NSW DISABILITY NETWORK FORUM

Introduction

The NSW Disability Network Forum (DNF) thanks the National Disability Insurance Agency (NDIA) for the opportunity to provide a response to the discussion paper on the critical issue of quality and safeguards in the National Disability Insurance Scheme (NDIS).

About the NSW Disability Network Forum

Initiated in June 2011, the NSW Disability Network Forum comprises non-government, non-provider peak representative, advocacy and information groups whose primary aim is to promote the interests of people with disability. The aim of the NSW Disability Network Forum (DNF) is to build capacity within and across all organisations and groups so that the interests of people with disability are advanced through policy and systemic advocacy. The Council of Social Service of NSW (NCOSS) provides secretariat support to the DNF.

NSW Disability Network Forum Member Organisations:

Aboriginal Disability Network NSW	Multicultural Disability Advocacy Association of NSW
Association of Blind Citizens of NSW	NSW Consumer Advisory Group - Mental Health
Brain Injury Association NSW	NSW Council for Intellectual Disability
Deaf Australia NSW	NSW Disability Advocacy Network
Deaf Society of NSW	People with Disability Australia
DeafBlind Association NSW	Physical Disability Council of NSW
Deafness Council (NSW)	Positive Life NSW
Information on Disability and Education Awareness Services (IDEAS) NSW	Self Advocacy Sydney
Institute For Family Advocacy	Side By Side Advocacy Incorporated
Intellectual Disability Rights Service	Council of Social Service of NSW

Overview

The DNF welcomes this discussion paper, which thoughtfully addresses a range of issues in relation to quality and safeguards in the NDIS.

In considering the options presented, the DNF seeks to maximise the choice and control of NDIS participants. A crucial part of maximising choice and control is building the capacity of participants (and their allies where appropriate) to be informed about their rights and to direct their supports with consideration of the individual risks they face.

In developing a safeguards framework, it should be acknowledged that people with disability commonly have not had the opportunity to develop their skills for choice and control and self-protective behaviour. Accordingly, development of the capacity to exercise choice and control will be a slow and gradual process, particularly for people with intellectual disability. This underscores the importance of the safeguarding framework.

While the discussion paper focuses on quality control of services at registration, an ongoing approach to quality and safeguards should be adopted. An independent complaints system with an educative function, transparent reporting of oversight bodies and a well-resourced. Community Visitors Scheme are important in ensuring both strong safeguards and ongoing quality of services.

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The DNF urges the NDIA to take a broad approach to quality control of services, for example collecting data on complaints made to generalist complaint bodies regarding NDIS services.

Commentary on the specific topics explored in the discussion paper, as well as some important safeguards omitted by the paper, are outlined below.

Accessible NDIS information system

The DNF commends the recognition in the discussion paper of the importance of independent information on a wide range of topics, including

- rights, choice and control;
- supports available;
- quality of supports and choosing a provider.

While the online resources outlined in the discussion paper appear useful and relevant, people with disability have a wide variety of communication needs to which the NDIS must be responsive. The DNF applauds the recognition that information must be provided in community languages, and adds that information should also be delivered in a culturally sensitive way. For example, the NDIA should seek to employ Aboriginal people to work in Aboriginal communities.

Additionally, to ensure accessibility, information should be provided in alternative formats such as Braille and plain English. Crucially, printed and online information should be supplemented with face-to-face information, as this method is preferred by many people with intellectual disability. Additionally, online resources are predicated on a presumption of literacy which is not always accurate. Face-to-face information is particularly valuable in regional and remote areas, where people with disability and their families may be more isolated. Real-time information exchanges for this group of people would provide opportunities for them to access information that is both topical and relevant to their location.

It is important that possible participants, including people who are currently not accessing disability services, such as people with psychosocial disability, know where to find information relevant to accessing the NDIS. This may require using more mainstream communication channels such as radio, television and newspaper, and placing promotional material at common community areas such as libraries, or shopping centres and bus shelters.

Information is never 'value free', but is viewed within an individual's personal context. This is why it is important that information is relevant to a person's individual circumstances. For example, the idea of choice and control makes little sense when a person's whole life is or has been determined by others. Accordingly, information should be tailored to specific needs. For example, the NDIA should develop communication plans to target vulnerable cohorts, such as people who have been institutionalised.

Further, the provision of information should be viewed as a capacity building tool. For this to occur, information needs to be presented in a step-by-step and up-to-date way and that decision-making supports should be provided to assist people to know what questions to ask, to think through information, ask follow-up questions and make a judgment. In Sweden, an advocacy organisation developed a supported decision making tool to support children and young people to exercise greater choice and control over how personal assistance they require is delivered (as required by a

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2011 legislative amendment).[1]This approach could in implemented in Australia.

It is particularly important to ensure that people who are isolated and have been institutionalised have enough access to information and decision making support to begin to implement choice and control in their lives. Without these supports, there is a risk that the NDIS will deliver 'more of the same' poor quality outcomes to the most vulnerable people with disability.

The DNF recommends that a supported decision-making tool be developed for NDIA planners, to cement supported decision making in the planning process. A useful tool has been developed by Inclusion Melbourne and is available at http://www.inclusion.melbourne/wp-content/uploads/2013/06/Its_My_Choice_Vol2_web.pdf

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Recommendation 1

That information is be provided in multiple languages (including Aboriginal languages) and formats, and supplemented with up-to-date, face-to-face information delivered in a culturally appropriate manner.

Recommendation 2

That information be tailored to participants' individual needs; including the development of communication plans to target vulnerable cohorts, such as people who has been institutionalised.

Recommendation 3

That information about the NDIS be disseminated through mainstream communication channels such as radio, television and newspaper, and placed at common community areas such as libraries, or shopping centres and bus shelters.

Recommendation 4

That decision-making supports are provided in a comprehensive manner to assist people to think through and interpret information. Children and young people, and people who are isolated and have been institutionalised should be a particular focus of decision-making supports, which should be provided to NDIA planners.

Building natural safeguards

Strengthening natural connections in the lives of people with disability is a crucial safeguard against abuse, and lack of choice and control.

In relation to the discussion paper's focus on building capacity within the NDIS planning process and through Local Area Co-ordinators (LACs), planners themselves may need to strengthen their capacity to enhance natural supports. This process takes time and skill, and may be challenging in light of the pace of the NDIS roll-out. This is further discussed below in relation to "Facilitating Relationships".

Natural safeguards are formed when a person feels a sense of belonging within their local communities. Relationships of caring and connection, which safeguard a person against abuse, cannot be 'brokered' or 'bought', but must be intentionally built. For some people with intellectual disability, or those who have been systemically isolated, for example through institutionalisation, greater effort may be needed to strengthen and maintain natural support networks.

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[1] See Goodwin, 2015, at 83-84.

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Circles of Support

Snow (1998**)** describes four circles of support in a person's life:

The closest circle is our "circle of intimacy", our family or very close friends. This is followed by the "circle of friendships", which consists of people who are friends or relatives with whom we could share a movie or go out for dinner but are not those who we consider our most dear friends or those we must see regularly

Circle 3, the "circle of participation" includes the people in the social groups to which a person belongs, such as employment, school and leisure. Friendships may develop with people in this circle over time.

Finally, Circle 4, the "circle of exchange" is made up of paid people – those that are in our lives because they are paid to be. This could include paid support workers people like doctors, teachers, dentists, social workers, therapists, hairdressers, car mechanics and beauticians.

For many people with disability, there are people in Circle One and Circle Four with fewer people in other circles. "Circles of support" exist to bring together people with an interest in the life of vulnerable people (including with disability), allowing these people to play an active role in assisting the person to make and achieve goals, to form relationships and be included in their local community.

More information on Circles of Support can be found at
http://www.resourcingfamilies.org.au/building-support-networks/ (Resourcing Families is auspiced by a DNF member).

Facilitating relationships

The aim of support workers who assist people with disability to strengthen natural supports should not be a 'paid friend', but rather a facilitator of opportunities to develop relationships, build informal support, and fade out paid support.

Planners and support should adopt the following strategies for assisting people with disability to build relationships:

- **Focus on a specific geographic neighbourhood**. Learn about the neighbourhood. With the person with disability, spend time getting to know the people who are part of the local community.
- **Develop allies within the group, social club and community**. These are people who persuade others to open doors and recognize the contributions the person with disability has to offer. Their connections will begin developing a positive networking system.
- **Ask the association to welcome someone who has been excluded**. Community members tend to wait to be asked.
- **Pay attention to natural cues**. When relationships of natural support develop, support workers should gradually fade, but be available to intervene when problems arise.
- S**tand alongside the person with disability and alongside community members**. The support worker should act as a community member, rather than the professional, building the capacity of people with disability.

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As NDIA planners and LACs are unlikely to be adequately resourced to 'intensively' facilitate natural supports in an ongoing way for NDIS participants, it is important that this support be able to be included in a participant's plan, and that planners, LACs and support workers be trained to facilitate new relationships for the people they support, rather than 'providing' the relationship.

Recommendation 5

That NDIA planners and LACs receive support to facilitate relationships for people with disability, and resources to facilitate natural support are funded in an NDIS participant's plan.

Finally, safeguarding is the responsibility of the whole community. Through the Tier 1 of the NDIS and the National Disability Strategy, there is the opportunity to educate and engage the wider community about their role in creating an inclusive community that helps to prevent the abuse and neglect of people with disability.

Strong advocacy/ Disability Support Organisation sectors as natural safeguards
Independent advocacy is crucial to the capacity development of people with disability, performing functions including:

- Standing beside vulnerable individuals and groups and taking necessary action to defend and protect their rights and interests – while maintaining their integrity by avoiding conflicts of interest. Many people with disability and their families do not have the capacity, knowledge or skills to advocate on their own behalf without this assistance, but this capacity can be learnt.

- Being an independent point of first contact where initial concerns about abuse and neglect can be raised and more information about next steps can be accessed. The support of timely, non-aligned, independent advocacy empowers people with disability to imagine new possibilities and speak up about their concerns, including reporting abuse.

- Raising government, service provider, family and general community awareness about the rights and interests of people with disability.

To achieve its purpose effectively, both individual and systemic advocacy services need to be 'block funded' by government, rather than purchased through an individual's support package. It is unrealistic and unjust to expect a person with disability to put money aside in anticipation of the system failing them. In addition, advocacy is equally important for people with disability who are ineligible for an individual support package.

The Council of Australian Governments Disability Reform Council (Disability Reform Council) recently agreed that systemic advocacy and legal review and representation will be funded outside of the NDIS. [2] While this decision ensures independence of advocacy, there is a need for greater clarity about future funding as current funding for independent advocacy, information provision and representation in NSW is only guaranteed until 30 June 2016. More urgent action than the further consultation and reporting proposed by the Disability Reform Council is needed to ensure continuity of service. By the time of the proposed report of December 2015, many organisations providing systemic advocacy will have only six months of secure funding remaining.

Additionally, the Disability Reform Council communiqué announced that the NDIS will fund decision-making and capacity building support, including support to approach and interact with both disability and mainstream services. These supports are important but do not squarely correspond to

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[2] COAG Disability Reform Council 24 April 2015 Communiqué.

individual advocacy services, which must be delivered independently of service providers and the NDIA, and be available to all people with disability; including those ineligible for individual support packages under the NDIA. More information is needed regarding the funding of individual advocacy.

There is a legislative right to advocacy in England and Scotland under the *Care Act 2013 (Eng)* and the *Mental Health (Care and Treatment) (Scotland) Act 2003*[3] and urges that the *National Disability Insurance Scheme Act 2013 (Cth)* be amended to include a similar legislative right to advocacy.

Recommendation 6

That a strong block-funded advocacy sector be funded to assist people with disability to build capacity to exercise their rights, manage their supports and make complaints.

Recommendation 7

That the *National Disability Insurance Scheme Act 2013 (Cth)* be amended to include a legislative right to advocacy.

Disability Support Organisations (DSOs)

In its 2011 inquiry into disability care and support, the Productivity Commission recommended the development of Disability Support Organisations (DSOs), run by and for people with disability. Such organisations have been successful in the UK in assisting people with disability to build their capacity to direct their supports.

People could choose to use DSOs to:

- provide them with personal planning services over and above what they obtain from the NDIS;
- assist them with decision making supports;
- help them get the best value from their self-directed funding, once that has been determined under NDIS procedures;
- help them develop the skills and confidence to practically exercise choice;
- provide them with information of the quality and choice of support services available from specialist and mainstream providers;
- assemble 'packages' of supports from specialist and mainstream providers;
- undertake administrative tasks such as record-keeping and tax returns; and
- provide them with information about other sources of informal, unpaid or local supports.

The DNF applauds the work in capacity building currently funded by the NDIA and strongly believes that this work must continue. It is particularly important for groups of people with disability who have been marginalised, including Aboriginal and culturally and linguistically diverse (CALD) communities. Unfortunately, this funding is for a limited period of 2 years.

Recommendation 8

That the NDIA continue to invest funding for the establishment and continuity of DSOs, including with a specific focus on Aboriginal, CALD and other marginalised communities.

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[3] See Goodwin, 2015, at 49.

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Provider registration

The NDIS registration process needs to be rigorous enough to ensure quality of services, while not so onerous as undermine choice and control for people with disability using the services. In essence, it is crucial that people with disability, rather than government, be the main selector of services and supports under the NDIS.

The best way to maintain a balance between quality and choice of supports is to implement a differentiated registration process, so that greater safeguards are put in place in relation to services that have the potential to place people with disability at greater risk. For example, more conditions should be placed on personal care services offered under the NDIS than gym memberships purchased, because of the potential of abuse of people with disability in the context of personal care.

Option 2 in the discussion paper allows for this balance between choice and quality assurance, proposing that services be subject to specific registration conditions, in addition to the NDIA Code of Conduct and general law. Specific conditions would allow regulation to be targeted to the service provided, and ensure that disability specific services considered issues of risk minimisation.

While the benefits of quality evaluation are recognised, the experience of DNF members has demonstrated that quality evaluation in itself is not a guarantee of a good service, particularly when a 'check box' approach is taken to the evaluation process. To be effective, quality evaluation should involve deep engagement with people with disability (together with their families and allies where appropriate) to ascertain the nature of their experience with the service. The evaluation needs to be responsive to the specific communication needs of the person with disability. An example of this approach occurred in the 1990s, when consumer trainers met with residents of group homes with intellectual disability over six sessions to evaluate the group home from their perspective. Quality evaluation should ask open-ended questions about the values of the service.

Additionally, while the discussion paper focuses on quality assurance at the registration level, the safeguarding framework would be improved if quality assurance was an organic, ongoing process, with regular consideration of how the service was travelling. Taking a holistic approach, it appears inconsistent if quality evaluation was to be made public, while quality assurance was not (Option 3) as these processes are supplementary.

Recommendation 9

That registration conditions be differentiated according to the type of service.

Recommendation 10

That quality evaluation involves deep engagement with people with disability (and their allies where appropriate).

Recommendation 11

That if quality assurance and quality evaluation reports are conducted in relation to services, all reports should be made public.

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Independent complaints system

Features

A complaints system that is independent from providers of supports is a crucially important safeguard of quality of supports, and choice and control for people with disability. As flagged in the discussion paper, self-regulation or an industry-initiated review body are unlikely to give service providers an incentive to act on complaints. Additionally, people with disability can fear retribution in a self-regulated complaints system. This is especially true where service delivery and accommodation are provided by one organisation and people may feel making a complaint could undermine their security of tenure. Therefore, these options would provide insufficient safeguards to vulnerable people with disability.

Due to the vulnerability of people with disability, the complaints system should apply to all disability supports, whether or not they are funded by the NDIS. Following the UK, a 'no wrong door' approach should be adopted to complaints, which will assist with data collection and systemic improvement. The DNF is not advocating for an NDIS-specific complaints body to handle all complaints, including those about mainstream services. Rather, there should be processes developed to allow complaints to be referred to the appropriate body through warm transfer processes. This removes the onus from the person experiencing difficulty from having to navigate a complex system of multiple jurisdictions.

Further, data collection, subsequent policy analysis and opportunities for continuous improvement would be enhanced if complaints made to generalist and specialist complaints bodies relating to NDIS funded services were collated. For example, a complaints body should automatically complete a 'warm transfer' to generalist bodies such as Fair Trading NSW upon receipt of a complaint about a mainstream service; details about the complaint should then be collected for the purposes of the independent body reporting about NDIS funded services.

It is important that an independent complaints body be established outside the NDIA, to avoid a potential conflict of interest if de-registration would leave an inadequate supply of services in the geographic area. The independent body should be able to deal with complaints in relation to the NDIA as well as support providers since the one complaint may often raise issues about the actions of both the NDIA and the support provider.

If an independent disability complaints body is to be established, its independence needs to be assured by:

- The Head of the body having statutory security of tenure, and complete control over its staff and budget;
- Annual reports of the body being made public;
- Annual reports to parliament; and
- Quarterly public reports of headline issues, such as those published in the newsletter of the Energy and Water Ombudsman NSW, providing consumers and other stakeholders with valuable information about complaint trends (see http://www.ewon.com.au/ewon/assets/File/Publications/Newsletters/EWONews_30.pdf)

This body should also have a presence in each jurisdiction e.g. a NSW office and a budget that allows it to work proactively to identify and respond to systemic issues where these are identified during the course of their duties.

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A complaints body of this nature is likely to have a unique and evidence-based overview of the experiences of participants in the NDIS. It is important that this overview is used to enhance and improve the quality of NDIS services and make informed comment on how safeguards can be strengthened where gaps are identified. There may also be scope for the body to play a role in community and stakeholder education aimed at minimising the root causes of complaints.

Powers

The DNF endorses the recommended powers and functions of a complaints body in relation to complaints handling and investigation put forward by the Disability Complaints Commissioners in their paper of March 2015**;**
- assist people with disability to make complaints,
- include the provision of information, education, training and advice about matters relating to complaints and complaint handling ;
- receive, resolve and investigate complaints ;
- conduct 'own motion' inquiries and investigations, and
- review the pattern and causes of complaints, identify systemic issues for service improvement, and make recommendations to improve the handling and resolution of complaints.

The focus on rights protection and education is crucial, as people with disability need to be aware of their rights in order to complain about any breach of them. In addition some mental health consumers have expressed distrust in complaint handling by Government bodies, due to previous poor interactions with public mental health service which have led to a bad impression of Government bodies/agencies in general.

Accordingly, there should be a statutory prohibition against reprisals against complainants including whistleblower protection provisions.

Recommendation 12
That a completely independent complaints body with a wide range of powers, including the power to initiate 'own motion' inquiries, be established outside the NDIA.

Recommendation 13
That a complaints body be adequately resourced to proactively respond to emerging issues and 'own motion' inquiries, and to perform an educative function.

Recommendation 14
There should be a statutory prohibition against reprisals against complainants including whistleblower protection provisions.

Recommendation 15
That a 'no wrong door' approach be adopted to complaints, which will assist with data collection and systemic improvement. The complaints body should complete a 'warm transfer' to generalist bodies such as Fair Trading upon receipt of a complaint about a mainstream service; the data should then by collated, and publicly reported by the Ombudsman.

Community Visitors Scheme

Robinson and Chenoweth (2011:71) observe:
> *"Complaints-based systems rely on articulate, assertive and empowered complainants. The abuse and neglect of highly marginalized people – those living in segregated settings, in prisons, with multiple disability, with very high support needs – is less likely to be uncovered within a complaints regime, unless that person has a staunch advocate."*

Individual advocacy provided by Community Visitors is a crucial safeguard to people in institutions or residential care facilities. Proactive visits help to mitigate against the risk of over-reliance on a complaints system that is largely reactive. The role of Official Community Visitors in NSW is to promote the best interests people with a disability in care, by providing information to the Minister and Ombudsman about the quality of care provided to residents. Among other functions, Community Visitors perform a critical role in independent monitoring, resolution of complaints and emerging issues, and advocacy support to educate residents about their rights.

It is crucial that the Community Visitors Scheme be continued under the NDIS, and be adequately resourced to enable the visitors to be proactive in pursuing emerging issues. It is also important that the Community Visitors be remunerated, as they are in NSW, in recognition of the important and challenging role they play.

Keeping the scheme under State jurisdiction would facilitate a close relationship with police in terms of investigation, however there needs to be a differentiation between the Community Visitors Scheme and the Ombudsman itself.
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Recommendation 16
That the Community Visitors Scheme be retained, and adequately resourced to allow for proactivity. This should include the continued remuneration of Community Visitors.

Options for ensuring staff are safe to work with people with disability

Option 2 as outlined in the discussion paper – whereby prospective employees undergo police and reference checks, is the law as it applies in the *Disability Inclusion Act 2014 (NSW)*. Under this Act, employment is prohibited if a person has committed certain serious 'prescribed' offences. Accordingly, employer regulation (Option 1) would represent a reduction in safeguards.

The framework of screening staff would maximise choice and control by:

1. Mandating that a "Working with Vulnerable People Check" be conducted on all prospective employees who are to have direct contact with people with disability, similar to the system in South Australia.

   The DNF believes it is beneficial to have the widest possible range of information available, as charges not proceeding to a conviction could indicate a non-desirable pattern of behaviour. The available information should include a centralised database of findings of misconduct against individual disability workers. Where possible, information should be drawn from other countries in relation to migrant workers. This approach would also allow

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for consistent tests to be applied to people working with children, people with disability and older people, so that non-desirable applicants could not be deemed unsuitable by one system and then try another.

2. Providing the employer (including an individual using direct payments) discretion to decide what action to take with respect to information uncovered by the Working with Vulnerable People Check, provided that a 'prescribed offence' has not been committed. New South Wales legislation sets out or 'prescribes' the most serious offences; Federal legislation could do the same.

This approach would allow the employer to consider the relevance of the criminal record (or other adverse information) to the prospective employee's role, and for each case to be considered on its own merits, while still ensuring employees with the most serious records cannot be employed.

3. Mandatory reporting of allegations and reasonable suspicion of serious abuse and neglect in support providers, including unexplained serious injury to a person with disability, as required by the *Disability Inclusion Act 2014* (NSW).

4. Amending the *Fair Work Ac*t *2009* (Cth) to make it clear that an employer in the disability services, child and aged care fields is obliged to terminate the employment of a person who does not have a Working With Vulnerable People clearance.

The creation of a "barred person list" as suggested in Option 4 in the discussion paper will not provide employers with this discretion and flexibility. If this option was implemented, the scheme would need to be set out in legislation and include protections for prospective workers, including a natural justice provision.

Many people with a lived experience of mental illness face disadvantages in the criminal and civil legal systems. The DNF is concerned about the potential biases/disadvantages that may arise for people, including those with a forensic history, through a Working with Vulnerable People check. Thus, the framework needs to safeguard against discrimination or unfair exercise of discretion by employers. For example, the scheme should be statute based with a right of independent review by an appropriate Tribunal.

While the discussion paper focuses on initial screening of staff, the DNF emphasises the importance of ensuring staff working *within services* do not pose a risk to people with disability. The need for continual monitoring of staff is illustrated by the inquiry into the abuse and neglect of people with disability in institutional and residential settings currently before the Senate Committee on Community Affairs.

Robinson and Chenoweth (2011) in their review of abuse prevention strategies in disability accommodation services also stressed the importance of moving away from what they identify as being primarily *'procedural'* or *'managerial'* responses to addressing abuse in services. These authors put forward the importance of services developing strategies which focus on changes to the culture and practices of services and building what they describe as *'protective cultures'*. The features of such service cultures include person-centred approaches, control and choice being vested in or close to the person, community connections and positive relationships between staff and residents based on respect and a recognition of rights.

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Further, staff should be given training in relation to the client's rights to freedom from abuse, including the right to respect, dignity, choice and control, and how to recognise and report abuse. The effect of this training should be evaluated by consulting with residents and their families (where appropriate) and observing staff interaction with residents.

Recommendation 17

That a Working with Vulnerable People Check be conducted on all prospective applicants for disability support roles, with employers then given discretion regarding what action to take (except where the most serious offences have been committed). Further, an employer should be obliged to terminate the employment of a person who does not have a Working with Vulnerable People clearance.

Recommendation 18

That where the most serious offence has been committed, legislation gives workers a right of review to independent Tribunal.

Recommendation 19

That the Quality and Safeguards Framework provide for mandatory reporting of allegations and reasonable suspicion of serious abuse and neglect in support providers, including unexplained serious injury to a person with disability, as required by the *Disability Inclusion Act 2014* (NSW).

Recommendation 20

That steps be taken to create protective cultures in services, including staff being given training in relation to the client's rights to freedom from abuse.

Options for self-management of funds

It is fundamental to the design of the NDIS that people who manage their own plans be able to choose unregistered providers of supports at their own risk. Options 3-3c in the discussion paper, whereby individuals who self-manage their funds are restricted to registered providers of supports, undermines the principles of choice and control and should not be implemented. However, there is a safeguard in the NDIA's power to refuse a person's wish to self-manage if there would be an unreasonable risk to the participant. The DNF suggests the NDIA make public how this power will be used in practice.

Option 2 in the discussion paper, whereby certain providers are prohibited from offering supports, may unduly restrict the freedom of NDIS participants to purchase mainstream services. For example, a local lawnmowing service, not prepared to be subjected to a negative licensing scheme, may instead refuse to take on a customer purchasing services with an NDIS package (the participant would bear the onus of making a complaint about this).

However, it is appropriate for there to be a capacity for disability workers to be excluded from working for self-managing participants on the basis of factors like relevant criminal records and histories of mistreatment of vulnerable people. As discussed above, the option of a barred person list would have to include protections for workers. If these protections were included, the list may prove a useful tool to people with disability managing their own supports, because they would be able to determine if significant concerns had been raised about their prospective employee.

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Capacity building through 'risk enablement' is a crucial way to assist people with disability to self-manage their support. Risk enablement is the process whereby people with disability (and their allies (where appropriate) gain the skills to deal with the risks that may arise as they self-manage their supports.

Risk enablement can occur in a number of ways:

1. **Explore risks and safeguards through the planning process**

The planning process should include a discussion of risks and safeguards specific to the needs, goals and aspirations. This will enable thoughtful consideration of risk, and will strengthen the capacity of the individual and those around them, to make informed decisions about options.

For example, a man who has quadriplegia and wants to live alone (but can't get out of bed alone or use the phone when in bed), a risk enablement conversation might cover scenarios such as what to do when early morning staff don't arrive or if there is a fire. Such planning conversations strengthen the nature of the supports used and enable the person to make informed decisions about their options.

2. **Provide skilled assistance with the implementation of the plan and support**

This will enable the participant to strengthen their skills at self-direction and self-management, meaning that a variety of people with disability will be able to self-manage their supports.

Assistance with risk enablement should be funded separately in the NDIS participant's plan, rather than included in their core package.

3. **Extend plan management options that share the management of supports between a participant and a service provider**

The use of a plan management provider enables participants to share the risk with a service and/or financial intermediary but the DNF understands that this option is poorly understood and hardly used by any participants. The plan management option seeks to replicate shared management systems available through State and Territory disability service systems for many years. Under shared management, the service is the fund holder and employer of staff and responsibilities for aspects of service management are delegated to people with disability and families reflective of their capacities and wishes at any time. The intermediary roles are highly valued, and assist people to increase their capacity to direct their own support.

4. **Provide clear information to assist people to use self-directed and self-managed options.**

The NDIA should develop resources that encourage and support people to enhance their authority within their lives including via self-management. These resources could be on-line and in appropriate alternative formats as outlined in Recommendation 1, and should be backed up by a telephone advice line that provides information necessary for the smooth and successful management of a support package e.g. wage rates, insurance, work, health and safety information.

Recommendation 21

That options for capacity building and risk enablement be explored to give all NDIS participants the option of self-managing their supports.

Recommendation 22

That the NDIA have a capacity to exclude from working for self-managing participants on the basis of factors like relevant criminal records and histories of mistreatment of vulnerable people.

Recommendation 23

That the NDIA fund the development of resources and a telephone information line to encourage and support people to successfully self-manage their supports.

Recommendation 24

That the NDIA make public how it will apply its power to refuse a person's wish to self-manage if there would be an unreasonable risk to the participant.

Over time, many family members may seek to become a participant's plan nominee with a view to managing their family member's NDIS plan or engaging a registered plan manager to do so. The DNF would generally welcome this as an indicator of enhanced capacity and engagement. However, it is crucial that all nominees comply strictly with the requirements in the *National Disability Insurance Scheme Act 2013 (Cth)*. In light of the barriers a participant may face in raising an issue about their nominee, it is particularly important that the NDIA monitor and evaluate the support of plan nominees, ensuring high quality and safeguarding against abuse.

Recommendation 25

That the NDIA ensure that all nominees comply strictly with the requirements in the *National Disability Insurance Scheme Act 2013*(Cth), and monitor and evaluate the support of plan nominees.

Restrictive practices

While the National Framework For Reducing and Eliminating the Use of Restrictive Practices in the Disability Service Sector and the discussion paper focus predominantly on restraint (physical, mechanical or chemical) and seclusion, DNF members are aware of a range of other restrictive practices including:

- confining a person to their home, in some cases by having the doors locked whenever the person is at home;
- restricted access to spaces within the person's home or to their belongings;
- monitoring devices.

While some restrictive practices may need particular regulation, all need some regulation.

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Approaches to authorising restrictive practices

Currently in NSW:

- Formal authorization is required before a restrictive practice can be included in a person's Behaviour Support Plan.
- A *Restricted Practice Authorisation (RPA)* must be strictly time-limited; valid for a maximum period of 12 months.
- The use of a *Restricted Practice* must be closely monitored to safeguard against potential abuse, and should be replaced with a less restrictive strategy as soon as possible.

In the experience of DNF members, the use of restrictive practices to minimise the impact of violence or 'challenging behaviours' can actually exacerbate these behaviours because their causes are not addressed. Many restricted practice panels lack the insight needed to assist the person to positively move past the anti-social behaviour and usually only look at crisis driven solution to mitigate risk. Additionally, the DNF members are aware of restrictive practices being used in *anticipation* of the behaviour in the behaviour support plan.

The discussion paper suggests that a support person be appointed to explain the impact of the restrictive practice to the person with disability before it is included in an individual's behaviour support plan. However, the fact that many families are not well informed or empowered to question what service providers recommend in relation to challenging behavior may diminish the value of this proposal

Option 3 whereby providers would be authorised to make decisions under specific conditions is not supported. The providers potentially face an unsafe conflict of interest, and proactive monitoring systems are required to detect situations where providers do not comply with the regulatory regime.

In addition, this approach does not address the question of whether the doctor prescribing any psychotropic medication is appropriately skilled in this area, or has enough understanding of the patient's situation to do so. Further, the distinction between chemical restraint and mental health treatment is unclear and therefore open to abuse. Arguably, regulation should focus on all prescription of psychotropic medication to people with intellectual disability or mental health conditions rather than just on what the doctor characterises as chemical restraint. The introduction of national legislation to address these issues is recommended.

It is crucial that any application to instil a restrictive practice must be coupled with an outline of what has been done to respond to the underlying cause of challenging behaviour and evidence that a plan to work with the person to resolve unaddressed issues is in place for the period after any restrictive practice has been instituted. In addition, restrictive practices must be authorised by an independent decision maker. This is similar to the role developed by the Guardianship Division of the NSW Civil and Administrative Tribunal (NCAT) and means that physical restraint and seclusion require the consent of a guardian with a specific restrictive practices function.

It is critical for the NDIA to establish:

- clear criteria for what professional qualifications and competencies are required to be a behaviour support practitioner; and
- a workforce development plan to ensure that there is an adequate supply of practitioners.

One of the required competencies should be in person-centred active support.

Recommendation 26
That each instance of a restrictive practice be authorised by an independent panel and used as a last resort in consultation with the person with disability.

Recommendation 27
That any application to instil a restrictive practice must be coupled with an outline of what has been done to respond to the underlying cause of challenging behaviour and evidence that a plan to work with the person to resolve unaddressed issues is in place for the period after any restrictive practice has been instituted.

Recommendation 28
National regulation of restrictive practices and behaviour could include a focus on:
- Physician skills;
- Cross disciplinary collaboration between behaviour practitioners, doctors and other relevant professionals; and
- The need for a positive behaviour program.

Recommendation 29
That the NDIA establish clear criteria for what professional qualifications and competencies (included person-centred active support) are required to be a behaviour support practitioner and a workforce development plan to ensure that there is an adequate supply of practitioners.

Approaches to monitoring restrictive practices

Every incident of a restrictive practice should be reported, to gain an overall view of such practices and when they are used. As the *Disability Inclusion Act 2014* (NSW) mandates the reporting of "reportable incidents", this data could illuminate any correlation between reportable and restrictive practices.

The DNF supports the establishment of a system for mandatory reporting of restrictive practices based on the Restrictive Interventions Data System in Victoria. This system would need to be supported by a Senior Practitioner or equivalent with a skilled team of professionals who can collate and analyse the data and carry out audits and reviews of concerning trends in relation to particular providers or particular individuals. The Senior Practitioner should also have a well-resourced power to conduct random audits and then work with providers to enhance their positive behaviour support and decisions in relation to restrictive practices. Community Visitors should report inappropriate use of restrictive practices to the Senior Practitioner.

DNF members are aware that, in NSW, it has become quite common for a supported accommodation worker who has been assaulted by a person with intellectual disability to call the police who then take out an Apprehended Violence Order (AVO) against the person. This is problematic since the root cause of the problem may well be inadequate general disability support and inadequate behaviour support, and the person may not understand the AVO process or the implications of the order.

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Recommendation 30

That the NDIA establish a system for mandatory reporting of restrictive practices based on the Restrictive Interventions Data System in Victoria, supported by a Senior Practitioner resources to collate and analyse the data and carry out audits and reviews of concerning trends in relation to particular providers or particular individuals, and work with them to enhance their positive behaviour support.

Recommendation 31

That AVOs taken against a person with intellectual or cognitive disability be included in the data provided to body oversighting restrictive practices.

Important considerations not included in the discussion paper

Responding to fluctuating capacity and needs

The capacity and needs of NDIS participants may fluctuate, for example, if they have a mental illness that is of an episodic nature. The NDIS Quality and Safeguarding framework needs to ensure that the NDIS will provide good quality supports and will maximise the choice and control of participants throughout any changes in people's circumstances.

To respond to the fluctuating capacity of participants, the use of advance directives or instructions may be discussed during the planning process with participants and NDIA staff. This may help ensure that people don't lose support and choice if their capacity reduces.

As people's needs change, they may need a level of support that services they are currently accessing cannot provide. There is a risk in these circumstances that people may lose support, or that their support becomes fragmented. The NDIA and service providers may need to work with participants to ensure they can access supports for their changing needs. This may require coordination across services and organisations to ensure smooth transitions in support.

Recommendation 32

That the NDIA support NDIS participants with fluctuating needs to develop a plan (including advanced care directives where appropriate) to ensure they can access supports for their changing needs.

The need for safeguards against a service withdrawing from a participant and leaving them without adequate support

The discussion paper does not outline any procedures to be followed before service is withdrawn from a vulnerable participant, for example because of "challenging behaviour". The safeguards in this area should include enforceable policies and rules around withdrawal of service, and an immediate ability for the participant to seek a review of the service's decision to withdraw support of the failure of the service to follow these rules and procedures.

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Recommendation 33

That safeguards against a service withdrawing from a participant and leaving them without adequate support be included in the Quality and Safeguards Framework.

References

Goodwin, A. (2015) "To identify programs that prevent abuse of people with disabilities who use direct payments to purchase services."

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