

Pearl Lifestyle Services Qld

Submission to the National Disability Insurance Scheme

Proposal for a National Disability Insurance Scheme Quality and Safeguarding Framework

- Safeguards for participants who manage their own plans

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BACKGROUND

Interest of Pearl Lifestyle Services Pty Ltd

Pearl Lifestyle Services Pty Ltd was established with the sole purpose of providing self-directed support to people with disabilities. The service continues the foundation work undertaken through earlier business structures that have been managed and directed by Kathy Rees since the early 1990s. Throughout this period of time, these structures have successfully managed all aspects of the support requirements of Ms Rees's daughter with significant disabilities and, more recently, supported other people who want to self-direct / self-manage their arrangements.

The specific functions of Pearl Lifestyle Services include:

- Encouraging and supporting people who want to self-direct / self-manage to consider the purpose and functions associated with sustaining their arrangement over time;
- Supporting people to develop and maintain their skills to manage their arrangement;
- Supporting people who want to develop their skills to manage their own arrangement and then separate from Pearl Lifestyle Services when they are ready to do so;
- Ensuring essential reporting and management practices underpin this work and that all relevant and required legislations, regulations and standards are addressed within this approach;
- Monitoring and reviewing the supports provided to people with disabilities through these self-directed / self-managed practices;
- Continually seeking ways to improve and refine our approaches to provide sustainable self-directed / self-managed practices over time

Focus of this Submission

The focus of this Submission examines some of the quality practices and safeguards required in situations where people manage components or all of their own self-directed arrangement or plan. This approach includes responding to the section on 'Safeguards for participants who manage their own plans' identified in the NDIS Quality and Safeguards Paper.

Pearl Lifestyle Services Pty Ltd places significant emphasis on sustaining these arrangements over time. We are also committed to ensuring that any person who wants to self-direct or self-manage their arrangement should have the information and support to do so, not just when they commence on this pathway but over the years that they undertake and manage this form of support arrangement. We also have seen that self-directed / self-managed support arrangements assist people with disabilities to experience tangible differences in their life, regardless of the source of the person's funding.

RESPONSE TO QUESTION 1

Question 1 asks:

Should people who manage their own plans be able to choose unregistered providers of supports on an 'at your own risk' basis (Option 1) or does the NDIS have a duty of care to ensure that all providers are safe and competent?

Option 1: Building the capacity of participants to manage their own risks

Priority actions for the NDIA:

- Practical information should be available to people who self-direct, both in the early stages of commencing with this form of support as well as over many years. This information should be provided using relevant communication methods and languages that the individual can understand, and be accessible to people seven days a week.
- Methods for acknowledging and working with non-registered providers should be established. There should be expectations for criminal screening, accountability and monitoring practices that match the NDIA's expectations for registered providers.

People involved in managing components or all of their self-directed support arrangements or plans frequently need support in understanding the long-term issues and risks that may arise, as well as having access to advice from knowledgeable practitioners as their situations, needs and capabilities change through time.¹ This process involves building the internal capacity of people to understand the responsibilities related to managing the practical aspects of these arrangements. Regardless of which approach the person may take in addressing these tasks, responsibilities generally entail being an employer of support staff and other people, accounts record keeper, staff supervisor, scheduler, planner, payroll manager, and the intermediary for managing external supports from fiscal intermediaries (such as the NDIS).² People undertaking this form of arrangement need to be more informed about perceived advantages and disadvantages associated with managing funds as well as staff, and have the opportunity to acquire other skills, such as developing a more robust understanding about the requirements of being an employer, the work involved in managing direct payments, and balancing friendships and relationships with personal assistants against the downside of meeting

¹ See, for example, Ashcroft, J. (2009). *Self-Directed Support: The Challenge of New Relationships*, Relationships Foundation [online] www.thewholesystem.co.uk/docs/Briefing_on_Self_Directed_Support.pdf

Blyth, C. & Gardiner, A. (2007). "We're not asking for anything special": Direct payments and the carers of disabled children, *Disability and Society*, 22 (3), 235-249.

Scourfield, P. (2007). Social Care and the Modern Citizen: Client, Consumer, Service User, Manager and Entrepreneur, *British Journal of Social Work*, 37, 107-122.

² Kendrick, M. (2002). Self-Direction in Services and the Emerging Safeguards and Advocacy Challenges that May Arise, Discussion Paper of the Connecticut Office of Protection and Advocacy for Persons with Disabilities. [online] http://www.ct.gov/opapd/lib/opapd/documents/adobe/michael_kendrick_paper.pdf

changing needs and circumstances.³

It is important for the NDIA to fully comprehend that managing components or all of the person's self-directed / self-managed arrangement or plan can take time to establish and to see the actual capacity of people to manage these arrangement. From one end of the spectrum, people may require considerable information and support to develop skills and confidence before they commence managing any aspect of their arrangement, while at the other end of the spectrum, the capacity of people to manage their own arrangements may be operational and discernible quite quickly due to the person's own experience or the existing experience of supporters to manage these types of arrangements or structures. Moreover, providing additional support to people from different cultural and ethnic backgrounds, and addressing situations where language may be an impediment towards understanding the NDIS and its requirements, also need to be factored into the management of these arrangements.

Option 1 refers to people being able to choose a provider who is either registered or not registered with the NDIA. The reality is that there are already many positive examples where people have chosen to have their supports managed by non-registered suppliers or where they have managed their arrangement themselves for many years. Examples include situations (amongst many others) where:

- The person with disabilities lives in a remote location and the person's supports have been brokered to the family property or business to oversee and manage.
- Family members assume responsibility for managing the person's arrangement through other government agencies (including trust management companies).
- The person with disabilities has been involved in a business that is prepared to take on the financial responsibilities associated with the person's funding.
- The service provider has supported the family member / supporter and/or the person with disabilities to undertake responsibilities, some of which the provider auspices, while other tasks are managed with the assistance of other community-based businesses.
- The person with disabilities and/or family members has managed the arrangement for many years without external agency involvement. This approach means the person has received funding directly from the funding agency.

Where people have engaged non-registered providers, there has been an expectation reports will be provided on financial expenditure and other nominated requirements in a timely manner through relevant channels, including financial reporting mechanisms to the funding provider as well as to through the Australian Taxation Office. In addition, there are opportunities to review the arrangement's function, for example, through audit processes. When people choose to use these other

³ Arksey, H. & Baxter, K. (2012). Exploring the Temporal Aspects of Direct Payments, *British Journal of Social Work*, 42, 147-164.

options to manage funding and to provide support, there are generally reasons for doing so, for example, location, relevant experience, strong commitment and desire to undertake these responsibilities, and/or difficulties with a registered service provider that cannot be resolved. In previous research, participants have noted that assuming these responsibilities is often a last resort, and people have considered that undertaking the management of the arrangement could not be any worse than what a service provider does⁴. This is supported by research suggesting that attempts to manage within mainstream service provision arrangements results in many people experiencing feelings of frustration and fatigue dealing with an apparently inflexible support system, the effects of time consuming, continuous battles for even the most basic support or provision, as well as misdirected resources, multiple funding streams, inflated needs, stifled innovation and over-management with existing service provision.⁵

Utilising non-registered providers is not necessarily a detrimental option for many people, particularly when they have lost faith with the current service delivery system. The NDIA should be aware of these reasons and consider, with the person with disabilities and his/her supporters, the benefits associated with seeking the services of a non-registered provider, including those of support workers and other forms of employees who assist the person to manage the arrangement or plan. Moreover, the NDIA should be able to acknowledge and have processes for obtaining relevant financial and information reporting mechanisms from these other agencies, organisations and businesses.

Option 2: Prohibiting certain providers from offering supports

Priority actions for the NDIA:

- The NDIA should have a defined process for reviewing situations where people progress through providers within a short time frame and/or over multiple occasions.
- There should be a mechanism for reporting unethical and/or unsafe practices to an Ombudsman (or similar) and to have these practices investigated in a timely and accountable manner.
- There should be an expectation that any provider maintains appropriate contact with the person with disabilities, and that ‘hands-off’ approaches are not supported.
- Discussion about risk management practices, including the requirement for police checks, should be conducted as part of the planning meeting process and on an ongoing basis.
- A defined Code of Conduct should be established and implemented across registered and non-registered providers throughout the Australian community.

⁴ Rees, K. 2012. “It’s not just about the support: Exploring the ways in which family members and people with disabilities evaluate their self-directed / self-managed arrangements”, commissioned by the Practical Design Fund, FaHCSIA, Canberra, ACT.

⁵ Hatton, C., Waters, J., Duffy, S., Senker, J., Crosby, N., Poll, C., Tyson, A., O’Brien, J., & Towell, D. (2008). *A Report on In-Control’s Second Phase, In Control*, London.

This option presumes that registered service providers do not currently pose any risk for people with disabilities. This is a problematic statement and ignores the reality of the abuse that has occurred, and continues to occur to people with disabilities by staff members working for existing service providers throughout Australia. Indeed, it would be extremely foolish to presume that people will only require additional levels of safety or become vulnerable when they choose non-NDIA registered providers.

The reality is that the NDIA needs to ensure mechanisms in the disability sector perform their roles and function. This includes addressing situations where people who self-direct their supports do not perceive the need for any external monitoring of their arrangement, including from the registered or non-registered provider or from any other agency, such as the Community Visitor (or equivalent in other states) when the person with disability resides in a home away from the family residence.

The statement about ‘establishing a mechanism in which information about unethical or unsafe individuals and organisations could be reported to a central source, assessed, and a decision made’ about ongoing provision of supports indicates that this is ‘limited to people and organisations providing support of specific types linked to the potential for harm’ (p70). Acting upon any form of unethical or unsafe practice should apply to any entity or individual providing services to people with disabilities. However, while there are existing mechanisms for reporting these matters, there is a gap in the current system when suspected abuse and neglect is reported and there is no real tangible evidence of investigations being undertaken by the funding provider. Examples include (amongst others) when:

- The person with disabilities is moved to another provider when the first provider raises questions about the safety and wellbeing of the person with disabilities following its own investigation processes. No questions are asked of the first provider, and no efforts are made by the funding provider to view any documentation related to the questions of safety and wellbeing of the person with disabilities.
- The person’s arrangement is moved a number of times from provider to provider by the family or significant supporters, in order to find a provider that will accommodate what they require with minimal involvement or scrutiny. Questions about the impact on the person with disabilities are not asked.

There are also times when the person with disabilities is exposed to risk as a result of situations where family members or the person responsible for the arrangement, either deliberately or through ignorance:

- Do not maintain, or have no interest in maintaining, quality of care and support requirements for the person with disabilities.

- Ignore information or insights from educated sources⁶ because these challenge the family member or person's views.
- Refuse to accept or are unaware of the external legislative environment that impacts on the foundation of the self-directed arrangement.
- Do not provide the avenue for support staff to raise concerns about the person's safety, or refuse to act on staff concerns, resulting in staff having nowhere to turn to address concerns.

While it may be the case that abuse and neglect may be unwittingly inflicted on the person with disabilities, for example, through ignorance or not keeping abreast of current support practices, it is of significant concern that people with disabilities can be moved to other providers without any consideration or questions being asked about what happened to provoke such a move in the first place. It is not clear what would trigger questions to be asked or at what time, and this approach has not been made clear in the forthcoming NDIS environment.

Similarly, the NDIA should be aware of, and take action to prevent, situations where service providers or people managing the arrangement through other structures take a 'hands off' approach to the self-managed arrangement. Under these arrangements, the registered or non-registered provider or other agency monitors the financial management plan and associated tasks (such as reviewing expenditure, allocating funds, managing the NMDS, annual financial returns to the funding provider), but has no defined obligation to meet the person with disabilities at all. Instead, discussion and negotiation occurs only with family or nominated supporters. While this approach may not pose risk in many situations, the consideration of safeguards for the person with disabilities may not be able to be readily monitored or reviewed when the person with disabilities is not known by the provider.

Police and /or working with people checks should be mandatory as one form of safeguard. These requirements, amongst others, should be openly discussed in the lead-up to and within planning processes. However, the NDIS should recognise that this is not a fool-proof process, particularly when:

- People choose to employ support workers and/or other staff and not go through these police checking processes.
- Decisions are made to employ the person even though they have a criminal record that could impinge on the rights of the person with disability.
- There are no checks undertaken for support staff from other countries.
- Contracted workers with relevant criminal screening records are employed and then take advantage of the person with disabilities. It has been noted that there have not been adequate

⁶ Howard, A. (2015). *Humanise: Why Human-Centred Leadership is the Key to the 21st Century*, Wiley & Sons Australia, p147.

sources of assistance to people with disabilities or family members when they are confronted with workers who operate in this way⁷.

Option 2a: Negative licencing scheme

Priority actions for the NDIA:

- Abiding by the NDIS Code of Conduct should be an expectation for any entity and/or person providing supports to a person who is in receipt of funding from the NDIS.

Pearl Lifestyle Services supports the concept of a NDIS Code of Conduct for all providers, whether registered or not. Any provider that acted in an inappropriate way should be prohibited from providing further supports to the person with disabilities. Complaints about providers should be investigated internally as the first step then by an impartial entity such as an Ombudsman when complaints are unable to be resolved.

Having a NDIS Code of Conduct should also be extended to include family members and supporters who manage components or all of the person's support arrangement or plan. This form of approach could prevent situations where family members and supporters take advantage of the person's funding to address their own needs, to the detriment of the person with disabilities' requirements, for example, incorporating the funding into the family budget and subsequently not providing the identified or nominated supports identified to the person with disabilities.

The proposal for a legally binding scheme that can apply to other sectors providing disability-related supports funded by other sources, such as health services, compensation or privately funded arrangements, could be problematic without a formal or legislative requirement to act in this way. Until this is determined, the NDIA should only focus on supports purchased with NDIS funds.

Option 2b: Creation of an excluded person or barred persons scheme

The creation of any Australia-wide excluded person or barred persons scheme should not occur without a legislative basis.

Reporting employees who behave in such a way as to endanger people with disabilities should be directed to the police. This approach should continue to be consistently applied across all settings, whether for a registered or non-registered provider or for the person with disabilities who is self-directing their arrangement. In the event the person requires assistance to perform the reporting task, they should be able to call on external specialists, such as HR/IR advisors, to assist them.

⁷ Rees, K. 2012. "It's not just about the support: Exploring the ways in which family members and people with disabilities evaluate their self-directed / self-managed arrangements", commissioned by the Practical Design Fund, FaHCSIA, Canberra, ACT.

Option 3: Self-managed participants would be required to use a provider who has been approved or screened by the NDIA

Priority actions for the NDIA:

- There should be processes, such as a Fit and Proper Person Check and the supply of relevant financial assurances, as part of the approval process for providers.
- There should be a national Working with Vulnerable People Check, instead of the current state-by-state response.

Pearl Lifestyle Services believes that this approach would provide reassurance to people with disabilities, family members and supporters that there has been some form of scrutiny undertaken by the NDIA to ensure the provider meets nominated criteria. In addition to police checks, there could be a process where people and organisations provide documentation and assurances, such as a 'Fit and Proper Person' requirement and the provision of relevant financial assurances as components of a background check.

Option 3a: Separate registration process with limited conditions

Pearl Lifestyle Services agrees that having a process to minimise the risk of workers and services taking advantage of vulnerable people with disabilities should be implemented. This approach should also be used to address situations where people with disabilities are preyed upon by unscrupulous individuals seeking to obtain financial benefits from the person with disabilities. In the event a person could not meet the police screening requirements or the person refuses to abide by the NDIS Code of Conduct, the person should not be engaged to provide any support to a person with disabilities.

Option 3b: Registration

Pearl Lifestyle Services believes that it is a reasonable expectation to have non-registered providers obtain registration under the special provision of the NDIS rules. This approach will address the wider community's expectation that the funding is being used to meet the requirements of the person with disabilities, and not being used for other reasons or purposes without scrutiny or accountability measures being in place.

Option 3c: Individuals to be employed have been screened

The NDIS, as well as the NDIA, has a duty of care to ensure that the providers of support do so in a safe and competent manner. There are strategies currently underway throughout Australian states to ensure people involved in the support of people with disabilities, whether in a voluntary, full-time or casual basis, undertake criminal screening / police checks. This practice should be expected for people involved in self-directed arrangements as well.

Having a national approach to a Working with Vulnerable People check would address the situation of workers moving across states and territories. In addition, it would make the process more economically attractive for staff and other people working or being involved with a vulnerable person to have one national card, instead of the current financially and administratively cumbersome process where individual states have their own separate processes, costs and timeframes for addressing criminal screening requirements.

RESPONSE TO QUESTION 2

Question 2 asks:

What kind of assistance would be most valuable for people wanting to manage their own supports?

Priority actions for the NDIA:

- There should be access to paid peer supports for people who are considering the management of their supports, as well as for ongoing access to relevant and practical information to manage the arrangement over time.
- There should be access to a national human resource and industrial relations advice line for people who manage their arrangements or plans.

Numerous studies examining self-directed arrangements have shown that the satisfaction levels for people with disabilities and family members or significant others refer to the benefits of greater autonomy, choice and control over who provides what personal assistance when, as well as flexibility over the supports they receive.⁸ Providing assistance to enable and empower people to manage their own supports should focus on strengthening, adding on or reconfiguring features that will ensure greater success on a prolonged basis and over many years.⁹ Frequently, practical support is required for many users to enable them to manage the financial responsibilities as well as other requirements

⁸ See, for example, Australian Government Productivity Commission (AGPC). (2011). *Disability Care and Support: Productivity Commission Inquiry Report No 54*, The Productivity Commission, Melbourne, VIC;

Arksey, H. & Baxter, K. (2012). Exploring the Temporal Aspects of Direct Payments, *British Journal of Social Work*, 42, 147-164;

Ashcroft, J. (2009). *Self-Directed Support: The Challenge of New Relationships*, Relationships Foundation [online] www.thewholesystem.co.uk/docs/Briefing_on_Self_Directed_Support.pdf

Askheim, O. (2005). Personal assistance: Direct payments or alternative public service – Does it matter for the promotion of user control? *Disability and Society*, 20 (3), 247-260.

Blyth & Gardiner 2007 “We’re not asking for anything special”: Direct payments and the carers of disabled children, *Disability and Society*, 22 (3), 235-249.;

Glendenning, C., Halliwell, S., Jacobs, S., Rummery, K., & Tyer, J. (2000). New kinds of care, new kinds of relationships: How purchasing affects relationships in giving and receiving personal assistance, *Health and Social Care in the Community*, 8 93) 201-211.

⁹ Kendrick, M. (2002). Self-Direction in Services and the Emerging Safeguards and Advocacy Challenges that May Arise, Discussion Paper of the Connecticut Office of Protection and Advocacy for Persons with Disabilities. [online] http://www.ct.gov/opapd/lib/opapd/documents/adobe/michael_kendrick_paper.pdf

that go hand in hand with managing their arrangement.¹⁰ While this level of support may be quite intense in the early stages of managing the components of their arrangement, this may level out and diminish over time, or have periods of time when additional practical support is required, for example, due to a crisis or unforeseen incident.

Practical assistance that may be of value to assist people to manage their own supports includes:

- Assisting people to consider why they want to self-direct their arrangement or plan, and what this will entail to manage over time.
- Providing relevant information, including in different languages and formats, to assist people to be more informed about what they can manage on their own or what they may require coaching and capacity building to manage.
- Considering the establishment of funded peer support practices throughout Australia. There are already many examples of people who have been self-directing or managing their plans for many years, and this experience may be drawn upon¹¹ to assist people entering into this form of management practice for the first time, or for people who require additional information about the practical aspects as incidents and changes occur within the arrangement or plan over time.
- Acknowledging that people from a range of cultural backgrounds may need additional assistance to comprehend the ways the NDIS can support the person with disabilities to live relevant and respected lives in their community.
- Supporting people to see that building their capacity to manage their arrangement can take time to see results.
- Providing information about sources of practical and relevant information and support, such as from independent human resource and industrial relations specialists. This information could prevent the types of situations where people ‘sack’ employees without an understanding of the *Fair Work Act 2009* or the implications of unfair dismissal actions. These specialists could also assist with relevant management of staff, address industrial matters and assist with complaints.
- Attention to building relationships with the community and building informal supports that can assist the person to manage their arrangement.
- Developing a ‘back-up’ or succession plan to address situations where things could go wrong or where the primary supporter or family member becomes unwell or their circumstances change.

¹⁰ Witcher, S., Stalker, K., Roadburg, M. & Jones, C. (2000). *Direct payments: the impact on choice and control for disabled people*, Edinburgh Human Services Trust and Lothian Centre for Integrated Living, the Scottish Executive Central Research Unit

¹¹ National Disability Insurance Scheme update 44 [online]

<http://us6.campaign-archive2.com/?u=055092cc7e42efbfc41d80045&id=c7fddd259c&e=4976acac80>

- Being aware of the personal implications, for example, the implications of the level of unpaid support that may be needed to make the plan or arrangement work, or loss of employment opportunities for parent carers.¹²
- Having a system to monitor routine processes within these arrangements and to ensure that practices, such as paying staff and reporting on expenditure, occur within specific timeframes.

Attention to supporting people to successfully manage their arrangement or plan can assist in minimising fear-based attitudes and concerns about people's capacity to manage that can impinge on self-directed or self-managed arrangements.¹³

Concluding comments

The Australian Government is to be commended for considering the development of a quality and safeguarding framework to accompany the National Disability Insurance Scheme.

As Australia faces the introduction of a National Disability Insurance Scheme (NDIS), there are important lessons to be gleaned from the ways people have already been managing their arrangements and plans. Addressing the safeguards for participants who manage their own arrangements and plans is particularly important, not only for people who are considering this form of support practice but for people who have been involved in directing or managing any aspect of their arrangement for many years. The reality is that discussion about safeguards can be achieved in respectful and effective ways, and they are an important component of the foundation of any arrangement that enhances the person's quality of life over time.

I would be pleased to provide further information or discuss the issues that have been raised in this submission, if required.

Yours sincerely,



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¹² See, for example, Qu, L., Edwards, B., & Gray, M. (2012). *Ageing parent carers of people with a disability*. Australian Institute of Family Studies, Australian Government [online] www.aifs.gov.au/institute/pubs/carers/carers.pdf
Spicer, I. (2007). Disability and Family Carers, *Family Matters*, No 76, 30-31

Hughes, J. (2007). Caring for carers: the financial strain of caring, *Family Matters*, 76, 32-33.

¹³ Fisher, K., Gleeson, R., Edwards, R., Purcal, C., Sitek, T., Dinning, B., Laragy, C., D'Aegher, L. & Thompson, D. (2010). *Effectiveness of Individual Funding Approaches for Disability Support*, Australian Government Department of Families, Housing, Community Services and Indigenous Affairs, Canberra, ACT.