

CHOICE AND CONTROL

Reflections on the implementation of the principle of choice and control under the NDIS – paper developed by the NDIS Independent Advisory Council, 28 August 2013

Purpose

The Council offers the following reflections on the implementation of the principle in the *National Disability Insurance Scheme Act 2013* (the NDIS Act) of “enable(s) people with a disability to exercise choice and control in the pursuit of their goals and the planning and delivery of their supports”. This paper is not intended to be formal advice to the NDIA Board under section 144 of the NDIS Act. Rather, it is intended that this paper provide some early reflections from the Council to inform the Board’s early discussions of a number of important issues.

Background

At its first meeting, the NDIS Independent Advisory Council (the Council) identified the need to provide advice to the NDIA Board (the Board) on the implementation of the principle of participant choice and control as an early priority for the Council’s consideration. At its second meeting, on 15 August 2013, the Council focused on this issue and sought input from a range of national experts. It reviewed the earlier work of the Choice and Control Expert Working Group and the National Approach to Choice and Control Expert Group and had a wide-ranging discussion on the opportunities and challenges in the implementation of this essential principle of the NDIS Act.

The Council recognises the critical and demanding role that the Board will need to play in the exercise of its governance responsibilities in balancing the principle of choice and control with other key legislative mandates including giving effect to Australia’s obligations under the *United Nations Convention on the Rights of Persons with Disabilities* and the financial sustainability of the Scheme. As such, the Council offers some preliminary reflections to the Board on this issue. It recognises the complexity and sensitivities of these issues and the need to develop clear principles to help frame operational decision making for the Agency.

This paper was developed in light of the presentations and discussions that took place at the second meeting of the Council on 15 August 2013. The Council would like to acknowledge the valuable contributions made by Belinda Epstein-Frisch, Advocate, Family Advocacy NSW, member of the National People with Disability and Carers Council; Robbi Williams CEO, Purple Orange, a Julia Farr organisation, and former member of the Choice and Control Expert Working Group; and Anne Skordis, NSW Department of Family and Services.

The Council also acknowledges the work undertaken and sponsored by the former Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) in seeking to better articulate principles of choices and control. This funding has supported work undertaken by the Royal Melbourne Institute of Technology (RMIT). A summary of this work was presented to the Council by Belinda Epstein-Frisch at its 15 August 2013 meeting.

1. The centrality of choice and control

Advice to the Council from experts reaffirmed the lack of choice and control in many aspects of the disability services in Australia and the imperative to give substance to this legislative mandate in the operations of the Scheme. It emphasised the centrality of participants' right to directing and making decisions about what is important to them in leading a good life. They emphasised that choice should be linked to building an individual's social capital and maximising the life chances available to them to enable greater social and economic participation and contribution to the 'common good' (Williams, 2013).

A consistent theme in the presentations was that of 'a good life'. A good life is dependent upon various diverse aspects such as where we live, what we do, how we feel, what and who we know, what we eat, what we think, how we love, how we grow, how we belong. They affirmed the need to respect the diversity of choices that contribute to leading a good life and the positive and negative implications of the choices made, on participation in economic and community life.

There are numerous ways of framing the domains of choice. The Council found the definitions of these domains offered by Ms Belinda Epstein-Frisch helpful. She identified three categories of choice:

Pervasive choices are choices that affect significant milestones in a person's life and their aspirations. These choices are the most significant for an individual and include decisions about school education, employment, housing, social relationships and community participation.

Lifestyle choices are connected to a person's identity, and can be choices about the way they look, how to spend spare time, and what sports to play and what equipment to purchase.

Everyday choices that are made throughout each day; these include decisions about what to eat, what movies to watch and the type of care that an individual may want.

Epstein-Frisch identified the hierarchy of choices with pervasive choices, that is aspirations and choices made from available options in education, employment, housing, social relationships and community participation framing choice on lifestyle and everyday lifestyle issues.

Epstein-Frisch also identified a number of factors that can be classified as either enablers or inhibitors of choice.

Enablers of choice and control include:

- Access to information, knowledge and experience to inform people with disabilities about the choices and options available to them
- Power over resources and relationships
- Opportunity to think and dream about alternatives to the current services and resources on offer

- Support in decision making from trusted others.

Inhibitors of choice and control include:

- Lack of money
- Experience of what is possible
- Cultural expectations
- Self- confidence

The contemporary literature on choice and control recognises that everyone in society has limitations and constraints on their freedom of choice. Limitations exist as a consequence of history, law, culture, geography, experience and opportunity. A key distinction is whether the limitations a person experiences are reasonable or not. Epstein-Finch argues that limitation on experience should be no greater for a person with a disability than it is for others, in other words, limitations on the experiences of a person with a disability should be no different in form or measure to community 'norms'. If there are reasonable limitations on choice, the person with a disability should have the opportunity to try and overcome these. Dignity of risk for the individual is an important part of choice and control.

People currently in receipt of restrictive practices are often the most marginalised and vulnerable people with disability. The Council noted that the operationalisation of choice and control within the framework of restrictive practices requires thoughtful and careful consideration and with regard to the development of the National Framework on Reducing Restrictive Practices.

2. Obligations under the UN Convention

Compliance with The *United Nations Convention on the Rights of Persons with Disabilities* (the Convention), ratified by Australia in July 2008, requires ensuring participation for people with a disability on the same basis as all people. Specifically, the Convention highlights the importance of having the opportunity to participate in economic and social life on the same basis as all people, and the right of the individual to make choices about their life (Article 19).

The requirements of this Convention impose obligations on the Board in their implementation of the choice and control principle. The choices to be funded need to meet this criterion of being "on the same basis as all people". In our interpretation of this requirement, it appears that choice within the framework of the Convention is not open ended. In our opinion, choice needs to be about normative options, that is reasonable options and choices available to all Australians. The principle that Council considers needs to be considered by the Board is that choice needs to be within the expectations of the Convention.

Council considered the implications of this principle in relation to housing choices and in particular on-going funding of large residential services and cluster housing. It considered a scenario where a participant who is a resident of an institution, wishes to continue living in that institution on an on-going basis as part of their support plan. On choice and control grounds, such a choice appears justified, however, on Convention-compliance grounds, it does not appear to be justified. People living in large or small institutions are making a choice which is greatly restricted by 'inhibitors' as mentioned in Section 1. This can only be

changed through a transitional process of increasing the personal, knowledge, material and social capacity of the resident and their family/guardian and providing access to independent advocates. Without this process their choice is severely restricted.

The Council recognised the dilemma involved for the Scheme in achieving compliance with the choice of the individual and compliance with the Convention. Our judgement is practice on choice and control within the Scheme needs to be Convention-compliant. While acknowledging the sensitivity with which individual situations will need to be dealt with, it considers that choices need to be Convention-compliant and recommends that the Board adopts this principle.

Council acknowledges that judgements about “on the same basis as all people” can be complex, subjective and value-laden. It suggests that it will be important for the Board to be comprehensively briefed on available evidence to ensure judgements are evidence informed. Evidence presented to Council on this matter and detailed in the attachments indicated that the best interests of people with disability are served by the closure of all large residential centres. Transition planning and resourcing should focus on engagement with residents and families / guardians to increase the personal, knowledge and social capacity of residents which is the basis for choice and control

The important consideration in relation to institutions is to ensure immediate measures to prevent facilities of this kind ever being built again, and to ensure that places are not back-filled and planning for de-institutionalisation is established. The view of the Council is consistent with Article 19 of the Convention and will ensure that no young person will ever be provided with this type of facility as an option again. Council discussed further the need for:

- a. plans for de-institutionalisation to be established
- b. there should be no more building of congregate care facilities
- c. existing facilities should not be backfilled as residents leave, and
- d. careful and sensitive work should be undertaken with individuals to provide them with opportunities to experience alternative lifestyles, community supports, and options so that they can exercise informed choice and control.

3. Disability Support Organisations

Another critical contextual factor is that choice needs to occur within the context of financial sustainability and equity amongst participants with similar levels of disability.

The Council recognises that choice will be framed by judgements about what are reasonable, necessary and fair support packages based on need and local circumstances. It appreciates that this is an area of priority and development for the Scheme and the Agency and that this will be an area for on-going actuarial analysis and review on a regular basis in the development of reference packages. The Council welcomes and supports this area of focus.

One of the clear aspirations for the Scheme is that it will support the opening up of broader, more flexible and informal resources and supports for social and economic participation.

The Operational Guidelines and Local Area Coordinators are important initiatives that seek to address this aspiration. One of the issues for the Scheme is how it best supports and encourages new and more flexible support options, self-management and mutual support which improve social and economic participation and over time hopefully reduces financial reliance on the Agency.

One of the strategies identified by the Productivity Commission to facilitate participant engagement and flexible choices was the concept of DSOs. The Council appreciates that with the demands of establishing the Scheme, it has not been possible to develop this initiative.

The Council considers that an investment in the development of thinking about the structure, role and funding is justified. The Council discussed the potential role for DSOs in supporting participants to exercise effective choice and control. Council noted that the role of DSOs may be important in light of the negative interactions that many people with disability have had with traditional service providers, where little to no choice has been afforded. Council defined DSOs as mutual support and self-help groups that could be diagnostic (e.g. Downs Syndrome Association), population group specific (e.g. Women with Disabilities) or generic (e.g. Family Advocacy) and may have extensive networks among people with disability. DSOs were not considered by the Council to be service providers, but rather organisations run by and for people with disability. It was noted that DSOs could potentially connect participants and their families to others who can share knowledge and experiences about what is possible and support the stretching of aspirations. Such DSOs would be organisations led by and for people with disabilities and their families, who are independent of government and service providers. Project design work on the development of DSOs is justified in our opinion and we encourage Board to consider such an initiative. Council considers that one of the defining features of a DSO should be its capacity to demonstrate lack of conflict of interest (or how potential conflict of interest will be managed) and knowledge of contemporary service options.

DSOs could play strategically important cost-effective roles in supporting and encouraging service innovation and more innovative service and support offerings. For example, encouraging new players such as social firms as an alternative to Australian Disability Enterprises; community adult learning in community settings, new more responsive recreational opportunities, leisure not adult day programs and innovative housing projects at local and regional levels to address housing availability and suitability.

For example, for a person that requires assistance at night to get into bed they probably have some choice if they are in a metropolitan area. However, what if the person is a young adult who wants to accompany their friends out socially, are they able to get assistance at two o'clock in the morning?

Conclusion

The reflections in this paper identify some of the opportunities and challenges in the implementation of the choice and control principle in the NDIA. The Council recommends that the Board takes these reflections into consideration when exercising its governance roles.

There are a number of challenges for achieving genuine choice and control for participants in the Scheme. For example, the need for development and innovation within the service sector to enable people to make genuine choices about how, when and from whom they receive support services. Choice and control will also be limited during the launch phase by existing contractual arrangements for service provision that are in place.

The commencement of the Scheme was predicated on the wishes and aspirations of individuals being taken into account. This presents a fundamental opportunity to change outcomes for people with disability through deliberate integration-based services that meet the aspirations of people with disabilities and while also meeting the financial sustainability obligations of the Scheme.