for flexible use by the participant in support of their decision-making and rights.

We also recommend careful consideration of NDIS planning and review processes (via co-design with participants, families/carers, disability advocacy and representative organisations) to seek to ensure that each NDIS participant has their voice heard, and decision-making rights are being maximised in relation to how NDIS plans are being funded, and how each NDIS participant is making decisions about how funds are subsequently utilised.

Better training of NDIA staff could assist in acting as a safeguard in seeking to ensure that an NDIS participant's decision-making is prioritised and their participation in decision-making maximised during NDIS processes including planning and any involvement of nominees.

NDIA planners also have a role to ensure that all participants can access SDM, and that funding in NDIS plans to access needed supports is additionally available as needed for those with complex planning decisions, or few supports. If funding for SDM is included from the participants very first plan, if needed as identified by the participant, their supports and/or the planner, the participant will have added access, if they choose, to support to enable further participation and engagement in supported decision making in the future

## vi. Conflicts of interest and Prevention of undue influence/abuse:

We acknowledge the complexity of approaches to managing conflicts of interests. We highlight the importance of a nuanced approach on this topic, and the NDIA recognising that conflicts of interest often need to be managed: it is not always appropriate to reduce or remove them. Important decision-supporters (such as those family and friends, who are seeking to uphold someone's decision-making rights), must not be unfairly excluded, as this could further reduce the chance of the person with disability having their decision-making rights upheld to the maximum extent.

Some of the ways to reduce conflicts of interest include ensuring that there are shared understandings of rights, and what it means to support rights (and the limits on the role of decision-supporters) – i.e. availability of ongoing education/training/mentoring etc for all parties, as highlighted earlier.

Another safeguard is in ensuring that people with disability have access to formal support for decision-making (of their choice) both within and beyond NDIS funded supports. As mentioned earlier, we emphasise the importance of independent support for decision-making such as that delivered by independent advocacy services, and of such supports being funded to such a level that they are available to assist people with disability when wanted, especially for pervasive, important, or impactful decisions. The Australian Law Reform Commission report *Equity, Capacity and Disability in Commonwealth Laws* (Australian Law Reform Commission, 2014) (and many reports since) recommended a shift away from substitute decision making models towards supported decision-making approaches which respect a person's will and preference. Once legislative change away from substituted decision-making models occurs (as we envisage it will): ADACAS would also like to see statutory bodies, such as the ACT Public Trustee and Guardian which currently have a significant independent role around best practice in supported and substitute decision-making, further focus on supported decision-making, as an additional avenue for independent support when needed.

A person with disability having extended and active supported-decision-making networks, and regular contact with multiple services/health professionals can also be protective against conflicts of interest and also potentially abuse, in that it is likely that there might be more trusted people that a person with disability is in contact with who might pick up on signs of abuse.

ADACAS notes the need, however, for there to be much broader awareness of abuse, what it looks like, and what to do if abuse is suspected (and highlights the role of the NDIA in ensuring the availability of training for workers, and service providers about such topics (The training needs to be offered for free, but workers/service providers also recompensed for their time to continue to develop their knowledge in these important areas). We also highlight the need for specific continued work on the prevention of abuse experienced by people with disability.

An additional safeguard can involve documenting of supported decision-making processes by independent parties.

Finally – we highlight – that most people (regardless of disability) seek support for decision-making, especially in relation to complex decisions. Most people will turn to trusted networks they might have for guidance, or advice, as they work through options/consider consequences. Being explicit about everyone having decision-making rights, and the similarities in how people seek support for decision-making regardless of disability is important. Many people with disability, however, continue to experience negative assumptions, discrimination (in some instances abuse) from people in their networks and beyond, that are barriers, and curtail their ability to engage with decision-making, having undue (and in the case of abuse), very harmful impacts on wellbeing. In planning next steps, ADACAS thus encourages NDIA staff to work directly with people with disability, their families, carers, supporters, experts in violence/abuse and advocacy and representative agencies to co-design training, initiatives, and responses to seek to address barriers and prevent abuse, including as it relates to decision-making.

## 7. Response to Appendix C – Proposed next steps

ADACAS is pleased to see some excellent goals listed as part of next steps, and some useful strategies being proposed. We would also like to see the NDIA working with advocacy and representative organisations to press state and territory governments for legislative changes to further embed moves towards supported-decision-making and away from substitute-decision-making approaches.

We would also encourage further work with Aboriginal and Torres Strait Islander communities (also culturally and linguistically diverse communities) to learn from models of decision-making that occur within those communities, both such that adjustments to existing policies can be made so that approaches are culturally appropriate, but also, if permission were to be granted by the communities involved to share learnings, such that the wider community can be

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informed by other approaches and ways of conceptualising decision-making and SDM that might be occurring.

Please also refer to comments in the sections above (section 6) in relation to opportunities for change – we would encourage this feedback to also be built into planning for next steps, especially with regards to the strategies proposed in relation to working more broadly around prevention of abuse, including as it relates to curtailing of options for decision-making.

## 8. References

- ADACAS. (2019). *Support my Decision Toolkit*. Retrieved from Support My Decision: <https://support-my-decision.org.au/wp-content/uploads/2019/03/Toolkit-final.pdf>
- Australian Government. (2013). *National Disability Insurance Scheme Act*. Canberra: Australian Government.
- Australian Law Reform Commission. (2014). *Equity, Capacity and Disability in Commonwealth Laws (ALRC Report 124)*. Canberra: Australian Government.
- Browing, M., Bigby, C., & Douglas, J. (2014). Supported Decision Making: Understanding how its conceptual link to legal capacity is influencing the development of practice. *Research and Practice in Intellectual and Developmental Disabilities*.
- Fetherstonhaugh, D., Tarzia, L., Nay, R., & Bauer, M. (2014). "The Red Dress or the Blue?": How Do Staff Perceive That They Support Decision Making for People With Dementia Living in Residential Aged Care Facilities? *Journal of Applied Gerontology*.
- Groen-van de Ven, L., Smit, C., de Graaff, F., Span, M., Eedsting, J., Jukema, J., & Vernooij-Dassen, M. (2017). Involvement of people with dementia in making decisions about their lives: a qualitative study that appraises shared decision-making concerning daycare. *BMJ Open*.
- Jenkinson, J. (2007). Who Shall Decide? The Relevance of Theory and Research to Decision-making by People with an Intellectual Disability. *Disability, Handicap & Society*.
- Ramcharan, P., Leighton, D., Moors, R., Laragy, C., Despott, N., & Guven, N. (2013). *It's My Choice! Toolkit*. Melbourne: RMIT University.
- Ramcharan, P. (2018), *Evaluation of the Link and Learn Supported Decision Making Project: a report for the Community Services Directorate, Office for Disability, ACT*. The Link and Learn Supported Decision Making Project was completed by the ACT Disability Aged and Carer Advocacy Service (ADACAS). Associate Professor Paul Ramcharan works with RMIT University, Melbourne.
- Victorian Law Reform Commission. (2012). *Guardianship*. Melbourne: Vic Law Reform.

Weid, T., Knebel, M., Tesky, V., & Haberstroh, J. (2019). The human right to make one's own choices - implications for supported decision making in persons with dementia. *European Psychology*.

UN General Assembly (2007), United Nations Convention on the Rights of Persons with Disabilities: resolution / adopted by the General Assembly, 24 January 2007, available at: <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>, accessed in August 2021.