Increase the opportunity for participants to be actively involved in making decisions about their lives and to exercise real choice and control,

support development of participants’ capability in making decisions (and helping participants to explore and make those decisions),

build the capacity of decision supporters, agency staff and partners to recognise and enable the will and preference of participants,

strengthen a support for decision making approach in the appointment of nominee

**Background:**

**The following commentary is written with particular focus upon intellectual, sensory and perceptual disability**

People with intellectual disability find that novel situations are challenging because the prospect of uncertainty is frequently, if not always, perceived as threatening. Novel ideas or suggestions need to be introduced to people that have cognitive, sensory or perceptual disabilities at a time that they are calm and attentive. Predisposition to rigid thinking means that upon reflection, a proposition that might have seemed acceptable at particular moment, might subsequently morph into an idea that is not so appealing.

Instead of fight or flight as a response to stress, often doing nothing seems safer and therefore easier as a means of alleviating uncertainty and feelings of anxiety that are manifestations of insecurity. This can lead to chronic stress becoming perceived as normal, which can lead to depression or other kinds of failure to adapt.

Living in world that is generally hostile to people with intellectual disability, means that often the status quo, though unpleasant, is regarded by them as preferable to embarking on a productive course of action that might ameliorate feelings of duress. Aversion to novelty becomes manifest as avoidance behaviour, which in turn exacerbates feelings of loneliness and isolation.

People who are hypervigilant are easily fatigued by tasks that require mental effort. Such fatigue can cause a sudden drop in the capacity to self regulate feelings and emotions, leading to impulsiveness, or stonewalling when faced with snap decisions. People with disability are not unique in this regard, but much more at risk because of their particular cognitive, sensory or perceptual mental processing challenges.

This inertia toward engaging in novel experiences presents a dilemma for carers when broaching new ideas and framing new opportunities to their loved ones. The challenge for carers is to not trigger avoidance. Does a carer “leave well alone”, even though they know that the person is under duress or engaging in self-defeating habits, or risk creating defensiveness or stonewalling by initiating a conversation about change or options that they might deem to be potentially helpful. A general rule of thumb is that structuring activities in a predictable way minimises uncertainty and the need for mental flexibility when anticipating and engaging in tasks.

A decision making process in which options are assessed and the consequences of actions are weighed up requires mental effort. The effort of simultaneously recruiting many kinds of thought processes may be derailed or falter because nuances of understanding are required that elude a disabled person.

Frequently there is dependence upon a trusted family member who may help bridge the gap between thoughts and actions, and who becomes accustomed to being relied upon to make decisions in the person's interest.

The carer/cared-for relationship is far from straightforward. The carer carries huge responsibility for consequences which are frequently not apparent to or able to be inferred by the disabled person. Consequences of either action or inaction may impinge upon the disabled person's safety, but just as importantly, their autonomy and respect for their identity. Acceding to the path of least resistance has the potential to lead to deterioration in the person's condition and become a barrier to a disabled person flourishing as they might if they were provided with optimum circumstances and support.

When addressing the question of how best to support the disabled, it is crucial to apply support to where it is required. Support is required in three areas:

to the individual recipient themselves, to better enable them to adapt to their living environment due to their special needs,

to the disabled person's immediate physical and social environment including advocacy

at a community level in aspects of their lives over which the disabled exert next to no control, such as access and community attitudes.

Because they lack the executive function necessary to plan and problem solve, an intellectually disabled person may not comprehend the consequences of their actions or inaction. Emotional cues, either external or internal, frequently displace the kinds of complex thought processes that are required during decision making. Our emotions are integral to feeling that the right decision has been reached, even if there is a tension between what might be easiest and what is for the best. Intolerance of novelty, anxiety and depression will tend to thwart efforts to provide help.

Ultimately help is only helpful if is perceived as such by the person receiving it. It is difficult to help someone who is constantly hypervigilant, a challenge that is common for carers of people with disability or history of trauma.

Flexibility is required on the part of the carer and supporters to shift focus and resources as required to avoid stasis or regression.

**NDIS support for carers?**

It therefore falls to carers and support workers to have the skills required to seed ideas and frame communication so that information is conveyed appropriately. Completing the communication loop to achieve mutual understanding is a delicate process. Reaching a decision that respects the person's dignity is fraught with pitfalls. If it is difficult for a carer to know whether they are “on the same page”, it is next to impossible for a novice support worker to be confident that they know that they have connected with an intellectually disabled person. An assumption that that someone with learning difficulties has integrated new knowledge, for example when consent has been given, requires validation. It is only when they engage in an action that has been agreed upon that an observer really finds out whether it is helpful or not.

Efforts to understand special needs through interrogation may lead to acquiescence with a narrative provided by a person perceived as having authority, or confusion that prompts withdrawal. Interviews that are structured around on checklists on clipboards are a disservice to people with intellectual disability. Multiple vantage points are required to fully understand the scope of a person's disabilities. Engaging with them without a set agenda is necessary to be able to gauge strengths and weaknesses. It is crucial that the effort and emotional cost of masking and camouflaging feelings are recognised and given due weight when assessing needs.

Carers need education in the skills required to advocate effectively for people unable to do it for themselves. Such advocates are required between the NDIS recipient and support coordinators.

The support coordinator's role is to provide an understanding of the market for services. The person with intellectual disability requires an interface between themselves and their support coordinator. If not a family member, that person preferably shall be someone with a deep and ongoing relationship, who has respect for the participant as a person rather than a clinician who may be inclined to view the disabled person through a professional lens as a having a particular set of handicaps or proclivities.

Support workers with those skills are potentially invaluable in bringing a deep understanding of manifestations of underlying conditions that contribute to disabilities, and should be drawn upon to provide guidance as to tactics and strategies for support, but while they may advise, the responsibility for advocacy should not fall upon them.

Clinicians and support workers may come and go, but continuity should be the priority for advocacy and it should be via a person known intimately by the NDIS recipient. Advocates must have personal experience of the factors in the disabled person's social environment that contribute to distress at both a practical level and conceptual level, for example an understanding of the effect of loud noises upon someone with hyperacousia, or noisy social gatherings for a person with auditory processing difficulties.

An effective advocate will help prioritise the kinds of services that may be drawn upon. Helping ensure the disabled person isn't treated within silos of professional services that are ignorant of each other is another vital role. Being available to help audit the quality of care requires expertise, the acquisition of which becomes an ongoing project of self-improvement on the part of carers.

**build the capacity of decision supporters, agency staff and partners to recognise and enable the will and preference of participants,**

Carers are likely to welcome a platform that could provide training in advocacy.

Well trained carers who understand how to not only elicit the felt needs of their loved ones, but also understand how to communicate effectively so as to minimise inertia against novelty can facilitate development of effective plans.

Effective plans are likely to minimise redundancies and improve outcomes. Well trained family members would also be better advocates for the disabled within the broader community, potentially lessening prejudice against the disabled.

Training should be delivered at arms length from the NDIS. Speaking as a lay person, it may be that national program could be coordinated through state disability services.

State disability services must not be allowed to run down because the commonwealth has stepped in with the NDIS. There is strong overlap between advocacy for mental health and disability as many of the same principles apply in both fields. Improved community awareness will help reduce barriers to access and inclusion.

Training should not be a for-profit enterprise, but rather developed as a public good.

**strengthen a support for decision making approach in the appointment of nominee**

Carer and advocacy training could be potentially run through lived experience advocacy organisations. Co-production of nationally accepted principles and guidelines could draw upon decades of reviews of mental health services, aged care and disability services.

Commitment by carers to participate in training programs should be supported so as not to be a financial burden, as many, if not the majority of carers are under financial duress.

The establishment of carer training would help clarify for carers themselves an understanding of their suitability to the task. Providing the opportunity to acquire and improve skills and potential networking with other carers as a source of support would raise awareness of the need for inclusiveness within the broader community.

Much of social infrastructure to enable this to happen potentially exists already. Targeted support from government is required for it to scale up. Relatively modest injections of funding may stimulate latent momentum in not for profit advocacy organisations that are already in this space.

**Fit for purpose?**

Numerous reviews of mental health services at both national and state levels have discovered that established systems are not fit for purpose.

If we look at the “big picture' we must consider the prospect that the NDIS is at risk of the same kind of failure. We must look at systemic factors that may be preventable, particularly those that depend upon government actions.

There are already fears of escalating and potentially unsustainable costs. Developing equitable systems of service delivery is a massive challenge.

The current paradigm relies upon a revenue stream being delivered to hundreds of thousands of individuals. Each discrete revenue stream requires assessment, approval and subsequent monitoring, an intricate process which itself amounts to an industry, given the massive scope of the program.

Recipients are very nervous that there will be attempts to streamline this huge administrative process by applying algorithms that predict need.

**Treating causes**

A long term strategy for early childhood development services aimed at mitigating the consequences of trauma and social disadvantage, which are known to impair intellectual development, will lead to disadvantaged people experiencing greater inclusiveness, participation and productivity as they advance into adulthood. This will mean potentially fewer people relying upon public support in future to enable them to live independently.

Commercialisation of early childhood development1 has coincided with decline in the ranking of Australia's educational standards compared with our international peers. Australia cannot afford to squander the human capital in current or coming generations of children by skimping on access to or adequacy of standards in education.

Just as there are deficiencies in early education, the federal government's expectation that tertiary education can be treated as a source of revenue instead of being an essential investment in Australia's future is ludicrous. The fact that Australia has to rely upon immigrants to prop up the nation's demand for qualified professionals such as medical doctors is a national disgrace. Social mobility through education ought to be a source of celebration. Due to the financial burden entailed, currently whether a child receives access to a good education or not is most likely reflection of their level of privilege.

Inclusiveness for the disabled is a national project that requires vision and top down leadership, just as is the case for women's rights and an effective response to the scourge of domestic violence.

Present demands upon the NDIS are a manifestation of lack of commitment and vision in the past. Effective programs and resourcing at a community level are required from birth through adolescence and into adulthood to prevent adverse childhood experiences wreaking havoc upon people's capacity to work or live independently as adults.

Despite being a wealthy nation, many Australians do not have a living wage and millions have little prospect of ever becoming financially secure. We are now experiencing the social consequences of over-concentration of wealth in the hands of the few in Australia. We must ask whether we wish to emulate the US where fractures in society are widening.

Chasing the mental health consequences of financial insecurity and disenfranchisement from the community at large will continue to be frustrating and immensely inefficient unless present trends can be reversed. While corporations and governments chase productivity improvements by shaving wages and conditions, there is a widening gap between who are scarcely able to get by and those who have “got it made”.

Corporatising disability care ensures that there will be a culture of competition between providers. Striving for efficiency through competition is devastating if the end result lacks effectiveness. The marketplace services requires oversight and regulation to prevent rorting. Governments cannot abrogate their responsibilities in this sphere. The way in which services are delivered to the aged care sector is so fraught with problems that systemic change is required.2

Governments have sold off most of the country's income producing assets, and are no longer in the business of directly delivering services, such as power, water, telecommunications. The federal government's capacity to deliver nationwide programs are now showing the effects of decades of attrition of administrative capacity. Lack of a viable national water policy, piecemeal responses to drought and management of Australia's biosphere, including the devastating extinction event now ravaging Australia 3 are examples of major challenges that appear to be beyond the capability of the federal government to effectively respond. Disparate responses to the COVID pandemic between states and the preparedness of the federal government to shy away from direct control of quarantine measures illustrate limitations of our federal system. This is a quandary for the federal government. Australia is not lacking in competent analyses of the many problems affecting our health and welfare.45 Taking up and implementing recommendations can languish often for decades.

Systems for service delivery that are not directly controlled by government may not be amenable to the oversight necessary for them to be effective. The drive toward small government and the practice of outsourcing control of services that are crucial to Australia's public good into the hands of for-profit enterprise has unravelled in the aged care sector and is not equitable for early childhood development. In the quest for lower costs or greater efficiency Australia is now paying huge costs for lack of effectiveness, such that any savings are being absorbed by government while costs are being pushed onto the community. Poor or non-existent of services in the regions and reliance upon a marketplace governed by private enterprise to resolve major policy challenges that impact the welfare and safety of Australians is not effective.

Collapse of the Murray Darling Basin plan is a glaring example6 of a federal plan not being executed properly. Set against preferential treatment of people in selected electorates for electioneering purposes, such failures gravely undermine confidence in principles of egalitarianism which Australians would consider to be a defining feature of its national character.

Potentially Australia should be prepared to draw upon upon the cultural values that underpin greater inclusiveness in other countries. Countries with smaller disparities between the living standards of the wealthiest and least well off have better health outcomes overall, productivity and life satisfaction than Australia. Not all countries have abandoned direct involvement of government in execution of national programs.

Disability services draw upon skills and knowledge developed within teaching institutions. Amplifying the capacity of tertiary institutions to provide a direct pathway to employment in the public sector would afford greater control over service delivery, a platform for professional development and continuing education.

Large scale subsidies to disability training and delivery of services in the public sector would alleviate the shortage and demand for highly trained professionals in the private sector. The public sector ought to be the source of information that must be disseminated into the community to generate the cultural changes that are required to advance the interests of disabled citizens. Public involvement in programs to alleviate discrimination against people with disability requires not only legislative powers of government, but also contribution 'at the coal face' to integrate its administrative role in the process of meeting actual need.

The foregoing is written from the perspective of a father caring for a son for whom services ceased to be available once he turned 18. Australia does not have centres of excellence for the care of adults with permanent intellectual, sensory and perceptual disabilities. Psychosocial support is expensive. There are no psychiatrists in Australia that specialise in intellectual disability. Public disability services have virtually disappeared and mental health services are overwhelmed dealing with crises, so finding the optimal way to help my son flourish is an ongoing challenge.

My views have been influenced by the work of authors such as Martin Seligman and Michael Marmot on systemic influences upon health, Stuart Shankar on the role of self regulation and Bessel Van der Kolk on the whole of body effect of trauma. There is a growing body of literature on the effect of loneliness upon general and mental health, which is particularly pertinent and of increasing value in responding to effects upon mental health during the current pandemic.

I believe that it is crucial that we are alert to the causes of ailments and strive to remedy those causes and not pretend that treating the symptoms will provide lasting relief. In particular, mental anguish arising from being shut out or cut off from nurturing relationships or losing the capacity to reason because reality is too hostile to contemplate are responses that require attention to their causes not symptoms to be quashed.

Human connection is essential to health and requires support not only to individuals but from within the community in which people reside. In parallel with direct support for the disabled, education and active measures to integrate disabled people into workplaces are vital to the future well-being of the community

The NDIS is providing welcome funding to our family member and has enabled receipt of services that would have been previously out of reach. For this as a family we are very grateful. Having flexibility as to where funding could be applied would enhance its value.

Thank you for your work

**Support for Decision Making consultation submission**

**Name:** Individual 14 (SA)

**Date and time submitted:** 9/8/2021 11:54:00 AM

**How do you identify:**

* A NDIS participant: No
* A family member, friend or carer of a NDIS participant: Yes
* A NDIS nominee: No
* A legally appointed guardian: No
* A disability support worker: No
* A health or allied health worker: No
* A community member: No
* Aboriginal or Torres Strait Islander: No
* Culturally and linguistically diverse: No
* From a rural or remote area: No
* A person with an intellectual disability: No
* A person with a cognitive impairment: No
* A person with a communication disability: No
* A person with a psychosocial disability: No
* Other: No

1. **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

1. **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: No
* LAC: No
* NDIA Partners: No
* Advocates: Yes
* Service Providers: No
* Other: No

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

Represent the interests of the person affected by the decision, have an understanding of and anticipate consequences. Be open to risk and be prepared to provide support

1. **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

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

* They are chosen by the NDIS Participant as a decision supporter: Yes
* 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

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

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

Strengths and weaknesses of the person needing help at both practical level and also a theoretical understanding of stressors and underlying factors, such as cognitive, sensory and perceptual disabilities.

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

Yes

**What worked well?**

When moving out of home help with settling in and access to either home or new environment

**What could have been better?**

Better understanding of sources of companionship outside of home

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

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

Collaborative relationship between providers, flexibility to allow changes to become routine, not overwhelm with too many changes at once. Searching for what works best takes time. Navigating the plethora of providers and discovering services that make a difference requires patience.

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

**An intellectual disability:** Yes, See accompanying commentary

**A disability that impacts how they think, a cognitive impairment:** Yes, See accompanying commentary

**A psychosocial disability:** Yes, See accompanying commentary

**A disability that impacts their ability to communicate:** Yes, See accompanying commentary

**From a CALD community:** Yes, Cultural sensitivity and appropriatenness

**From an Aboriginal or Torres Strait Islander Community:** Yes, Cultural sensitivity and appropriatenness

**From the LGBTIQA community:** Yes, Cultural sensitivity and appropriatenness

1. **How can we help reduce conflict of interest?**

Cultivate a culture of collaboration to ensure that multiple perspectives are brought to bear. Transparency and practices that review outcomes against objectives are important

1. **How can we help reduce undue influence?**

Coercion is a form of abuse. Public airing examples of abuse is an effective means of raising awareness of the risks associated with advocacy, such as imposing values upon another person that are not relevant to them.

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

Ignorance fear and apathy are primary causes of poor health. Enjoyment of good health requires healthy attitudes and consistent effort that is difficult enough regardless of abilities. Impulsive decisions aren't consistent with long term well-being.

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

Training in advocating for people with disability will help raise community awareness of impediments to access, discrimination and its impacts.

See accompanying commentary regarding work that is needed in the community at large and need for state based disability services to shift attitudes to people with disability over which they have no control.

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

No