Independent Advisory Council to the NDIS

Building capacity and reducing vulnerability in closed systems

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Purpose

The purpose of this paper is to focus on strategies that maximise outcomes and promote Scheme sustainability in relation to participants who live or spend time in closed systems.

Summary

The capacity building aspiration and infrastructure of the National Disability Insurance Scheme (NDIS) has the opportunity to be transformational in the lives of all participants, especially those who live in closed systems. The paper draws on previous Independent Advisory Council (IAC) and Intellectual Disability Reference Group (IDRG) work to outline the additional vulnerability of people in closed systems to argue that attention to capacity building, support for decision making and building personal safeguards will reduce risk and enhance opportunities for positive life outcomes.

Recommendations

Recommendation 1: That the Agency use existing risk assessment processes to identify vulnerable people in closed systems.

Recommendation 2: That the Agency prioritises strategies that build capacity and reduce vulnerability of participants who live and spend the day in closed systems.

Recommendation 3: That reasonable and necessary support for vulnerable participants in closed systems include support to:

   a) develop personal safeguards including support to:
        i. plan and implement safeguards;
        ii. develop self-advocacy skills; and
        iii. reduce the risk of abuse and neglect.
   b) build capacity especially where, as a result of the poverty of their lives, participants are unable to identify areas for growth and development
   c) improve decision making skills in people with disability and supporters using evidence based approaches.

Recommendation 4: That the additional requirements for vulnerable participants in closed systems are at the core of the NDIS as demonstrated in:
   a) reference Packages that reflect loadings for vulnerability;
   b) the Outcomes Framework through the identification and monitoring of outcomes for the most vulnerable; and
   c) the capacity of NDIA staff, outsourced planners and Local Area Coordinators (LACs) to understand vulnerability and allocate appropriate resources to strengthen safeguards, mitigate risk, facilitate the building of capacity and support for decision making.

Introduction

IAC advice has focused on approaches and strategies to maximise positive outcomes for participants while simultaneously ensuring the sustainability of the Scheme. On each topic the IAC has argued that, consistent with insurance principles, early investment will lead to more positive outcomes for the participant and will prevent a growth in costs associated with crises and unstable support arrangements.

The purpose of this paper is to focus attention on strategies to maximise outcomes and promote Scheme sustainability for participants who live and spend time in closed systems.

The NDIS has many processes and strategies in place to individualise its response and differentiate between participants on the basis of vulnerability. The streaming approach of the National Disability Insurance Agency (NDIA)'s Service Delivery Operating Model (SDOM) recognises that 20 per cent of participants will require intensive planning processes. The support catalogue makes provision for the additional support these participants will require to implement their plans. Anecdotal evidence suggests however that many people in closed systems do not receive capacity building support to enable them to experience new opportunities and increase their independence, self-management and community inclusion.

Identifying the vulnerability of NDIS participants in closed systems

The IAC advice on *Enhancing Personal Safeguards* sought to assist the NDIA to understand vulnerability and plan to reduce it. The advice argued that while vulnerability is part of being human, people with disability generally experience heightened vulnerability because they are more likely to experience disadvantages in life, to be severely affected by the vulnerability they experience and have fewer opportunities. .

The advice argued that some vulnerability arises from the nature of the impairment. Vulnerability is also heightened in interaction with systemic factors such as poverty, unemployment, inadequate housing, stigma, marginalisation, discrimination and pervasive power imbalances.

It is exacerbated when an individual is exposed to an unresponsive system,[1] experiences lack of control generally over life decisions,[2] lacks a credible or reliable voice in the complaints system, has challenging behaviour, does not have speech and has multiple impairments (Robinson: 2014:10). Many of these factors also contribute to the perceived risk of being a threat to others.

People whose lives are depleted of the enablers of an ordinary life[3] also experience additional vulnerability which can be seen in passive dependence, segregation, feelings of worthlessness, having very few or no friends and being seen as a risk to others.

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[1] including exposure to a large number of casual and agency staff, lack of control over which staff provide intimate care service.

[2] including enforced co-residency, vacancy management policies, residence in institutional settings, isolation,
lack of engagement with people who are there for you, capacity to recognise abuse (normative life experience).

[3] Positive relationships, sense of belonging, individual autonomy, active involvement in decision making, active
engagement in community, using our strengths to provide a challenge, making a contribution.

This advice seeks to sharpen the focus on people whose vulnerability arises because they live their lives in closed system, i.e. they live and spend each day in services that are closed from the outside environment, and all interaction and knowledge is transmitted from within the closed system.

While the NDIS provides participants with individual packages of reasonable and necessary support, there are features endemic to closed systems that reduce the potency of individualised support and hence increase the vulnerability of clients. Closed systems congregate people with disability together and segregate them from the community and in so doing reinforce group practices that prevent opportunities to address the physical, emotional social and skill development needs, isolate participants and do not enable or facilitate spontaneous exchange with people in the community.

In services that are closed systems, the person spends most time with people with disability, has very little or no interaction with people who are not paid to provide support and has very little or no individual interaction with people in their neighbourhood or community.

The key identifier of the vulnerability of people in closed systems is that the person lacks effective informal support, i.e. they lack relationships outside the service with individuals, especially unpaid individuals who could help the person and take action on behalf of the individual.

The Agency risk assessment process as part of NDIS planning provides means to identify vulnerable participants in closed systems and hence to begin a process designed to reduce risk and actively promote personal safety.

NDIS response to vulnerability

Consistent with insurance principles, it is imperative that the NDIS takes steps to increase capacity and reduce vulnerability in those who are in closed systems in order to enhance the opportunity for positive life outcomes and reduce the need for more intensive support arising from their heightened vulnerability.

Key strategies that the NDIS can take to reduce vulnerability of participants in closed systems include supporting participants to build their capacity, have a voice and make or contribute to the making of decisions, and plan and implement personal safeguards.

The IAC advice on *Capacity building for people with disability, their families and carers* argued that capacity building is critical to the sustainability of the Scheme because along with early intervention, it ensures that people can live their lives to the maximum of their abilities, less dependent on the service system and benefitting from opportunities for social and economic participation.

The advice argued that capacity building is a strengths based approach that taps into

existing knowledge, skills and motivations of the participant to promote self-efficacy; an increased sense of their capacity to influence their lives, their environment and their support. Capacity building takes place over time requiring a multitude of strategies at the individual, organisational and systemic levels to promote sustainable outcomes.

In any discussions of vulnerability of people in closed systems, there are factors that must be noted although they are outside the control of the NDIA. These include conditions under which people may be exposed to significant numbers of casual and agency staff; staff without supervision; and a lack of choice over staff, particularly those who provide intimate

It is urgent that the most vulnerable participants receive proactive capacity building that takes them outside the closed system even where the participant is unable to identify areas for growth and development. Many people who for example live in group homes and attend day programs may appear "settled" and "happy" but have never had the opportunity to experience anything different and so their base of satisfaction is very low. The poverty of life experience by many vulnerable participants means they have had little opportunity to be aware of possibilities for an ordinary life and may have left people with limited capacity to even recognise abuse. Capacity building may be the only avenue of support that draws the participant outside of a closed service.

Support for participants to have a voice and contribute to making of decisions

The *United Nations Convention on the Rights of People with a Disability* (UNCRPD) identifies active involvement in decision making as a critical step to identity formation and independence: one of the key goals of the NDIS. The IAC advice on *Reasonable and necessary support for an ordinary life* argued that the goal of independence requires people to be supported to maximize their self-determination and self-direction, be supported to have meaningful choices, make meaningful decisions about life and have access to the same opportunities as their peers without disability.

The paper outlined research that demonstrated however that many people with disability had little opportunity to make decisions and that in particular, young people with disability 'lack voice' in decisions about their lives.

The issue of support for decision making is highlighted in Article 12 of the UNCRPD and gained additional traction in Australia with the 2014 Australian Law Reform Commission Report *Toward Supported Decision Making in Australia.*

The IAC recommends that all participants in closed systems are provided with evidence

based support to assist them to make or contribute to the making of decisions about their lives and their support.

The IAC advice on *Enhancing Personal Safeguards* argued that priority be given to people with disability to identify and implement personal safeguards and build self-advocacy skills, including education about safety and action in the event of concerns about safety. This was argued as vital to contribute to people's personal safety and their confidence to experience increased independence, economic participation and community inclusion.

Specifically, the paper argued that NDIS reasonable and necessary support should be provided to:

    a) identify and plan personal safeguards
    b) develop self-advocacy skills; and
    c) develop relationships with people who are not paid to be there.

personal care. In addition, the impact of the limited normative life experience of many people with disability as a result of enforced co-residency, vacancy management policies, residence in institutional settings, isolation and lack of engagement with people who are trusted are critically important to understand in order to reduce risk and plan for personal safety.

Conclusion

The IAC believes that participant outcomes and Scheme sustainability are enhanced by the provision of targeted additional support to build capacity and reduce vulnerability in participants who live and spend the day in closed systems.

References

Robinson, S, (2014) *Preventing Harm: Can we shift our focus from responding to abuse to promoting personal safety?* Southern Cross University, www.nds.org.au/asset/view_document/979322767