# 1 QUALITY AND SAFEGUARDING PAPER

### 1. Who is National Respite?

National Respite is a small peak body for small-medium not for profits that provide respite outcomes. We have 91 members around Australia, with the largest concentrated in NSW, but with members in all states and territories.

Our primary aim is to lead a professional focus on the **inter-connected well-being of people** with disability, mental illness and frailty from age and their **chosen carers, families and supports**.

### 2. Broad Approach to Quality and Safeguarding

Until the advent of personalisation and the NDIS, support for people with disability was predominantly a 'one size fits all' approach, inflexible and poorly equipped to address individual needs, preferences and aspirations. Similarly, quality and safeguarding, with its focus on accreditation, training, baseline organisation policy, third party verification and close risk management has been largely process 'tick box' driven, generic and best suited to larger organisations providing disability support.

In contrast, personalisation is a whole of life approach which assumes that all people have the right to relationships and informal support networks, and should be able to participate as part of the community to form these meaningful relationships. Paid supports are the means by which people are able to live their life to the full. This is a huge shift away from how governments have understood disability in the past with the assumption of policy makers and service providers being that they 'worked for' rather than 'worked with' people with disability. The implications for quality and safeguarding are apparent.

The NDIS presents an opportunity for us to unify quality and safeguarding frameworks across Australia and to ensure that it meets the requirements of the personalisation agenda in putting people first and assessing each individual by their own unique attributes, personalities and desires.

An NDIS quality and safeguarding system should be human rights based and promote social and economic participation of people with disability. Instead of focussing on standardised processes to measure quality and ensure safety, the new quality and safeguards framework must adopt a 'people first' principle in all areas of quality and safeguarding through:

A. Acknowledging that people with disability can be supported in strong relationships and meaningful community involvement through:
   - a quality and safeguarding framework that measures success of supports through met outcomes that have been set and assessed by the individual
   - supporting natural safeguards such as family and friends
B. Empowering people with disabilities through a regulatory and legal quality and safeguarding system that meaningfully puts people first.
C. Catering to a changing disability supports market

### 3. Policy Approach to Quality and Safeguarding

### *3.1* Re-assessing Philosophy Underpinning Quality and Safeguarding

Traditional quality and safeguarding frameworks have assumed that output driven mechanisms protected people with disability from risk, abuse and ensured quality service. The experience of

people with disability suggests otherwise, with risk adverse cultures and generic supports restricting people with disability rather than ensuring quality of life.

As John O'Brien has pointed out, 'investing in formal means of regulating relationships hasn't increased consumer confidence in their safety'[1] precisely because these old quality and safeguarding systems weren't equipped to address quality and safeguarding from a human rights perspective which put people first.

Furthermore, these quality and safeguarding systems didn't acknowledge that relationships and community inclusion naturally safeguard people with disabilities with quality supports being ones that assist people with disability to live their life to the full. Measuring outcomes around relationships, community and social capital is difficult, but important. At the same time, evidence also suggests that supporting resilience of families to support people with disability reduces isolation and improves quality of life for the person. Both of these concepts are hard to measure but are important to the new quality and safeguarding framework.

### I. Measuring quality outcomes

If we accept that meaningful relationships and community involvement reduce risk and abuse of people with disability and that quality supports strive to achieve these ideals, then measuring outcomes becomes key to the new quality and safeguarding framework.

In the **United Kingdom**, the Joint Improvement Team Talking Points Outcomes Framework lists six areas where people using services should achieve outcomes which would ensure quality and safeguard from risk:

  a. feeling safe,
  b. having things to do,
  c. seeing people,
  d. staying as well as you can,
  e. living where you want/as you want and
  f. dealing with stigma/discrimination.[2]

These outcomes can only be measured by the individual in a collaborative dialogue with their provider of support. The UK organisation, In Control, have created the POET (Personal Outcomes Evaluation Tool), an online portal which asks people two sets of questions: 1) how have they experienced the process of getting support 2) are they happy with the outcomes - and the program aggregates the answers to these questions to assess quality.[3]

**New Zealand** has also done work on measuring outcomes for people with disability. The Council on Quality and Leadership have done work on measuring 21 individual outcomes in three key areas:

  - my self,
  - my world and
  - my dreams.[4]

Outcomes are measured through a conversation with the person and a separate conversation with the support person allowing organisations to know what needs to change or stay the same for an

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[1] O'Brien, John. 'Personalisation through person centred planning,' March 2010, Department of Health. http://www.pcpmn.cswebsites.org/Libraries/Local/805/Docs/Personalisation%20through%20Person%20Centred%20Planning.pdf.

[2] Ibid.

[3] http://www.in-control.org.uk/what-we-do/poet-%C2%A9-personal-outcomes-evaluation-tool.aspx.

[4] Drew Smith, MBA and Kerri Melda, MS, 'Trends in Outcomes Achieved for People with Intellectual and Developmental Disabilities: Findings from Twenty Years of Personal Outcome Measures Data, August 2014, Council on Quality and Leadership.

individual and what an organisation can do strategically to enhance supports. CQL also have a Basic Assurances Accreditation review which tests an organisation in the areas of: rights, protection and promotion, dignity and respect, natural supports networks, protection from abuse, neglect, mistreatment and exploitation, best possible health, safe environments, staff resources and supports, positive services and supports, continuity and personal security, Basic Assurances System.[5]

### I. Supporting networks of relationships

Though traditional quality and safeguarding frameworks emphasise regulatory and legal frameworks achieving results, it is natural safeguarding and quality mechanisms like strong relationships and community involvement which protect people and ensure quality of life.

 In the UK, it has been suggested that funding family support and education services and having mechanisms for families to be involved in planning future supports is one way of ensuring natural quality and safeguarding.[6] Another UK recommendation has been establishing family group conferences centred on the person with disability.[7] These kinds of processes help families and other important people in a person's life understand the rights of people with disability and 'dream big' with the person with disability.

The new regulatory and legal quality and safeguarding system must therefore capture two important philosophical ideas:

1. Quality and Safeguarding of provision of supports is best achieved by measuring individual outcomes on an individual by individual basis.
2. Processes must support natural quality and safeguarding by supporting strong relationships between people with disability and others in the community.

### 3.2 Regulatory and Legal Quality and Safeguarding Frameworks

The NDS position paper proposes a co-regulated quality and safeguarding framework featuring a National Industry Regulatory Body and a Consumer Complaints Body. We agree that a co-regulatory framework driven by the industry, but enforced by statutory backing would be useful in driving cultural change across the sector and assisting providers to adopt meaningful personalisation strategies, even when addressing safeguarding concerns.

Furthermore, a co-regulatory model of ensuring industry quality and safeguarding has been proven to work well in other competitive markets (such as banking), raising standards and improving information available to the consumer. Mechanisms for achieving co-regulation in other sectors have included information campaigns (such as responsible serving of alcohol), service charters, internal complaints handling, accreditation, licensing, membership, quality assurance systems, standards, industry body dictating codes and a dispute resolution scheme.[8] However, the best mechanisms for ensuring quality and safeguarding in the context of a co-regulatory framework for disability support have been a source of debate in the UK and New Zealand.

This is because traditional quality and safeguarding measures were originally created to regulate relationships between people with disabilities and those who provide them with support. These processes didn't acknowledge the dangers of overly-managing risk that could 'smother' a person

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[5] This information was shared via an email from Sarah Gimson at CQL 15/2/15.

[6] ADASS, Local Government Association, SCIE, 'Making Safeguarding Personal,' March 2013. http://www.local.gov.uk/c/document_library/get_file?uuid=8313fec0-348e-43ec-ab89-09694c990584&groupId=10180.

[7] Ibid.

[8] http://archive.treasury.gov.au/documents/1131/HTML/docshell.asp?URL=04_chap3.asp.

with disability. It also didn't acknowledge that risk is heightened when a person is isolated and unable to participate in community.

The learning from the UK is that putting people first requires service providers to meaningfully **'co-produce'** with people with disabilities and their carers through use of person centred tools and principles. **Co-production** is a completely new way for services to deliver quality to clients:

> It means working together with people to deliver a policy or service. Listening to how people want to live their lives is crucial. It means people are increasingly able to shape and commission their own services.[9]

Quality of supports can therefore only be achieved if providers really know who their client is (their wants, needs and dreams) and provide supports which help to achieve these outcomes. Providers also need to give the client directive control of their chosen supports.[10] In Control UK has done extensive work on how organisations can work with people with all kinds of disabilities to ensure meaningful co-design of supports.[11] Similarly, Louise Close Consulting have done extensive work on providing tips to providers on ensuring quality in a culture of personalisation, adopting five principles:

1. An **excellent service** is one in which people feel safe and are demonstrably free from direct harm or avoidable hazards, whilst at the same time are supported to make their own decisions and take risks which feel right to them.
2. An **effective service** is one which achieves outcomes, outcomes which are defined by the individual, not the service, the organisation, or professionals.
3. A **caring culture** is measured by the quality of relationship between clients and staff and between staff and the organisation.
4. A **well led organisation** is one in which staff feel that they are valued, that their opinions matter and that they are able to use their initiative to respond flexibly and creatively to the people they support.
5. Being **responsive to individual need** means listening to the person and working with them to create inputs that reflect a balance of what they want and need, recognise them as unique and value what matters to them most.[12]

A quality and safeguarding system needs to move away from over-emphasis on protection from risk to the concept of **'dignity of risk'** or 'acceptable risk' with workers trained in applying this concept to delivery of support. Positive approaches to risk taking minimises a safeguarding 'culture of blame where people fear that they may be held personally responsible for any negative events that occur in the lives of the people they support.'[13] This sort of culture leads to professionals persuading people to make choices which 'safeguard the professional's own vulnerability,'[14] rather than considering individual client outcomes.

These concepts are a revolutionary way of looking at support which requires culture change across the entire disability support sector and cannot realistically be driven by a government regulatory body. Rather, the industry needs to regulate itself with statutory backing of *The NDIS Act 2013* which gives authority to a national industry quality and safeguarding body, also allowing this body to

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[9] O'Brien, John. 'Personalisation through person centred planning,' March 2010, Department of Health. http://www.pcpmn.cswebsites.org/Libraries/Local/805/Docs/Personalisation%20through%20Person%20Centred%20Planning.pdf.

[10] Kendrick, Michael. 'Key dimensions of quality in individualised lifestyles and supports,' May 2008, *Interaction*, v22/4.

[11] http://www.in-control.org.uk/resources.aspx.

[12] Louise Close, 'Quality Assurance, Top Tips for Hampshire Providers,' *Louise Close Consulting*, May 2014.

[13] Louise Close, 'Risking a real life: The Challenge of Implementing Self-Directed Support Safely,' *In Control Scotland*, 2014.

[14] Ibid.

reward providers who are meaningfully person centred. In this context, tools like third party verification may not actually be helpful as they place provider emphasis back onto 'tick box' processes rather than directing energy to ensuring individual outcomes are met for clients.

> **Core features** of a co-regulated industry quality and safeguarding under the NDIS should include:
>
> I. National industry regulation body with **statutory backing** of *NDIS Act*.
>
> II. National industry regulation body which enforces quality and safeguarding through principle of **co-design of industry with people with disability** and providers of supports.
>
>     a. This would require people with disability and carers holding key positions in the National Industry Regulation Body.
>
> III. Mechanisms so providers are meaningfully person-centred and staff are trained in how to work with people with disabilities to meet their needs, wants and aspirations.
>
> IV. The principle **of 'acceptable risk'** is applied to providing support.
>
> V. Outcomes are set for individuals and feedback is demonstrably sought from these individuals on whether outcomes have been met.

### 3.3 Tailored Quality and Safeguarding Frameworks for an Emerging Supports Market

Putting people first also means that we need to respect people with disabilities right to meaningful choice of support. Therefore, the new quality and safeguarding framework must carefully consider a changing disability supports market. The NDIS will change the current make-up of the disability sector from predominantly not for profits to a mix of for profit, not for profit and micro business providers as well as Personal Assistants employed by participants self-managing funds. This diverse market is essential in ensuring that participants have choice and control of their supports. Traditional regulatory and legal quality and safeguarding frameworks are not well suited to this new market, and in particular, to micro businesses and those who self-manage funds. Both of these new ways of 'doing' supports need a tailored approach to quality and safeguarding.

#### i. *Micro Businesses*

Micro businesses (businesses comprised of 5 staff or less)[15] can be an important aspect of providing choice of support to people with disability because they are often:

- Local

- Flexible and quick to respond to changing needs of their clients due to being small

- Develop social capital through use of volunteers, social franchise or cooperative business models

- Provide healthy competition and help to drive innovation and quality[16]

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[15] http://toolkit.smallbiz.nsw.gov.au/part/20/99/449.

[16] Community Catalysts, 'Working to Stimulate and Support Micro Enterprise,' Background Document. http://www.communitycatalysts.co.uk/wp-content/uploads/2010/09/Background-Document-for-Community-Catalysts-supporting-microenterprise-March-12.pdf.

BUT

- Micro businesses are hard to find and engage with

- Regulatory and legal quality and safeguarding frameworks are burdensome and ill - suited to micro businesses

- UK studies have found that micro businesses fold after 18 months with 90% failing in the first year.[17]

In the UK, Community Catalysts developed and tested a quality marking system that was 'accessible and appropriate to many service types whilst also being comprehensive and robust.'[18] This quality mark system is now used by local authorities to ensure quality and safeguarding of micro businesses. The three stage Quality Mark focusses on:

1. Preparation – support and information to the micro-business
2. Gateway – application and assessment  process leading to a silver Quality Mark
3. People – continuous improvement based on user feedback leading to a gold Quality Mark[19]

The manual for Quality Mark is available from the Community Catalyst website for a small fee.[20]

### ii.    *Self-Management*

One of the likely benefits of the NDIS is that it will aid a future where people with disabilities can exercise choice and control through self-management of funds. Though evidence from the trial sites suggests that there is minimal take-up of self-management at this stage, as education, information and advocacy improves for participants, it is likely that more will choose this option of funding. Therefore, new quality and safeguarding systems must suit a landscape where a substantial amount of people choose to self-manage.

Self-managed funds empower people with disabilities through:

- Autonomous nature of support
- Increased independence
- Increased flexibility with the participant 'in control'

BUT

- Requires readily available information and education for participants considering self-management
- Additional safe-guarding and quality considerations due to the nature of employment of supports, and possible increased risk of abuse.

Evidence suggests that people won't choose to self-manage and employ their own supports unless they are empowered to do so with education, information and ongoing training.

A paper in New Zealand found that self management works when there is:

- provision of good information to the person,
- active outreach to marginalised or at risk groups,
- transparent decision making regarding resource allocation,

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[17] Ibid.

[18] Community Catalyst website: http://www.communitycatalysts.co.uk/products/quality-mark/quality-mark-the-process/.

[19] Ibid.

[20] Ibid.

- ongoing third part support to assist with the management of finance and employment relations,
- staff/service passing control to the client and
- adequate funding to cover administration costs for providers assisting people with self-management, with the evidence indicating that high administration costs upfront return better outcomes for the person with disability in the long-term.[21]

Similarly, the New Zealand Enabling Good Lives Report literature review found that 'there needs to be greater focus on **risk enablement** (e.g. supporting disabled people and their families to define their own risks and to recognise, identify and report abuse, neglect and safeguarding issues as well as incorporating it into on-going reviews of outcomes)... that building the capacity of disabled people and their families to manage the money needed to go hand in hand with individualised funding.'[22]

One UK Local Authority panel addressed these new quality and safeguarding concerns by creating a Direct Payments Support Service (DPSS) based within local council to provide on-going advice and support to Direct Payment participants with assessors receiving training in positive risk taking. Issues of employment, finance or care plan concerns can be raised with the DPSS.[23] This system could be re-created in Australia. At the same time, support for networks of family members, guardians for friends, facilitators, brokers, network builders, financial intermediaries, advocacy and consumer organisations, micro boards, or independent living centres are all important to ensure a culture of self-management flourishes.[24]

### 4. Key Principles of New Quality and Safeguarding Framework

The new quality and safeguarding system must ensure that people with disability are networked into strong relationships and are not isolated from the community, with legal and regulatory mechanisms to ensure safeguarding and quality highly personalised. This shifts our current way of looking at quality and safeguarding from a 'tick box' process driven quality system, to one which is driven by individual outcomes and is necessarily highly personalised.

The NDS position paper proposes a co-regulated quality and safeguarding framework which encompasses the role of the NDIA and creates a National Industry Regulatory Body and an independent Disability Consumer Rights Complaints Body. We agree that a National Industry Regulatory Body and independent Consumer Rights Complaints Body are necessary to ensure quality and safeguarding under NDIS. However, we believe that a quality and safeguarding framework would be strengthened by adopting the following five principles:

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[21] Te Pou o Te Whakaaro Nui, 'Individualised funding for New Zealand mental health services, a discussion paper,' September 2014.
[22] Office for Disability Issues, *Enabling Good Lives*, http://www.odi.govt.nz/what-we-do/improving-disability-supports/enabling-good-lives/.
[23] Stockport Council, 'Scrutiny Review of Safeguarding and Personalisation in Adult Social Care,' http://www.stockport.gov.uk/2013/2996/41105/scrutinyreviewsafeandpersasc.
[24] Office for Disability Issues, *Enabling Good Lives*, http://www.odi.govt.nz/what-we-do/improving-disability-supports/enabling-good-lives/.

I. A quality and safeguarding framework should ensure **resilience of informal supports** to support people with disability to live in the community and form meaningful relationships.

II. Promoting and measuring **density of family and natural supports** /friendships /relationships community: isolated people are more at risk.

III. A self-regulatory quality and safeguarding framework which is underpinned by the philosophy of '**people first'** where people with disability are empowered to co-design their supports. This requires rewards for organisational cultures which promote real person centred practice and education and advocacy support for people with disabilities to make meaningful decisions about their supports.

IV. A quality and safeguarding framework which makes a specific, prominent commitment to a **market of choice** for participants with regulatory and legal quality and safeguarding mechanisms tailored to the unique needs of micro businesses and participants who self-manage supports adopting the proportionality principle in relation to risk and size of the organisation.

V. A quality and safeguarding framework predicated on the concept of '**acceptable risk**,' which promotes the right of people with disabilities to take the same risks as others in our society.

### 5. Additional Recommendations

National Respite has the following specific suggestions about quality and safeguarding of micro-business and self-managed supports:

i. A separate quality and safeguarding system based on the Community Catalyst UK model could be piloted to support micro businesses to remain in the market whilst ensuring quality and minimised risk for participants using micro business supports.

ii. This model would sit alongside the standard quality and safeguarding process required for larger organisations. A parallel micro-business quality and safeguarding system would require a funded body to provide information and support and to assist micro businesses with quality and safeguarding. This body would need to have local reach to identify micro businesses and connect with them. This reach could be achieved by using local government staff.

iii. The Quality Mark model should be adopted by the industry self-regulating body to register micro business services. The above funded body would encourage all micro businesses to complete this Quality Mark as part of best practice.

iv. Participants are given appropriate information, training and education about self-managing support to ensure choice and protect participants and employees from risk.

v. Local NDIA branches are given a clear role in supporting people with disability who wish to self-manage and employ supports. This would be consistent nationally.

vi. A specific role is created with each local NDIA office which is dedicated to assisting those self-managing funds. The person/s in this role would be trained in acceptable risk taking as well as employment and industrial relations issues relevant to self-management.

vii. The NDIA should establish a way for participants to publically rate quality of supports. This could be through an online feedback facility that allows reviews of supports 'Amazon style' and the creation of an e-market place.

viii. We strongly support the creation of an independent consumer rights complaints body in an NDIS world. The NDIS centres on putting people with disability at the centre of support and

this should also extend to quality and safeguarding. We would also strongly support this consumer rights complaints body being run by consumers.

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