NDIS
Safeguards and Risk Enablement

DECEMBER 2018

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JFA Purple Orange is a social policy agency, working to improve the life chances of people living with disability. We are an independent, non-government organisation that fosters innovation, shares useful information, and promotes policy and practice that support and improve the life chances of people living with disability.

Foreword

NDIS
Safeguards and Risk Enablement

The arrival of the National Disability Insurance Scheme (NDIS) is a major policy reform across the Australian disability sector. JFA Purple Orange recognises the importance of managing anxiety about risk and exploring views on risk with all NDIS stakeholders, including the need for support services to be equipped with frameworks that provide appropriate levels of support and negotiate risk management on a person-by-person basis. Therefore, this policy position paper addresses the primary issues relating to NDIS arrangements for safeguarding participants and advocates for an alternative framework to be considered and implemented.

The NDIS offers the most significant disability policy reform in Australia for over a decade. The Scheme will provide all Australians under 65 who have a permanent and significant disability with reasonable and necessary supports to enjoy an ordinary life. This includes the ability "to have choice and control, emphasising the participants' right to direct and making decisions about what is important to them in leading a good life".[1]

Embedded within the roll-out of the NDIS are several significant policy developments, one of which is the recent National Quality and Safeguarding Framework. The Framework has been developed to ensure that capability is built into the new market-based system, that the rights of people with disability are upheld and that the benefits of the NDIS are realised.[2]

A consistent, national approach to quality and safeguarding will be needed to implement this Framework. In addition to advancing the rights of people with disability, a national approach via the Framework is required to support choice and control in the NDIS by empowering individuals and driving quality improvement. Choice and control also mean that participants are able to make decisions about the level of risk they are prepared to take and have the tools and information they need to make informed judgements about the suitability of providers.

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[1] *My NDIS Pathway Factsheet*, n.d., NDIS, viewed 27 July 2017, <www.ndis.gov.au>.

[2] *NDIS Quality and Safeguarding Framework*, Australian Government, Department of Social Services, 9 December 2016, viewed 5 August 2017, <https://www.dss.gov.au/sites/default/files/documents/04_2017/ndis_quality_and_safeguarding_framework_final.pdf>.

Introduction

JFA Purple Orange regularly interacts with members of the disability community who are or will become NDIS participants. Although we are not a service provider, we seek to amplify the voices of all people with a lived experience of disability. Consequently, we are well placed to provide feedback about what needs to happen to improve the experience of individuals living with disability in the South Australian community. JFA Purple Orange is committed to improving the outcomes for people living with disability who are engaged with the NDIS system.

JFA Purple Orange asserts that the NDIS safeguarding and risk arrangements must be crafted so that they give NDIS participants the best chance of achieving control and choice (Personhood) and participation in community life and the economy (Citizenhood).

The onset of the NDIS era within Australia marks the possibility of genuine progress: a transference from 'the norm' of people living with disability being continually confronted by welfare systems dictating how they will live their lives to a progressive, human-rights-driven era of negotiation around appropriate arrangements that uphold and advance each individual's control and choice.

As part of the NDIS policy roll-out, significant focus has been given to the notion of safeguarding people living with disability against risks, both existing or assumed, as potential threats to safety. Such discussion of safeguards for people living with disability is neither new nor radical. In fact, the roots of notions such as avoidance of harm, risk and prioritising safety are firmly established in the history of medicine, healthcare and service provision. The Hippocratic Oath establishes a solemn promise by all members of the medical profession to non-maleficence towards patients (from the Latin *primum non nocere,* colloquially 'first, do no harm'). This code of values and ethics has become firmly embedded across medicine and healthcare with the saying 'first, do no harm' widely touted as being the bedrock for the practice of high-quality and safe practice within medicine.

Recent Australian research has challenged the sustained meaning for the Hippocratic Oath in current practice, suggesting that our attention should be directed towards the wider ethics of healthcare more generally to reach a set of codes and values more commensurate with contemporary needs within socio-political contexts.[3] Certainly, it can be argued that this Oath and its slant to risk avoidance sets the tone across the context of service provision for a 'safety first' approach. This does not lend itself to a framework in which an individual can easily negotiate control and choice across a full range of options within their service provision.

JFA Purple Orange advocates that NDIS policy related to safeguards and risks should focus on 'risk enablement' in support of strong outcomes for participants living valued lives with a full range of options. There are examples from other settings where such an approach has worked well. For instance, in their risk enablement policy guidelines, Southend, Essex and Thurrock councils in the United Kingdom (UK) recognise that systems which foster an overpowering fear of organisational risk (for example, financial, reputational or compliance risk) inadvertently inhibit the organisation's ability to achieve good outcomes for people.[4] Such fear epitomises the approach that can overpower disability policies and frameworks; a mindset that 'risk equals harm' and that protecting individuals and service organisations is paramount, prioritised ahead of choice and control. The reality is that we have to face a variety of risks in everyday life, and a component of advancing people living with disability towards a good life means navigating risk.

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[3] M Walton & I Kerridge, *'Do no harm: is it time to rethink the Hippocratic Oath?',* Medical Education, vol. 48, no. 1, 2014, pp. 17–27.

[4] *The Southend, Essex and Thurrock (SET) Safeguarding Adult Guidelines,* NHS Southend CGC, March 2017, viewed 24 August 2017, <http://www.essexsab.org.uk/Portals/68/SET Safeguarding Guidelines - V4.2 March17.pdf>.

Risk enablement in the context of a good life

JFA Purple Orange believes that a good life for all people, including people living with disability, is characterised by:

- authorship of our own lives (often described as control and choice); and
- having valued roles in community life and the economy (often described as inclusion).

At JFA Purple Orange, our work is guided by a model based on what we know about how people living with disability can achieve a good life. People living with disability want to be first and foremost regarded as citizens in their community, have access to relevant support in doing so, and make decisions based on their personal goals, wishes and needs. They want to undertake valued roles. The *Model of Citizenhood Support* developed by JFA Purple Orange provides a framework for conceptualising what a good life looks like for people living with disability. This Model describes a good life as being characterised by valued roles (termed Citizenhood) and by the decisions each person makes (termed Personhood).

Unlike citizenship, Citizenhood is a dynamic experience: it can rise and fall depending on the person's circumstances. The extent to which any person can naturally take up Personhood and Citizenhood is influenced by the degree to which that person lives with vulnerability. For the purposes of this policy paper we define vulnerability as the presence of circumstances that can adversely impact the person's capacity to build their own life chances and the person's capacity to take up valued roles in community life and the economy.

The Model refers to an intentional set of arrangements that authentically advance a person's life chances towards Citizenhood, in keeping with each person's lifestyle choices, including education. The Model provides a comprehensive contextual framework for organising policy and practice in support of people living with disability. It asserts that our life chances comprise four different, but interrelated, types of assets we can call upon, termed the Four Capitals.

These are:

1. **Personal Capital**
   how the person sees themselves;
2. **Knowledge Capital**
   what the person knows and can apply;
3. **Material Capital**
   money and other tangible things in the person's life; and
4. **Social Capital**
   the other people in the person's life.

These apply to any person and can help explain what might be useful for someone to build a good life for themselves. It is worth noting that each of these types of assets is involved when a person is seeking support measures from the NDIS to live a good life.

JFA Purple Orange asserts that the Four Capitals could be a helpful system for building the details within the NDIS Quality and Safeguarding Framework. We have had success using them to assist people living with disability and their families build personal capacity across a range of life issues. We have also had success using the Four Capitals to assist service agencies develop their approach (including strategy development, staff training, audit and benchmarks) to building individual supports and safeguards. Finally, we have had success using the Four Capitals to diagnose issues and frame solutions when arrangements go wrong and complaints emerge.

The National Disability Insurance Agency (NDIA) suggests that participants will be encouraged to take reasonable risks appropriate to their circumstances. JFA Purple Orange commends NDIA for adopting this approach. However, there are areas within the existing NDIS arrangements where we consider that the balance between duty of care and permission for risk-taking is skewed. This policy position paper discusses the areas where we have identified that a stronger focus on positive risk-taking would allow NDIS participants greater freedom to explore life options and experiences. In turn, this would enable them to authentically advance their capacity for having authorship of their own lives and having valued roles in their community.

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[5] R Williams, *Model of Citizenhood Support: 2nd edition*, Julia Farr Association Inc, Unley South Australia, 2013.

[6] Williams.

Definition of safeguards: what do we mean?

> Risk management is not an end in itself, but rather a means to an end.

The NDIS defines safeguards as:

> "a range of supports and mechanisms that ensure safety and wellbeing while supporting a person to have a good quality life, to be an active and equal citizen, and to be able to reach their potential. Safeguards include natural safeguards such as personal relationships and community connections, and formal safeguards such as service standards, regulations and quality assurance systems that apply to individuals and organisations providing supports".

Put simply, safeguards are strategies, procedures, processes and regulations that are used to minimise risk to an individual. NDIA has committed to an ongoing monitoring and assessment of safeguards for people living with disabilities through the NDIS National Quality and Safeguards Framework. Furthermore, NDIA has undertaken to work with participants to build supportive networks to minimise potential harm and empower individuals to participate in the community. However, it is important to note that risk management is not an end in itself, but rather a means to an end, and the end is not to keep someone safe per se, it is to support someone to safely take up valued roles in community life.

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[7] *Safeguards*, n.d., NDIS, viewed 11 July 2018, <https://www.ndis.gov.au/participants/safeguards>.

Why is there risk aversion in the context of disability?

The approach to risk in the Australian disability context needs a paradigm shift. Historically, people living with disability have been excluded from community participation through care models such as institutionalisation, leading to separation from mainstream societal services, opportunities and settings. This has led to the historic experiences of people living with disability who found themselves 'shut in' (either institutionalised or housebound). The *Shut Out* report, a landmark 2009 Australian Government paper[8], highlights that these same community members now speak of feeling 'shut out', resulting in feeling unable to gain equitable access to community, education, training or social activities.

Concurrently, over the last few decades, a distinct shift has occurred in the governance, liability and risk frameworks used by service organisations. Services, organisations and community activities are heavily regulated with a focus on harm minimisation and liability management. While there are many benefits to having effective oversight arrangements to ensure the ongoing care and safety of service recipients, it is necessary to maintain a balance between offering adequate safeguards and protections for people living with disability and allowing these same people the opportunities to explore options that would allow them to experience the most meaningful, valued and full life as possible. Not all people living with disability are as innately vulnerable as society tends to believe; in fact this may be far from the case. In particular, a recent Australian practice review paper[9] has highlighted this fact across different contexts and settings occupied by people living with disability. This practice review recommends that organisations and services recognise the capacity and potential for people living with disability to manage their own safety and that this should be used by people living with disabilities acting as peer mentors and modelling this empowerment and capacity.[10] Similarly, research in the area of positive risk-taking from the UK has advocated for a reduced focus on vulnerabilities and increased attention to decision-making abilities of students living with disability in community settings such as education.[11]

Sadly, there are everyday examples where an over-emphasis on safety, regulations and risk avoidance for people living with disability has come at the loss of opportunities or ongoing meaningful activities. For example, a recent article offers the following examples where sustained vigilance towards the realities of harm and abuse has been used to allow highly restrictive decisions to dominate:

> "Take the case of Ben, a support worker, who has been supporting John for the past eight years. However, when Ben changed jobs, he was told that he wasn't allowed to keep in touch with John, despite both men wanting this to happen.
>
> Then there is Alice, also a support worker, who was told by her manager that she was not allowed to buy and apply suncream on a hot day for someone she supports because 'suncream needs to be prescribed by a GP'."[12]

These examples demonstrate a narrow exploration of risk by service organisations that do not enable choice or control by the individual whose interests are to be met. In its well-cited report *Enabling risk, ensuring safety,* the UK's Social Care Institute for Excellence states that "the most effective organisations are those with good systems in place to support positive approaches to risk rather than defensive ones".[13] This rings true with policy work previously disseminated by JFA Purple Orange regarding the importance of establishing the assessment and planning arrangements that best reflect the principles the NDIS seeks to live by.[14] These principles include personal control and choice. As such, a 'safety first' approach that does not concurrently support people to have choice and control is an inhibiting factor for achieving good outcomes for people living with disability and increased vulnerabilities.

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[8] The National People with Disabilities and Carer Council, *Shutout: the experience of people with disabilities and their families in Australia,* Australian Government, 2009, viewed 11 August 2017, <https://www.dss.gov.au/our-responsibilities/disability-and-carers/publications-articles/policy-research/shut-out-the-experience-of-people-with-disabilities-and-their-families-in-australia>.

[9] A Meltzer, S Robinson, Y Proud & KR Fisher, *Literature and practice review: Support to make decisions that promote personal safety and prevent harm,* Social Policy Research Centre, UNSW Sydney, 2017.

[10] A Meltzer et al.

[11] J Seale, M Nind & B Simmons, *'Transforming the discourse of positive risk taking in special and inclusive education'*, Scandinavian Journal of Disability Research, vol. 15, no. 3, 2013, pp. 233–48.

[12] B Tindall, *Decisions to safeguard adults with learning disabilities can make them less safe,* 2015, CommunityCare, viewed 11 July 2018, <wwwcommunitycare.co.uk>.

[13] S Carr, *SCIE Report 36: Enabling risk, ensuring safety: self-directed support and personal budgets,* Social Care Institute for Excellence, London, 2010.

[14] S Duffy & R Williams, *The Road to NDIS: Lessons from England about Assessment and Planning,* JFA Purple Orange, Julia Farr Association, Adelaide, 2012.

Problems with current NDIS safeguarding arrangements

JFA Purple Orange suggests that people are not appropriately safeguarded when there is a mindset that 'risk equals harm', because this can close off ordinary valued opportunities to the person. In such situations, the pursuit of safety has often blocked meaningful and valid opportunities to that person. The loss of such opportunities could be detrimental to the person's life chances to the extent that this approach could be considered 'harmful', the very experience that safeguarding and risk management are designed to circumvent.

The circumstances that can drive a sentiment that 'risk equals harm', and which the NDIS safeguarding arrangements must therefore avoid, include:

1. services being fearful of people/consumers/participants making unwise decisions or choices that could reflect poorly on the services received;
2. the mistaken belief that if a person is deemed to not have full decision-making capacity, that this somehow means they can't be supported to understand and adopt risk in pursuit of normal things that are important to them;
3. people not having a good understanding of the choices they are considering; and
4. a belief that safeguarding means avoidance of exposing vulnerable people to any unnecessary risks.

JFA Purple Orange advocates for time and energy to be invested in creating thoughtful plans that include the full range of options available to a person, with any risk factors duly considered and explored. It is important to spend time with an individual to develop a good support plan with a completed risk assessment. High-quality and clear information is required to help people make informed choices.

In March 2017, the Australian Government responded to an inquiry led by the Senate Community Affairs References Committee into violence, abuse and neglect against people with disability in institutional and residential settings, including the gender- and age-related dimensions, and the situation of Aboriginal and Torres Strait Islander people with disability, and culturally and linguistically diverse people with disability. In acknowledging concerns raised towards the proposed National Safeguarding and Quality Framework, it was stated that:

> "Proportionality forms a component of a risk-responsive regulatory system, which recognises that risk of harm is experienced differently by individuals, and that regulatory tools for mitigating risk must be responsive. The Framework is therefore designed to be risk-responsive and person-centred, with measures tailored to the strengths, needs and circumstances of participants that increase or decrease risks, and the risks inherent in certain types of supports."[15]

We commend NDIA for adopting a risk-responsive and person-centred framework while still embedding the necessary regulatory and oversight functions required for mitigating risk. However, JFA Purple Orange can identify ways in which the current NDIS safeguarding and risk management arrangements need to adopt a stronger acceptance of explorations of risk-taking for all participants. It is our view that being overly cautious is as bad as being overly reckless in that a person's life chances have been harmed. Therefore, it is necessary to establish a system in which options involving risks can be explored thoroughly, openly and with appropriate support structures in place. Some ways in which this can be promoted are through:

1. growing a culture change within Australia and NDIS policy such that risk enablement is considered as 'positive risk-taking'. In this way, positive risk-taking can be embraced by people living with disability and their supporters to grasp opportunities for greater life participation instead of being constrained by a risk averse 'safety first' approach that limits experience;
2. establishing a delicate balance between empowerment and safeguarding;
3. growing an understanding of positive factors that reduce vulnerability;
4. designing risk management activities that are grounded in a sound understanding of what real and known risks are for NDIS participants across Australia, based on data wherever possible.

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[15] Australian Government response to the Senate Community Affairs References Committee report: *Violence, abuse and neglect against people with disability in institutional and residential settings, including the gender and age related dimensions, and the particular situation of Aboriginal and Torres Strait Islander people with disability, and culturally and linguistically diverse people with disability,* Australian Government, March 2017, p. 6.

While JFA Purple Orange recognises that these strategies require the NDIS to change its practice in some areas, we believe these changes are necessary to achieve NDIS policy that offers participants genuine choice and control. This includes the possibility of a nation-wide focus on disability population data that is not currently evident or reported on to establish an evidence-based understanding of real and known risks for NDIS participants.

In a policy position paper in 2013, David Craig wrote:

> "This trade-off between freedom and security produces ongoing tension between these two intense needs. It is not so much a case of finding the perfect balance but creating the negotiating space for movement between these competing needs for adventure, excitement and risk up against an enduring need for safety, security and comfort. It is finding some balance within this shifting and dynamic tension that lies at the heart of a solution to the dilemma we face around risk and rights. The ongoing management of this balance demands a swinging pendulum, not a static one."[16]

Craig's words urge us to move forward into a more creative thinking space as the NDIS unfolds across Australia and allows for new and exciting opportunities. Fundamentally, it is essential that we allow ourselves to take a critical look at what makes people safer. Research has shown that it is the things that are often most prevalent in our lives that serve to make people safe and affect our well-being, for example, the presence of people we know and feel comfortable with, being active in local communities, and having sound avenues for social participation.

John O'Brien, a well-cited disability advocate, laments that "we have created a rigorously managed space that too often trades off opportunity for community participation and the exercise of autonomy for liability avoidance".[17] O'Brien's statement is clear, particularly if we consider this in the context of understanding the factors that make people safer: valuing people means not only having a regard for the safety of people who live with disability, but also having a commitment to honouring their choices, their preferences and their right to live life in the way they want.

In accepting this viewpoint, it stands to reason that the more individuals are known and looked out for by people they know, the safer they are likely to be. For example, if individuals living with disability are active within their communities, this in turn can lead to others being aware and concerned about their well-being. This is a very different scenario to individuals living with disability simply being protected by family members or paid professionals working with them. Factors such as community inclusion, social connectedness and any opportunities to increase these, therefore, become the best safeguards to offer into this space of thinking. A strength in numbers approach could be a straightforward avenue of promotion, through a simple yet logical stance such as 'the wider the circle, the greater the protection'. Therefore, activities such as peer support, circles of support and participation in local community activities are areas in which the NDIS can seek to build protective factors and increase individual safeguards while maintaining an approach that allows individuals to explore risk openly.

Unfortunately, there is a lack of illustrative accounts of positive risk-taking in action for professionals and individuals, which limits any opportunity for reflective practice, shared information exchange, or any concrete evaluation of the impact of positive risk-taking on the lives of people living with disabilities. This is especially the case in Australia, where unlike the UK, specialised risk enablement advisory groups and panels are not widely established.

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[16] D Craig, *Dignity of Choice and Risk*, Baptcare Policy Position Paper, 2013, pp. 3–11.

[17] J O'Brien, 'Numbers and faces: The ethics of person-centered planning' in S Holburn & PM Vietze (eds), *Person-centered planning: Research, practice, and future directions*, Paul H. Brookes Publishing Co., Baltimore, 2002, pp. 399–414.

Examples of better practice

Methodologies such as supported decision-making and risk enablement panels are positive ways of dealing with the issues related to balancing risk-taking and duty of care for people living with disability. The emphasis is on supporting positive risk-taking while maintaining duty of care and making decisions in a shared and informed way, with transparent, shared responsibility.

In the UK, focusing on enabling risk while concurrently ensuring safety to people living with disability continues to be pushed as part of the conversation about disability policy.[18] Such discussion promotes the viewpoint that person-centred thinking to support positive risk-taking offers a solid framework in which to adequately allow people with disability the freedom to explore risk safely. For example, core principles that foster person-centred, positive risk-taking while maintaining safety are adequately described in the SCIE report and extensively detailed in a 2009 review offered by Neill and colleagues.[19] Fundamentally, these reports are in favour of a person-centred approach by service providers, which allows freedom of choice through honest and open discussion of risks, costs and benefits to the life of an individual.

For example, in Gateshead Council (UK), a positive risk-taking policy for social care has been established since 2009, which also applies to its sports, leisure, libraries and arts services when it works with adults living with disability and older people.[20] By adopting a person-centred approach[21] to risk, the policy emphasises the full involvement of disabled and older people in decision-making and the need to support them to pursue their goals and aspirations. The policy also provides a clear list of expectations for staff working in this sector of the council. It recognises that any positive risk-taking approach must be balanced with the council's responsibility to meet safeguards, care standards and health and safety requirements. Reports on the success of this policy suggest that leadership staff are committed to a positive risk-taking approach, a factor critical to its success. This policy approach provides an example that could be readily promoted and supported within Australia.

In overviewing the core components of best practice in risk enablement and supported decision-making, the Social Care Institute for Excellence identifies several factors. Firstly, involving the people who form the individual's informal 'circle of support' is considered essential; that is, genuine and open dialogue between people who are involved from an initial point to source information, identify any potential risks from the individual's point of view and to then discuss ways to enable and manage these risks. Additionally, using a strengths-based approach to encourage positive and informed risk-taking is necessary if innovative ways are to be identified for people to do things rather than avoid doing things based on risks. Other principles recommended as 'best practice' for risk enablement include:

1. paying careful regard to the time and effort spent on managing a risk, as ideally this investment should match the severity of that risk;
2. ensuring that professionals involved in a person's support have an appreciation of the person's history and social environment, and their previous experience of risk;
3. ensuring that the decision-making process is easily auditable, to the extent that a clear rationale for decisions made and the discussions that led to the decisions are recorded, with clear negotiation of risk and safety issues to identify what is acceptable for everyone concerned.[22]

These recommendations are clear and fit with that advocated by Neill and colleagues in their person-centred approach to risk:

> "We feel it is important to remember people's rights, including the right to make 'bad' decisions, and to gather the fullest information and evidence to demonstrate that we have thought deeply about all the issues involved and made decisions together based on what is important to the person, what is needed to keep them healthy and safe and on what the law tells us."[23]

Establishing oversight groups in Australia, such as risk enablement panels and advisory councils, can help the nation progress, as we can show that such issues have been considered deeply based on what is important to the person living with disability. This is a key component of allowing NDIS participants choice and control.

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[18] S Carr.

[19] M Neill, J Allen, N Woodhead, H Sanderson, S Reid & L Erwin, 'Feature: A positive approach to risk requires person-centred thinking', *Tizard Learning Disability Review*, vol. 14, no. 4, 2009.

[20] *Positive risk taking policy*, Community Based Services, Gateshead Council, United Kingdom, 2009.

[21] J O'Brien & C Lyle O'Brien, *A Little Book About Person Centred Planning*, Inclusion Press, Toronto, 1988.

[22] S Carr.

[23] M Neill et al., p.23

How the NDIS can better support positive risk-taking

> “JFA Purple Orange challenges the current narrative around safeguarding and focusing on risk minimisation…”

As previously stated, the NDIS is the largest policy reform Australia has seen in more than a decade. Despite advocating for ‘choice and control’, this policy shift has still not readily amounted to a ‘good life’ for people who continue to experience restrictions, abuse, harassment and ongoing lack of choice and control. This is likely in part due to the fact that the NDIS has not yet had a chance to build momentum towards transformational benefits. That aside, a conceptual framework is still needed that enables Australia to shift into creative and innovative thinking by promoting positive risk-taking and the advancement of people’s choices.

JFA Purple Orange challenges the current narrative around safeguarding and focusing on risk minimisation and advocates for a more transparent dialogue and language of risk that transforms this mindset and opens up new ways of thinking about risk management. The language used in relation to this is especially important, as currently notions of ‘safeguarding’ and ‘supported decision-making’ do not cultivate a common understanding or acceptance of risk enablement or positive risk-taking. Rather, the more progressive phrases ‘risk enablement’ and ‘positive risk-taking’ offer a helpful and affirmative alternative, which could be clearly defined and applied.

Recommendations

RECOMMENDATION 1

That the NDIS — through NDIA practice and the National Quality and Safeguarding Framework — revises its policy to develop a common understanding and acceptance of risk enablement and positive risk-taking. Further, the phrases 'risk enablement' and 'positive risk-taking' are defined and applied.

Risk enablement is a direct way of allowing people to exist at the centre of their own support. This offers rich synergies with the core principles of the NDIS and is an approach that has been used with positive outcomes in various parts of the UK.[24] Some possible outcomes should risk enablement panels be established include a transformation of social care rather than simply a committee formed for the purposes of abuse prevention. This is significant, because a shift towards risk enablement in the context of disability is in line with a wider cultural shift from risk aversion identified in other areas of community life. For example, schools and community spaces are now reintroducing play areas that are 'more risky' such as nature-inspired tactical designs, following an age of ubiquitous 'safe' plastic play equipment built on a soft foundation to support falls.[25] Similarly, wider discussions of encouraging children to navigate risky situations that provide the skills to identify and manage these situations are steadily emerging within risk-related research.[26,27] In the context of people living with disability in Australia, NDIA is in an ideal position to lead the way towards a risk-enabled framework via methods such as formal panels offering decision-making and guidance towards risk enablement.

RECOMMENDATION 2

That NDIA promotes the use of risk-enablement panels (similar to those established in UK councils), which provide organisations with a formal method of discussing individual cases and evaluating risks and freedom of choice.

Currently, the NDIS Quality and Safeguarding Framework is based on several core principles, one of which is presumption of capacity, meaning that the Framework makes the presumption that all people with disability have the capacity to make decisions and exercise choice and control.[28] This is a welcome presumption in the context of risk enablement and JFA Purple Orange commends NDIA for the focus on natural supports, such as through support activities that allow participants to strengthen family and other support networks and participate fully in their community.

However, the focus remains on safeguards at an individual level within the Framework (for instance, discussion is centred towards supporting participants as they undertake their pathway). While this is necessary, it seems likely that many of the strategies suggested for embedding 'natural safeguards' in an individual's life will only eventuate through participation in a community that is receptive to this. As such, strategies such as fostering good relationships, being able to rely on community members/neighbours, seeking the company of a trusted person, being able to complain effectively, knowing how to raise help should an emergency arise, telling someone about things that are going on, etc, are often reliant on the responsiveness of members of one's local community. As it is imperative the Framework does not lessen the chances of participants creating these strategies within their lives, we propose that the existing Framework is extended to focus significantly on educating the community about safeguarding and providing 'good support' to individuals with disability.

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[24] S Carr.

[25] National Quality Standard Professional Learning Program, *Talking about practice: Adventurous play – developing a culture of risky play*, National Quality Standard Professional Learning Program e-newsletter, no.58, 2013.

[26] J Greenman, *Caring Spaces, Learning Spaces: Children's environments that work*, Exchange Press Inc., United States, 2005.

[27] D Curtis, 'What's the risk of no risk?', *Exchange Magazine*, 2010, pp. 52–56.

[28] *NDIS Quality and Safeguarding Framework.*

JFA Purple Orange steadfastly asserts that freely given relationships are the greatest protections or safeguards for people living with disability. This is especially important as NDIA staff are unlikely to have adequate resources to maintain 'hands-on' facilitation of natural supports for NDIS participants. Historically, service provision across Australia for people living with disability has been a programmed way of life with funded positions acting as the main anchor points for relationships for many individuals. With the new era emerging via opportunities made possible through NDIS funding, it is an ideal time for communities to establish a greater level of capacity and awareness around the important issue of safeguarding vulnerable people. In particular, communities would be well served through an NDIA-led capacity building program that invests in awareness-raising around the tension between duty of care and dignity of choice and ways to offer ideal support to people living with disability.

RECOMMENDATION 3

That NDIA invests in community capacity about key safeguarding strategies for individuals living with disability, focusing on the positive angles of risk-taking rather than promoting risk as a negative experience.

Furthermore, we propose greater capacity building of NDIA staff around risk assessments and strategies that allow individuals to consider positive risk-taking following careful assessment of options. This lends itself to an improved planning service where planners or supporters can be less directive and allow an individual choice and control to explore options using appropriate tools and methodologies.

It is important that the level of support regarding facilitating natural safeguards and supports be included in a participant's plan. We recommend that NDIA support workers be trained to effectively facilitate new relationships for the people they support, rather than be in a position where there is an expectation that they will 'provide' the relationship. It is via relationships and social connections that natural safeguards are likely to occur in an individual's life, therefore staff associated with NDIA play a key role in being able to facilitate these safeguards. Relevant training to upskill key staff in this area might see careful risk assessments of individual options translate into greater opportunities for social inclusion and new points of social connection.

RECOMMENDATION 4

That NDIA invests in staff capacity building around facilitation of relationships.

We advocate for people living with disability to build their networks in such a way that concepts of risk and safety can be navigated openly, with the capacity for natural safeguards through relationships to evolve. NDIA staff have a significant role to play in this. If a person's network could be used as a framework to identify and seek views of who is in their life and the roles these actors play in a person's network, then this is a key foundation for conversations around risk enablement and safety.

Furthermore, the practice evidence highlights that some specific types of support help people to make decisions about promoting safety, navigating risk and their own care. These insights could be adopted by NDIA and implemented by support workers in practice with NDIS participants. Examples include using role-playing to 'practice' situations or interactions, using peer-to-peer storytelling, or encouraging individuals to create a diary or video journal of their personal circumstances to facilitate decision-making.[29] See Table 1 at the end of this paper for a comprehensive review of the current practice evidence.

RECOMMENDATION 5

That NDIA develops a resource for participants and their supporters that provides examples of situations where people have navigated risks safely and positively using a strengths-based framework.

We propose that NDIA designs, evaluates and develops a fit-for-purpose resource tool that can be used by family members and supporters of people living with disability to openly discuss risk enablement in the life of the person they are supporting. A key component of such a resource would be a suite of guided questions and statements that help family members and supporters to understand from the perspective of the individual as far as is possible what level of risks or types of risks they are happy to live with. For example, the resource tool could precipitate discussion of situations such as risk of falling or becoming lost.

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[29] A Meltzer et al.

> Freely given relationships are the greatest protections or safeguards for people living with disability.

We advocate for NDIA-led tools that help individuals to explore risks and benefits in the context of a good life and accept risk in the pursuit of greater independence and adventure.

RECOMMENDATION 6

That NDIA provides funded supports to accommodate support work associated with facilitating natural safeguards and relationships for participants.

JFA Purple Orange recognises that the previous recommendations rely on NDIS-funded supports. We therefore recommend that support pricing be carefully reviewed to make sure the various per-hour support costs are inclusive of the work involved in nurturing natural safeguards and relationships.

We note that there are existing NDIS Outcomes Frameworks associated with the 'domains' of Social and Community Participation and Relationships.[30] It is critical that the support work associated with facilitating these domains within funding packages is considered and accommodated so that NDIS can offer a framework that adequately safeguards participants while allowing them choice and control through positive risk-taking.

RECOMMENDATION 7

That NDIA reviews the NDIS 'menu' to include circles of support and related methods as default options available to participants.

JFA Purple Orange advocates that social connections, peer support and community participation are paramount in establishing relationships and allowing natural safeguards within an individual's life.

Therefore, the NDIS 'menu' of options needs to include the ability for participants to readily 'buy' access to social support mechanisms such as circles of support. This is especially necessary for people living with higher vulnerability and lower personal and social capital, for whom local area support networks are a critical mechanism for building genuine relational supports in their life.

RECOMMENDATION 8

That NDIA commits to recording national disability population data to establish an evidence-based, grounded understanding of real and known risks for NDIS participants that can in turn lead to a redesign of NDIS risk-management activities.

The data captured to inform the sector of the 'actual' risks and vulnerabilities faced by NDIS participants is critical to establishing a collective understanding of these issues in the context of NDIS policy reform. Currently, Australia has little consistent and long-term data relating to this issue, with the Victorian database used by the Office of the Senior Practitioner a lone example of data capture and reporting in this space.[31] It would be useful for future arrangements to include a stronger

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[30] National Disability Insurance Agency (NDIA), *NDIS Price Guide 2016–2017*, NDIA, July 2016.

[31] Department of Health and Human Services (DHHS), *Senior Practitioner Report 2015–2016*, DHHS, Victorian Government, 2016.

undertaking of data collection related to the disability population that helps to inform actual and known risks for this population. Significantly, building a database of information capturing people's situations, outcomes of choices made where risk is involved and the options available for people in particular situations will help to achieve a better understanding of what really makes people living with disability safer.

RECOMMENDATION 9

That NDIA addresses outcomes measurement so that any outcomes framework includes a measure of a person's social capital.

Lastly, we recommend that any existing outcomes measurement framework be extended to incorporate a measure of participants' social capital.

The nature and extent of one's connectivity to other people represents Social Capital and is an asset that can be used to help advance a person's life chances. It is known that individuals whose social connections are primarily made up of workers in paid, formal support roles will have far less opportunities to increase their personal and social capital than individuals with strong connection to social networks. Unfortunately, for many people living with increased vulnerability, the service agencies that provide services are sometimes focused on the goal of service delivery itself rather than the life chances they are meant to support. In other words, the person's day, even the person's identity, is defined by the receipt of services. This obviously has grave implications for developing a person's social capital and therefore their ability to foster relationships and the natural safeguards that emerge from relationships and connections with others.

In light of this, JFA Purple Orange recommends that NDIA establishes a mechanism for measuring outcomes of participants as they reach full scheme participation, including a measure of their social capital. By this, we are referring to measuring the extent to which they have connections with other people or groups of people such that these could be considered social assets. Measurements such as this would better inform NDIA as to how many connections participants have that they can draw on to advance or uphold their chances of a good, valued life complete with strong relationships and networks that build natural safeguards.

Conclusion

It is important to ensure that people living with disability are free from harm. But if it becomes the context it can generate unforeseen consequences when safety measures stop people having access to things that are conducive to their well-being.

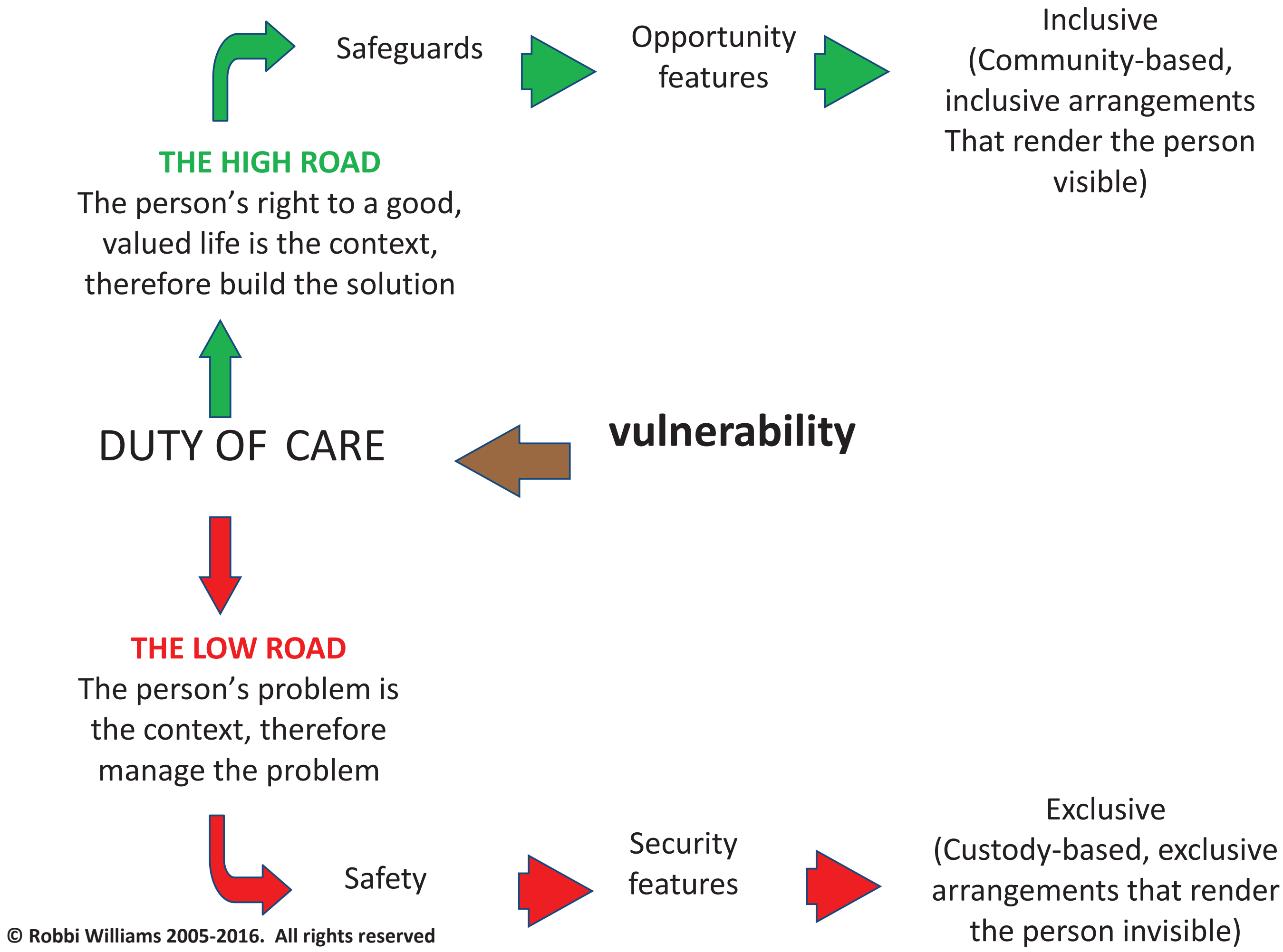
For many people living with disability across Australia, their lives are at risk of being unduly restricted as a result of an overly risk-conscious system that they rely on to live an ordinary life. Coupled with this is the widespread phenomenon of liability avoidance, resulting in staff and service providers being fearful of having to go through the process of justification if something negative happens.

A more progressive approach would be to undertake a confident and hopeful analysis of the factors that constitute safety in the lives of NDIS participants. Figure 1 illustrates how such a pathway could be navigated to make taking risks safer rather than making the context of safety risky. This is in the interests of people with disabilities and staff working in Australia's disability sector experiencing a culture of fearing blame as an outcome of the decisions they make while meeting a duty of care.

Such a mindset could see Australia enter an era of authentic progress where people living with disability are supported to explore decision-making in their everyday lives, within a framework that enables positive risk-taking. The era of the NDIS provides a critical policy narrative within an infrastructure and disability system reform through which these optimistic outcomes could — and should — be realised. PO

Appendix

Figure 1: Thinking about taking risk safely (instead of making safety risky)



Safeguards

Opportunity features

Inclusive (Community-based, inclusive arrangements That render the person visible)

THE HIGH ROAD
The person’s right to a good, valued life is the context, therefore build the solution

DUTY OF CARE

vulnerability

THE LOW ROAD
The person’s problem is the context, therefore manage the problem

Safety

Security features

Exclusive (Custody-based, exclusive arrangements that render the person invisible)

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Table 1: Key types of support to people living with disability.

Type of support	Promising practices — academic evidence	Promising practices — practice evidence
Being provided with information, including information about their legal rights and about how other people should be expected to treat them.	Information can be effectively provided through multiple accessible formats, including DVDs and comics. In some cases, accessible resources have been developed for specific groups, for example, people who use alternative and augmentative communication although other research has also reported that a lack of such resources is a major barrier to discussing safeguarding issues.	Group work: • Co-develop rights and empowerment language • Physical activities to illustrate concepts Individual work: • Scaffolding learning General strategies: • Visual resources and tools, e.g.: - About emotions - About a spectrum of control of decisions
Having opportunities for problem-solving discussions and activities.	Promising practices for delivery of these discussions and activities often draw on tailored and innovative methods such as role play, consideration of different scenarios and use of pictures	Group work: • Discussion of a vignette scenario • Discussion of amusing pop culture examples • Modelling qualities admired in mentors • Reflection activities Individual work: • Diaries, photo/video journals, video storytelling General strategies: • Education about decision-making processes • Identifying the steps in making a decision
Having opportunities to gain advice and/or support from a trusted person or trusted supporter.	To be effective as a trusted person or supporter, a range of qualities are often necessary, including good interpersonal and communication skills, a non-judgemental demeanour and enacting an effective balance between care and control. In some cases, knowledge of complex communication needs may also be necessary. In one study, peer educators who also had an intellectual disability played a role.	Group work: • Co-facilitation by peers • Personal stories from peers • Peer-to-peer storytelling • Active listening General strategies: • Reassurance
Practice at knowing how to talk with people to address problems and at knowing how to 'speak up' more generally.	Role play may be a promising strategy for practising these kinds of interactions. Practical examples of speaking up could also relate to specific areas, for example, knowing how to make a complaint or a person having a say in which service providers and staff work with them.	Group work: • Role play power relationships • Practising presenting/speaking in front of peers • Leadership opportunities Individual work: • Leadership opportunities • Observation of behaviour General strategies: • Focusing on strengths, not deficits

Source: A Meltzer et al.

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