Independent Advisory Council of the NDIS

Peer Support and Disabled Persons and Family Organisations

December 2017

Table of Contents

Introduction

The purpose of this discussion paper is to identify what is required to strengthen the role of community organisations of and for people with disability and families to support the goals of the NDIS.

The paper will:

- draw on the work of Disabled Persons' User Led Organisations in the UK to describe similar organisations in Australia
- outline the role, effectiveness and sustainability of peer networks
- demonstrate the value of these organisations to people with disability and the NDIS
- identify the way in which the NDIA could strengthen their capacity to deliver Scheme goals.

It is important to commence with a word about language. Mutual support and membership organisations have existed around people with disability in Australia for many decades. New Disabled Persons' Organisations (DPOs) and advocacy organisations emerged in the 1980s, signifying the emergence of the rights based era with names that clearly differentiated them from providers of core supports. The 2011 Productivity Commission Report into Disability Care and Support, envisaged yet another new type of organisation called 'Disability Support Organisations' or DSOs that would 'act as an agent for a person with disability on a range of matters, including in relation to the implementation of that person's package of services from the NDIS'[1]. The term DSO was taken up by a range of DPOs and advocacy organisations when they accepted grants from the NDIA to run peer networks in 2014.

The term DSO was always confusing. The name had no resonance with people with disability and provided insufficient differentiation from disability service providers.

This paper proposes the NDIA recognise and strengthen the role of this broad group of community organisations of and for people with disability and families. In doing so, the paper calls for the adoption of the term Disabled Person and Families Organisations (DPFO) to consolidate their identity and differentiate them from providers of core supports.

Disabled Persons and Family Organisations

In the UK

The 2011 Productivity Commission Report modelled the role of DSOs on Disabled Persons User Led Organisations (DPULOs) in the UK. DPULOs are distinguished from other similar organisations in three broad areas:

- Values: the values of the organisation include promoting the social model of disability, independence and peers support;

---

[1] Productivity Commission, 2011, *Disability Care and Support,* p414

- Power: people who use services control the organization (with 75% of the management committee as people who use services);
- Knowledge: the services a DUPLO provide such as advocacy and peer support are based on the direct lived experience.

Typically DPULOs provide support so that people can exercise choice and control over how their support needs are met. Typical activities include information and advice, advocacy, peer support, support in using personal budgets, direct payments, support to recruit and employ personal assistants, support with recovery, rehabilitation and overcoming social isolation, assistance with self-assessment, support planning and care reviews, equality training, campaigning, employment and return to work support and partnership activities with civil society organisations, health and social services.

From 2008 to 2015, the UK Government provided financial support to build the capacity of DPULOs, in order to enable them to support the transformation of adult social care. The UK government argued that DPULOs offer unique added value in:

- Changing perceptions – a user led organization enables people who use services to gain knowledge, skills and experience in leading and being actively involved in the running of an organization, demonstrating competence to people with disability and the community at large

- Giving people with disability a stronger voice in the local community providing advocacy, campaigning

- Building the capacity of people with disability who use services:

- As a resource for government, commissioners and service providers by

  o Supporting systemic transformation
  o Providing an understanding the needs of local people who use services
  o As a one stop shop for a thoughtful user voice
  o Coordinating user networks, which are an effective way of channelling user views on their local social care system
  o Coordinating coproduction and user engagement mechanisms to contribute to every part of the commissioning cycle: analyse, plan, do, review
  o Capturing local intelligence as to how the local social care market is operating in practice.

Evidence of effectiveness

UK evidence of effectiveness of user led organisations indicates that harnessing the voice of disabled people locally has both quantitative and qualitative benefits[2]. The Social Care Institute for Excellence reports the involvement of user led organisations associated with increased choice and control, increased adoption of direct payments and greater ability to

---

[2] Social Care Institute for Excellence (2013) A Commissioner's guide to the developing and sustaining user led organisations p21, Accessed at http://www.scie.org.uk/publications/guides/guide36/assets/files/guide36.pdf 9 August 2017, p15-17

navigate the care system.

In Australia, the Mental Health Commission of NSW[3] (the Commission) reports on number of research studies showing services controlled and run by people with lived experience of mental illness are effective in supporting recovery.

The Commission sought to identify features of 'successful' consumer run and/or led services. They confirmed the findings of multiple studies[4] that wide variety of size, structure and focus in consumer-operated services can be successful. The Commission commented on the difficulty in imposing standardised evaluation criteria on services that have a fundamentally different philosophical approach to traditional professional services and called for the development of a more nuanced approach[5] to the measurement of how change occurs in people's lives.

In the NDIS

Disabled Persons and Family Organisations or DPFOs have a variety of roles. They can focus on a specific experience of disability, for example Down Syndrome or Multiple Sclerosis, a specific target group such as people of CALD or Aboriginal background, young people, parents of people with disability and DSOs can be geographically based. Consistent across all DPFOs is the image projected to the community of people with disability as contributor not clients.

To be eligible to be called a DPFO, an organisation must be able to demonstrate:

- Values: A mutual support organisation promoting human rights, the social model of disability, independence, social inclusion and peers support AND
- Membership: Majority of the direct membership are people with disability and/or families AND
- Governance: Majority of Board of management must be drawn from membership AND
- Staff: Reflect the organisation's constituency and values AND
- Is not a provider of core supports

DPFOs can support a person with disability to build a vision of what is possible in their life and to find and use resources in their community to make that a reality. DPFOs can also help a person with disability to take action, by themselves or with others, on issues of access or inclusion in their community.

Depending on the DPFO, it can help a person with disability to:

- Think about how to plan for what a person wants in their life

---

[3] Sax Institute for the Mental Health Commission of NSW (2015) *Evidence check, the effectiveness of services run or led by consumers in mental health* Accessed at https://nswmentalhealthcommission.com.au/resources/the-effectiveness-of-services-led-or-run-by-consumers-in-mental-health-rapid-review-of 15 August 2017
[4] op cit p15
[5] For example, the Commission noted that it was difficult to establish concrete participation rates in consumer operated services due to the explicitly fluid nature of people's involvement where people were free to come and go, using the service as they saw fit and 'attendance records' were not kept.

- Develop skills to accomplish personal goals
- Connect to other people with similar experiences, sharing stories about what is possible for "someone like me", through peer networks, events and online forums
- Take action, either individually or with other people, to improve access and inclusion in community
- Learn about the NDIS including eligibility for funded support and how to use it

A complement to the role of the LAC

DPFOs complement the role of the LACs by supporting people with disability via:

- Information and capacity building sessions that inspire people to the possibilities of an ordinary life and provide information about NDIS
- Facilitation of peer support
- Individual discussion
- Work with mainstream services and community organisations to increase opportunities and remove barriers to participation.

> Whilst an LAC is a guide for a person with disability on the Participant Pathway, a DPFO has the capacity to be their guide for life.
>
> Where a participant experiences a challenge 6 months into their plan, if the first point of contact is the LAC, a participant will focus on the need for increased reasonable and necessary support. If the first point of contact is a DPFO, a participant will experience emotional support in the context of problem solving and for some, a need for additional reasonable and necessary support may be identified.

Comparison of LAC and DPFO roles

	Local Area Coordinator	Disabled Persons & Family Organisations
Scope	A guide on the participant pathway and connects people to mainstream and community services	A guide to life of which the NDIS participant pathway is one element Varies between DSOs but likely to have sources of funding that promote connection, problem solving, emotional support and advocacy. May be funded by NDIA to undertake defined functions related for example to: • peer networks • capacity-building of people with disability and community • information facilitation

	Local Area Coordinator	**Disabled Persons & Family Organisations**
Relationship to NDIA	Perceived as agent of the NDIS	Perceived as agent of the person
Frequency and depth of contact	Strongest on the Participant Pathway extending to opportunity for ongoing relationship for general and supported participants	Varies between DSOs but as membership based community organisations, provide opportunity for ongoing relationship
Assistance to access mainstream services	Supports participant to negotiate access as required	Many engaged in grassroots community connection and development. Can undertake systemic action on local mainstream services and resources (across all three sectors – government, community and private) re access and inclusion, based on aggregation of individual barriers
Assistance to participate in community	Provides information about opportunities and assists participant to connect as required	Many build capacity in people with disability and in community, to advance participation and belonging in community life. Able to work on participation on multiple levels of: • enhancing participant confidence and competence • building bridges to community • supporting capacity of organisations and activities to be welcoming and inclusive of people with disability
Participant capacity building	Within short contact with participant, difficult to sharpen the person's appetite for capacity building and increased independence	Longer more continuous relationship provides increased opportunity to ignite appetite for capacity building and increased independence. This is important because life experiences to date will have left many people living with disability carrying a low expectation of what is possible inn their lives. Access to information and an individual NDIS budget per se will not necessarily change the person's view of what's possible or sharpen their appetite for how to build capacity towards that
Workforce	Professional, preference	A mix of paid staff and volunteers, and a mix of

	Local Area Coordinator	Disabled Persons & Family Organisations
	given to people with lived experience	professionals and people with lived experience

DPFOs as a resource to the NDIA

The NDIA might commission DPFOs to undertake:

- vision building work that supports people with disability to have an ordinary life embedded in community
- individual planning
- capacity building for people with disability. Work of this nature will contribute to NDIA readiness for price deregulation because it will assist participant to be informed consumers able to negotiate service agreements that reflect their interests
- assistance to remove barriers to using mainstream services, such as supporting parents to negotiate the inclusion of their child in the regular class of the local neighbourhood school
- support for people with disability to participate and belong in community
- facilitation of peer support groups
- community development to remove barriers in community and mainstream services.

These roles assist participants on the Participant Pathway; for example in stages 1-3 to provide information and peer support, stage 4 to facilitate connections to mainstream, informal and community supports before a plan is in place, stage 7 to understand quality services and what they should be able to expect from their service providers and stage 10 to support transition for participants who exit the NDIS. Organisations may also provide support at life transition points or when circumstances change. This could be through peer based supports, workshops, and 1:1 coaching where appropriate.

The NDIA can enhance the effectiveness of DPFOs in assisting participants by building the organisational capability and ensuring quality and accuracy of advice. The Agency would work with organisations to provide the appropriate resources, dedicated technical support, training, mentoring and coaching, and platforms to share effectives practice. This will require the creation of an (outsourced) national Technical Support Team to provide targeted support to these organisations and expand their skills in building the capacity of people with disability. The Support Team will also help to ensure organisation gain a much stronger understanding of the NDIS principles and pathway.

DPFOs will require funding from the NDIA to undertake the commissioned roles identified above. It would be desirable to provide grants to approximately tow hundred (200) DPFOs including potential commissioning to seed establishment of DPFOs across Australia. Grants will supplement and not substitute or replace other funding sources, including philanthropic sources. In receiving the grant, the organisations would then benefit from:

- the support and training provided by the Technical Support Team.

- NDIS approved communications material and reinforce consistent messages about the role of the scheme, including its role as an insurance scheme and the focus on goals and outcomes.

Individual capacity building through DPFO

There is broad consensus that user led organisations offer a distinctive approach to capacity building with their adherence to the social model of disability, their accountability to members and service users and their promotion of independent community living.

In Australia today, most people with disability do not have access to individual capacity building through a user led organisation because very few DPFOs offer individual capacity building. Most were not eligible for state and territory transition funding that assisted providers of core supports to ready themselves for NDIA registration. In addition their concern to avoid conflict of interest meant they did not initially respond to the NDIA differentiation between providers of core and capacity building supports.

It is highly desirable for DPFOs to become accredited to provide capacity building supports to provide choice of providers. The Support Team (described above) would provide ongoing support to these DPFOs who want to become registered capacity building providers, to help them build capabilities and put in place systems and processes required to become registered providers. This will see employment of people with disability and in particular commence the building of peer-based workers in the disability sector that has been so successful in the mental health sector.

Not all DPFOs may choose to become registered providers of capacity building supports. For those that do, funding for individual capacity building will be through participant plans where DPFOs will be incentivised to demonstrate the value they bring, their track record in delivering outcomes including participants becoming more independent. Individual capacity building will also provide an alternative income stream to support ongoing financial sustainability.

The Support Team will continue to actively engage with and support this accredited network.

Measures the success

Measures of success in relation to NDIA commissioned roles identified above include:

- People with disability
  - know about the NDIS and feel prepared for planning / plan implementation / plan review
  - use and benefit from the same mainstream services as everyone else
  - participate in and benefit from the same community activities as everyone else
  - have increased connections, relationships and support networks in the community

- o have the skills and confidence to participate in the community and protect their rights
- Mainstream services
  - o exhibit positive change in attitudes and culture
  - o have more inclusive behaviour
  - o have increased knowledge and capability
- Community with which a DSOs has worked
  - o exhibit positive change in attitudes and culture
  - o have more inclusive behaviour
  - o have increased knowledge and capability

Peer networks

Strobel [6] provides a framework to differentiate peer support groups from professionally led and self help groups in terms of leadership, experiential knowledge and auspice.

	Professionally led	Peer	Self help
Leadership	Qualified facilitator	Trained novice facilitator	Community member
Experiential knowledge	Not required	Critical	Critical
Auspice	Varied	Usually organisation that provides information and support	Autonomous independent group

Role of peer support

It is widely accepted that someone who has been through a similar experience can offer invaluable support to anther person embarking on their own journey. The defining feature of peer support is that it refers to relationships and interactions between people who are peers and who are equal in ability, standing, rank or value[7]. Research by the Centre for Social Welfare reform found that peer support was associated with increased self-esteem, increased self confidence, increase sense of belonging and improved motivation. Peer support groups can form around disability, geography or interest and can meet face to face or online.

Mead and MacNeil[8] argue that peer support groups 'maintain a non-professional vantage point (that) is crucial in helping people rebuild their sense of community when they've had a disconnecting kind of experience'. Distinct beliefs, styles and values that distinguish peer support groups include:

[6] Strobel, N., Adams, C., Rudd, C., 2014, *The role of support groups and ConnectGroups in ameliorating psychological distress,* Edith Cowan University, http://connectgroups.org.au/wp-content/uploads/2014/11/ConnectGroups-final-report.pdf. Accessed 15 April 2015.
[7] Fulton, K, Winfield, C.,2011, *Peer support,* A discussion from the Centre for Welfare Reform & Paradigm, Accessed at https://www.centreforwelfarereform.org/uploads/attachment/294/peer-support.pdf on 15 September 2017
[8] Mead, S., MacNeil, C., 2004, *Peer Support: What Makes it Unique?*, <http://nhcornerbridge.org/PeerSupport.pdf>

- The peer principle: joining together with others with similar life experience and having an equal relationship

- The helper principle: the notion that being helpful to someone is also self healing

- Empowerment: finding hope and believing that recovery is possible; taking personal responsibility for making it happen

- Advocacy (self and systemic advocacy skills)

- Choice and decision making opportunities, skill development, positive risk taking, reciprocity, support, sense of community and developing awareness.

Auspice

Organisations hosting peer networks have a responsibility to use practice elements that assist peer groups to frame understandings toward empowerment. Mead and MacNeil identify these elements as:

- facilitate discussion that keeps people on track toward empowerment

- achieve difference: help people change their perception of themselves and their situation to be more empowered

- mutuality: assist participants to help each other and make a contribution,

- support a different language and self perception

- facilitate mutual responsibility for the group

- share risk: help people feel safe to share

Measures of success

In comparison to people who are not involved in peer networks, participants of peer networks:

- have a 'better' NDIS experience than people including being:
  - more able to express goals
  - more able to identify what they want from services
- are more empowered
  - more able to speak up
  - more connected to people not paid to support them
  - can identify more / people to support them in emergency/
- use more mainstream services or use mainstream services more effectively
- are more engaged in the community.

Cost effectiveness

Programs designed around peers are comparatively low cost in comparison to interventions

requiring the use of professionals and complex resourcing. It must be acknowledged however that a peer network that is properly designed will still require facilitation, the development of resources such as training packages and print materials, as well as ongoing support and monitoring of the health of the networks, all of which have the potential to require financial outlay. Peer networks for people with disability may also incur disability related costs associated with participation such as interpreters.

There is strong evidence[9] that peer support helps individuals take steps to prevent disease, manage chronic conditions, cope with emotional and psychological challenges and become more engaged in the health care system. Research studies[10] also indicate that peer support may be a cost effective and cost saving strategy for providing person centred care.

Sustainability

The extent to which peer networks can and should be self-sustaining is topical. The NDIS DSO project found that most peer networks benefit from the ongoing support of a host organisation. As would be expected, members of peer networks associated with the NDIS are vulnerable people who lack the skills and experience to maintain a network without support. The majority of DSO peer network members have a cognitive impairment including networks for people who are deaf blind, who have an acquired brain injury, who have an intellectual disability and are in touch with the criminal justice system and who live in boarding houses.

The value of an ongoing role of a host organisation can be seen in research[11] that demonstrates the importance of matching and monitoring of volunteer relationships to ensure positive outcomes. Research in relation to mentoring[12] that demonstrates enhanced outcomes for the 'helper' and not necessarily the 'helpee suggests the importance of structuring groups to maximize the opportunities for people to see themselves in the helping role, reinforcing the value of a guiding hand that can be played by an organisation hosting a peer network. This is a significant difference between a peer network and a self-help group.

Similarly research demonstrates that moderated online forums produce positive outcomes not seen in un-moderated forums in which mis-information and negative message can be prevail. Lindsay (2009)[13] found that moderated on-line groups increase social support, build motivation, enhance knowledge and self confidence and in turn, reduce risky behaviours and these outcomes are not replicated in un moderated support groups.

---

[9] http://peersforprogress.org/wp-content/uploads/2015/04/150417-economic-analysis-in-peer-support.pdf
[10] According to a literature review of economic evaluations of peer support between 2000 and 2014, 15 cost effectiveness studies and 12 other economic analyses of peer support interventions highlight the economic value of peer support using a variety of approaches. These evaluations focus on peer support in the context of diabetes, mental health and substance abuse, breast feeding and post natal care and primary care.
[11] DuBois, D.L., Holloway, B.E., Valetine, J.C., Cooper, H., 2002, 'Effectiveness of Mentoring Programs for Youth: A Meta-Analytic Review', *American Journal of Community Psychology,* Volume 30, Issue 2, pp.157-197.
[12] Allen, T.D., Eby, L.T., 2003, 'Relationship Effectiveness for Mentors: Factors Associated with Learning and Quality', *Journal of Management,* Volume 29, Issue 4, pp.469-486,
Karcher, M.J., 2005, 'The effects of developmental mentoring and high school mentors' attendance on their younger mentees' self-esteem, social skills, and connectedness', *Psychology in Schools,* Volume 42, Issue 1, pp. 65-77.
[13] Lindsay, S., Smith, S., Bellaby, P., Baker, R., 2009,; 'The health impact of an online heart disease support group: a comparison of moderated versus un-moderated support', *Health Education Research,* Volume 24, Issue 4, pp.646-654.

In the DSO project, support from a host organisation has been invaluable to meeting the goals of the NDIS of promoting independence and social and economic participation. Most peer networks are facilitated by a paid person with lived experience of disability. Where peer network members are very vulnerable, a staff member from the host organisation co-facilitates the network. One organisation, Families4Families, only uses volunteer peer network facilitators (family members of people with acquired brain injury) and reports that administrative support, information and training packages of activities are critical for success of the networks.

Whilst the DSOs assisted many networks to build relationships with local community organisations to support sustainability, the majority of networks continue to need some level of ongoing support from the DSO.

Risks associated with not investing in DPFOs

Many DPFOs will cease to exist

DPFOs tend to be small community based organisations. In recent years state government funding for capacity building and NDIS readiness work has been a mainstay of their presence. They are embedded in community and are deeply understand the challenges people with disability face across their lifespan and within their communities. They are not well placed to attract philanthropic funds and will require NDIS funding to provide the functions identified in this paper.

The NDIS will loose a one stop shop for a thoughtful user voice

DPFOs harness the voice of people with disability in their local community, often representing the visible face of disability. Like Disabled Persons Users Led Organisations in the UK, DPFOs have given people with disability a stronger voice in breaking down barriers and changing perceptions of the contribution of people with disability in the wider community. Importantly, in many areas, local NDIS offices have consulted broadly with DPFOs to strengthen their engagement with people with disability and to learn about the local community. Many DPCOs are a regular resource to government and services, providing an understanding the needs of local people who use services, coordinating consumer networks and supporting systemic transformation.

There will be less community and informal support for people with disability

DPFOs provide a major source of information and support for people with disability who will not become NDIS participants. Their work in connecting to community opens many opportunities for people with disability.

There will be pressure on the NDIS to provide increased reasonable and necessary support

Without the guidance, problem solving and mutual support of DPFOs, many people with disability will have reduced participation in the community and economy and will seek

increased reasonable and necessary support for a meaningful life. Many participants will go directly to the NDIS with their concerns where local peer support could have led to problem solving obviating the need for requests for additional reasonable and necessary support.

The way forward

This paper has suggested it is in the interests of the NDIS and people with disability to strengthen DPFOs for their role in supporting community engagement and sharing and solving challenges people experience in their lives. DPFOs are part of civil society, working with community to welcome all people. Their role contributes to the reduction in the need for reasonable and necessary supports.

The paper also recognises the value of peer networks including acknowledging the long term benefit of connection to and support from a host organisation in order to address emerging issues early that may have a negative impact on the group, provide accurate information and insights consistent with the goals of the NDIS and ensure outreach and provision in hard to reach communities.

The challenge however is that DPFOs do not exist across Australia and those that exist are small with little infrastructure for growth. They need assistance to strengthen their evolving capability. The IAC draws attention to the fact that the strength of the DPULOs in the UK came from a strong commissioning approach by the UK Government over a number of years.

The IAC confirms the importance an NDIA initiative to strengthen the inclusion of people with disability including:

- an initiative to strengthen DPFOs to assist people with disability in local and regional communities
- support for peer networks to flourish
- incentives and support for some DPFOs to provide capacity building supports to build participant independence
- the consolidation of a technical support for user led organisations to provide:
    - o training and development and facilitate a community of practice for all funded organisations
    - o resources to support the work of the organisations with people with disability including NDIS participants
    - o consultancy support to assist some user and family led organisations to become intermediaries and provide individual capacity building
- small grants to make community organisations such as sporting, leisure and cultural organisations more welcoming.