



NDIS Consultation Paper  
Proposal for NDIS Quality  
& Safeguarding Framework

30 April 2015

**yooralla**  
choosequality

# Yooralla

Yooralla has a proud history of working within the community to build a world where people with disability are equal citizens.

Established in 1918 by Ms Evangeline Ireland (Sister Faith), Yooralla today provides a diverse range of support services to about 30,000 people each year and employs nearly 2,000 staff working in people's homes, in the community and across 100 sites in Victoria; ranging from early childhood services to supporting young people and adults in varied service models.

Yooralla's services range from a kindergarten inclusion program, a family options service, residential and respite support, in-home services, therapy, peer support and self-advocacy development, recreation and arts, education and employment services.

Yooralla supports persons with disability whose support needs are high and more complex than the Victorian state average, as evidenced by an independent comparative analysis in the area of restrictive interventions. This independent review was commissioned by the Victorian Senior Practitioner's office and Yooralla. Another independent review was undertaken by the University of Sydney's Centre for Disability Studies using the ICAN tool. The results showed that Yooralla's customers have higher support needs than when they first accessed Yooralla. Yooralla is responding to the changing support needs of these individuals in an on-going manner.

A disclosure of sexual assault against some clients in a Yooralla residential service was first made at the end of 2011 and in early 2012. Subsequently, two more sexual assaults against two women were disclosed in two regional areas in 2012 and in 2014. It was a traumatic and painful experience for the survivors of the sexual abuse. Yooralla has apologised to the survivors and to the community for the abhorrent events. Yooralla continues to therapeutically support the survivors by way

of engaging external trauma counselling services and support if the individual and his/her family chose to accept the offer.

Yooralla has learned a lot in responding to disability abuse disclosures. Learning from our own experience in dealing with disability abuse and the research evidence, Yooralla champions and is leading an organisational approach to safeguarding the rights of people with disabilities. The Yooralla strategy is called “Embedding Safeguarding Rights”.

In preparation for this submission, Yooralla has proactively sought the views of its customers and families, Board members and advocacy groups to inform Yooralla’s submission to this consultation paper. This is important because we need to make real the Convention on the Rights of Persons with Disabilities and Optional Protocol, 2006 (CRPD), and the National Disability Insurance Scheme Act, 2013 (NDIS Act); particularly in the intent of dignity, equality, power and control, and participation. Two customer forums were organised and one of them was facilitated by VALID, a Victorian advocacy organisation. The feedback, from the forums, is incorporated within this submission.

Yooralla will be keen to share case studies and several of its strategies with NDIS, such as the RiskMan reporting capability; the Speaking Up program, My Rights training and other such initiatives. Yooralla promotes the belief that “Safeguarding rights is everyone’s business”. While there are legislative and departmental safeguards, all of us in the community have a role to play in upholding human rights. Learning from past experience, Yooralla sees it as one of its core businesses to champion the equality of people with disabilities and to prevent disability abuse.

It is important that we stress, however, that we fully appreciate that we are in the process of embedding change. We understand that we need to continue our reform process in the interests of all people with disabilities and their families. It is in this spirit that we offer this submission and invite further contact if NDIS would find that of assistance.

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# 1 Executive Summary

- 1.1. Yooralla applauds the landmark social reform of NDIS and will collaborate with NDIS to deliver the objectives of NDIS.
- 1.2. Yooralla has proactively sought the views of our customers, particularly people with cognitive disability or communication impairment, and its internal advocacy groups to inform this submission.<sup>1</sup>
- 1.3. Yooralla fully supports the underlying intent and principles proposed in this consultation paper, particularly in the objective of advancing the rights of people with disabilities. Yooralla customers reiterate the importance of needing to feel safe, the ability to make choices and exercising the dignity of risk.
- 1.4. The development of self-advocacy is very important in order to build the voice of people with disabilities, particularly for people with cognitive disability. This may include development of peer support and leadership coaching.
- 1.5. There needs to be a proactive strategy in engaging the whole community in promoting and safeguarding rights – in all facets of life, not just in service environments.
- 1.6. Yooralla emphasises the role of building and enhancing the communication abilities of individuals who have communication disability. Technology now offers (particularly through the iPad and similar devices) new opportunities for people to communicate independently in ways understandable by all community members. Strengthening people's ability to speak for themselves gives them power, enables choice and control and is an important factor in the prevention and reporting of abuse.
- 1.7. The role of families and friends as part of a social network is critical in safeguarding rights. Families, friends and social networks can provide a level of emotional empowerment and support, oversight of service quality and assistance in advocacy, when required. The role of a social network and the family featured strongly in Yooralla's customer feedback.
- 1.8. Advocacy plays a complementary and effective role in safeguarding rights. Advocacy, in its many forms, both at an individual level and a systemic level, is a vital and central part of quality and safeguards. For people with cognitive disability and/or communication disability, advocacy support can have a life-changing impact and, therefore, it should be supported. Yooralla customers ardently argue for the role of advocacy to be maintained

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<sup>1</sup> Yooralla customer feedback was sought at two forums initiated by Yooralla and Yooralla's Independent Advocacy Advisory Committee. One of the forums was independently facilitated by an external agency. There were 17 participants at the forums, of which two were parents. The remaining participants were people with disabilities, mainly individuals with cognitive disability.

and for it to grow, and some of them indicated that they would be happy to pay for advocacy with NDIS funding.

- 1.9. Yooralla supports the independent oversight of NDIS and the establishment of National legislative oversight bodies similar to the Victorian Disability Services Commissioner and the Senior Practitioner. Registration and quality accreditation should apply to all providers, that is, the same standard of quality and rigor should apply to all providers so as to ensure and maintain a high level of quality and service delivery.
- 1.10. Yooralla supports the establishment of an oversight body that has the powers to investigate and address complaints and incidents, instigate positive change for health and social equity, promote a human rights function and set standards.

## 2 Principles guiding this submission by Yooralla

- 2.1. Respecting, protecting and fulfilling the rights of people with disabilities consistent with the CRPD and NDIS Act; particularly in the principles of equality, choice, power and control; and participation. This principle should be applied regardless of the settings in which a person with a disability lives and interacts with other people.
- 2.2. Promoting dignity of risk and informed consent, balanced with a service provider's duty of care and obligations to other relevant legislative and contractual requirements.
- 2.3. Promoting individualised and tailored supports, within a home environment, balanced with rights protection of the person.
- 2.4. Transparent quality of life and community participation outcome indicators, at the level of both whole of community and service providers, will be important measures of quality and safeguards.
- 2.5. Promoting individualised supports based on research evidence and contemporary practice.
- 2.6. Balancing regulatory mechanisms versus efficiency and effectiveness of service provision to promote a person's independence and decision-making.
- 2.7. Achieving national consistency, balanced with state or organisational unique value contributions.
- 2.8. Building empowerment and capability of the person and sector versus the market driven cost imperatives.

## 3 Feedback on Part 1

### 3.1 Part 1: Proposed Quality and Safeguarding framework for the NDIS

- 3.1.1.1 There are several definitional issues and the use of language that will benefit from further clarification or elaboration. The use of language, at times, appears incongruent with the CRPD and NDIS Act. These will be highlighted below.
- 3.1.1.2 To begin with, clarification is required on the paper Attachment 1. Attachment 1 highlights that the proposed NDIS Quality and Safeguarding framework applies to participants who are self-managing. The majority of Yooralla's customers present with high and significant level of support needs, more than 80% of them present with cognitive disability, mental illness, high health-care needs and/or deteriorating medical conditions. This is consistent with the Australian data. For example, over half a million Australians have intellectual disability and a majority (61%) of those people have a severe or profound limitation in 'core' activities of daily living. People with intellectual disability are a major group of users of disability support services in Australia.<sup>2</sup> The Australian data in 2005 showed that over half of people aged under 65 years with intellectual disability and a severe or profound limitation required support with self-care (51%), mobility (68%) or communication (57%). The proportion of people with intellectual disability who needed help with communication was markedly higher (57%) than for people without intellectual disability but with physical/diverse (3%), acquired brain injury (6%), psychiatric (8%) or sensory/speech (25%) disability.<sup>3</sup> As such, majority of Australians with disabilities with significant support needs will find it a challenge to self-manage and similarly, majority of Yooralla's customers will find it a challenge to self-manage also.
- 3.1.1.3 The term "challenging behaviours" is an evolving term which is now surpassed by Victoria's more contemporary use of the term "behaviours of concern".<sup>4</sup> Secondly, "behaviour support plan (BSP) is defined in the glossary of terms as applicable to adults with an intellectual or cognitive disability. A BSP is applicable to children and adolescents, and not just adults. Secondly, the Victorian, Queensland and Tasmanian legislative contexts have been applied to the definition of Positive Behaviour Support with reference to restrictive interventions/practices. This is actually an

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<sup>2</sup> AIHW 2005. Australia's welfare 2005. Cat. no. AUS65. Canberra: AIHW. AIHW 2007a. Disability support services 2005–2006: national data on services provided under the Commonwealth State/Territory Disability Agreement. Cat. no. DIS 51. Disability Series. Canberra: AIHW.

<sup>3</sup> AIHW 2005. Australia's welfare 2005. Cat. no. AUS65. Canberra: AIHW. AIHW 2007a. Disability support services 2005–2006: national data on services provided under the Commonwealth State/Territory Disability Agreement. Cat. no. DIS 51. Disability Series. Canberra: AIHW.

<sup>4</sup> Chan, J., Arnold, S.R.C., Webber, L., Riches, V.C., Parmenter, T.R., & Stancliffe, R.J. (2012). Is it time to drop the term 'challenging behaviour'? Learning Disability Practice, 15(5), 36-38.



artefact of the respective legislative requirements. Positive Behaviour Support (PBS) is an empirical science focussed on positive ecological support and driving social change in the person's environment; hence PBS is very much consistent with the CRPD.<sup>5</sup> This is one of the problems of the term BSP used in the legislative context, a more appropriate and evidence-based term ought to be "Restraint Reduction or Elimination Plan" that forms a subset of the BSP. This would clarify the intent and purpose of a Positive Behaviour Support or a BSP versus that of restrictive interventions where the intent is rights limitation. PBS is about promoting appropriate and positive behaviours before the behaviour of concern occurs. It is also about changing the ecology to promote skills development in people with disabilities. This issue, within this consultation paper, will benefit from further refinement in light of the CRPD and NDIS Act, and the research evidence on PBS.

- 3.1.1.4 Thirdly, the definition of "preventative action" is defined as "designed to prevent harm being caused to people with disability". This definition requires clarification in light of dignity of risk; this is explained, below. The definition in its current form is problematic because it infers a notion of an absence of risk. In reality, there are life situations and activities in which there is statistically an element of risk of harm, where the risk cannot be totally removed. For example, young male drivers aged 17 – 25 years old are more likely to be involved in road trauma or death,<sup>6</sup> despite campaigns and road safety measures.
- 3.1.1.5 The definition of harm can be strengthened so as to avoid a risk-averse approach by service providers and families. As it currently reads, service providers appear to carry much of the responsibility of the risk and the weight of its consequences. This is incongruent with the CRPD and NDIS Act on dignity of risk. Yooralla customer feedback emphasises balancing dignity of risk and feeling safe when receiving support from a provider.
- 3.1.1.6 Another example requiring clarification is the notion of "reducing restrictive practices" as a preventative measure. In fact, reduction or safe elimination of restrictive practices should be considered as a corrective measure rather than a preventative measure based on the definitions of "preventative" and "corrective", and the research on PBS and restrictive practices. In the context of restrictive practices, prevention should be the full implementation of positive behaviour strategies to prevent the need for the use of a restrictive practice in the first instance.
- 3.1.1.7 Formal individual safeguards ought to be the implementation of positive behaviour support strategies, person-centred active support and person-centred planning. These strategies form the basis of best practice standards to appropriately support a person in light of the CRPD and NDIS Act, and the research evidence.

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<sup>5</sup> Chan, J., French, P., & Webber, L. (2011). Positive behavioural support and the UNCRPD. *International Journal of Positive Behavioural Support*, 1(1), 7-13

<sup>6</sup> <http://www.youngdriverfactbase.com/key-statistics/> Retrieved on 24<sup>th</sup> March 2015

- 3.1.1.8 The notion of safeguarding as defined in this paper is narrowed to be “free from abuse and neglect while maximising choice and control.” It would be more appropriate to strengthen the definition of safeguarding to include actions taken to uphold human rights, particularly the dignity and equality of the person. And that embraces the full essence of the CRPD to include advancing social change in the community. As such, the term “safeguarding” could be better elaborated using a human rights discourse and analysis in terms of rights-bearers and duty-bearers.<sup>7</sup>
- 3.1.1.9 It is important to define more clearly the notion of minimising the “risk of harm” throughout the paper, that is, how does “risk of harm” interface with ‘dignity of risk’ as mentioned above. The notion of “risk of harm” appears as articulated on page 10 para 3 – “There is also a risk that people with disability could be harmed in some way.” And para 4 – “to be free of harm, abuse, exploitation...” may appear to hinder dignity of risk. For example, a person with cognitive and/or physical disability with a medical condition may wish to attempt para-gliding, although there is potential risk and harm in this activity. As it currently reads, such an activity carries an element of risk of harm and should, therefore, be avoided. Therefore, it is important to reflect more clearly the importance of the dignity of risk versus “could be harmed in some way” so as to avoid what is an “every day life event or activity” that may carry an element of risk, not being curtailed by providers.
- 3.1.1.10 Hence a human rights starting point is essential. It is important to emphasise that in the context of the CRPD, people with disabilities are rights-bearers and providers are duty-bearers who hold the responsibility of upholding human rights.
- 3.1.1.11 A human rights approach is particularly important, particularly in controversial discussions and topics such as abuse prevention, where there has been lobbying for CCTV cameras in residential areas, or for a return to congregate care settings by particular interest groups.<sup>8</sup>
- 3.1.1.12 It also appears the consultation paper’s notion of ‘harm’ focuses on the more overt behaviours of concern, such as physical aggression exhibited by the person with a disability as opposed to the less overt behaviours of concern; such as withdrawal or depression. It is advisable that a safeguarding rights framework articulates this difference and makes an explicit note of the difference between overt and less overt behaviours.
- 3.1.1.13 It would be useful to further clarify the structure of a national quality and safeguarding framework. It currently describes the structure in terms of “developmental, preventative and corrective”. The latter two terms are usually derived from the paradigm of a regulatory framework, occupational

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<sup>7</sup> Yooralla Policy on Human Rights

<sup>8</sup> Chan, J. (in press). Challenges to realising the CRPD in Australia for people with intellectual disability and behaviours of concern. *Psychiatry, Psychology and Law*.

health and safety, risk management and in the reporting and management of incidents. This framework does not appear to be congruent with the CRPD and NDIS Act, where the notions of empowerment, capability development and capacity building of the individual are emphasised, thus enabling service providers to play a part in empowerment. These goals could be more strongly emphasised.

- 3.1.1.14 Furthermore, underlying the structure's notion is the assumption that at the developmental level; people with cognitive disability and/or with physical access issues are able to build natural safeguards through "high quality, meaningful and credible information". The example cited on page 13, the "Purple Orange project", has very limited evidence. The assumption that objectives of information can be achieved by providing and/or training people on the navigation of information systems, while laudable, ought not to be the primary starting point as implied in the consultation paper. There appears to be an assumption of a "level playing field" in information technology access. Consideration should be given to rural and remote communities, indigenous populations, diverse cultural groups and costs as these factors may influence accessibility to technology.
- 3.1.1.15 The research evidence indicates that the notion of building natural networks, such as friendship building; social inclusion and neighbourhood integration is far more complex than implied in this consultation paper; particularly for people with cognitive disability, those with communication impairment and those with high and complex support needs; such as those with dual disability of intellectual disability and mental ill-health.
- 3.1.1.16 The consultation paper appears to be discussed in an absence of advocacy, for people with cognitive and/or communication disability; advocacy has an important and life-changing role. Yooralla customer feedback reiterates the importance of advocacy.
- 3.1.1.17 Information provision through an ICT strategy is only one methodology. Yooralla will respond more fully on this matter in the questions below. It is critical to reiterate that an information system must include face-to-face contact or training and on-going support within the context of developmental growth for the individual.
- 3.1.1.18 Information technology is a critical element for consumer engagement and participation, but not the key starting point. There are financial, physical, cognitive barriers to access, and there are significant needs in the training and supervision of support staff to enable people with cognitive impairment to access and use this technology.
- 3.1.1.19 The cited example of work and employment at Karingal is one of many other examples that disability service providers offer to people with disability. It is important how these projects connect to education at the vocational and tertiary level, and it interfaces with the education department to ensure educational continuity that creates pathways to employment. Yooralla is undertaking a systematic literature review; models of open employment is another example.

3.1.1.20 It is very important to highlight that safeguards require participation at the level of the broader community, it requires a targeted societal response at the 'developmental phase'. This issue will be discussed in later sections.

### **3.1.2 Question 1: What are the most important features of an NDIS information system for participants?**

3.1.2.1 Yooralla customer feedback highlighted the importance of customers being able to tell someone if they were not happy with a service. The people that the customers would talk to included family, staff, manager, "the boss" of the service and friends. Face-to-face contact is an important feature of an NIDS information system according to customer feedback..

3.1.2.2 Hence, an information system must be multi-faceted and in varied mediums, and not contingent on technology alone.

3.1.2.3 There should be capacity for online forums that are independently moderated.

3.1.2.4 Credibility in terms of ease of use, accessibility and accuracy from the perspectives of both the customer and provider should be considered.

3.1.2.5 It is important to consider access to technology in rural and remote communities, indigenous populations and diverse cultural groups; and how technology may be applied in their various environmental contexts and for people who speak and understand languages other than English.

3.1.2.6 Children and adolescents' views and attitudes should be considered in terms of its relevance, applicability and design.

### **3.1.3 Question 2: How can the information system be designed to ensure accessibility?**

3.1.3.1 E-accessibility must no longer be approached as an afterthought but rather as a core component of information systems, with the potential to increase business and performance.

3.1.3.2 Yooralla proposes referring to widely recognized standards and technical guidance; and its application to the sector.

3.1.3.3 Guidance can be found at <http://www.brailenet.org/documents/G3ICT-White-Paper-eAccessibility-at-the-core-of-IS.pdf>

- 3.1.3.4 Another reference is the Australian Human Rights Commission's <https://www.humanrights.gov.au/accessibility-electronic-commerce-and-new-service-and-information-technologies-older-australians->
- 3.1.3.5 Other references include <http://www.w3.org/>
- 3.1.3.6 Reference to the CRPD is recommended. The following references are useful, CRPD Article 4 General obligations, Article 9 on Accessibility and Article 21 on Freedom to expression and opinion, and access to information. Article 4 General obligations requires State parties to ensure and promote the full realisation of all human rights and fundamental freedoms for all persons with disabilities, and the implementation of measures to promote research and development of, and promote the availability and use of new technologies, including information and communication technologies .... giving priority to technologies at an affordable cost. Article 9 Accessibility, mandates State parties to enable persons with disabilities to live independently and participate in all aspects of life, and have appropriate measures to ensure access, on an equal basis with others, to information and communications, including information and communications technologies and systems. The implementation measures of Article 21 Freedom to expression and opinion, and access to information includes for example, that the information and expression of views and opinions should be in accessible formats, such as the use of sign language or recognized alternative and augmentative communication systems. Article 24 Education and Article 30 Participation in cultural life, recreation, leisure and sport also have application in terms of ensuring education and participation in cultural and leisure activities are provided and available in accessible formats.
- 3.1.3.7 There are ample augmentative and alternative communication systems and accessible technologies to guide the NDIS on this matter.
- 3.1.3.8 It is pertinent to also state what types of information methodology and communication systems should be supported and funded. For example, a facilitated communication system should not be a funded service because of the risks it poses to the person.<sup>9</sup> The research evidence on this issue should be noted.
- 3.1.3.9 Careful consideration needs to be given to financial, physical and sensory access factors when considering technology. Equivalent emphasis should be given to developing staff expertise and support capability to ensure people with cognitive and communication disability have access to technology that builds their independence in communication, learning and entertainment.
- 3.1.3.10 It is important for industry leaders to rise to the challenge and provide all stakeholders, from designers to end users, with the necessary tools and training to make e-accessibility feasible in

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<sup>9</sup> Chan, J., & Nankervis, K. (2015). Stolen voices: Facilitated communication is an abuse of human rights, Evidence-Based Communication Assessment and Intervention, DOI:10.1080/17489539.2014.1001549

large organisations; including the means to design, build and distribute accessible products and services; and the importance of implementing accessibility in the day-to-day activities of digital content and service providers.

### **3.1.4 Question 3: What would be the benefits and risks of enabling participants to share information, for example, through online forums, consumer ratings of providers and other means?**

- 3.1.4.1 Some of the benefits include immediate consumer feedback and rating, the direct experience of the person with disability and the family are valuable as part of building and enhancing brand reputation.
- 3.1.4.2 A fundamental assumption made in Part 1 of this paper is that the voice of people with cognitive disability will be heard equally. Observed data by way of scrutiny of on-line forums such as those promoted by NDIS, appear to be used predominantly by people without a cognitive disability. This observed data is reinforced when the presence or representation of people with cognitive disability appears to be usually minimal to none at many disability forums. Therefore it is critical to be inclusive and mindful that training and development opportunities are offered to people with cognitive disability to share information, and to facilitate social equity principles.
- 3.1.4.3 A second fundamental assumption is the notion that there are equitable market service provisions in regional, rural and remote communities as there would be in metropolitan regions. Hence, consideration should be given to geographic locations and range of service providers when considering the implementation of consumer ratings of providers.
- 3.1.4.4 Online forums and consumer ratings should be moderated in order to ensure that people with disabilities do not inadvertently find themselves facing legal challenges associated with an open market economy.
- 3.1.4.5 Consumer ratings of providers are welcomed but there should also be more than one avenue of consumer rating schemes, channels or sites; as there are in the current context such as restaurant or hotel ratings.

### **3.1.5 Question 4: Are there additional ways of building natural safeguards that the NDIS should be considering?**

- 3.1.5.1 It is important to reiterate that natural safeguards development must be actively pursued and established as a specific policy platform. Safeguards are not limited to information and referral. Abuse prevention should be a primary level of intervention; it is essential to design safeguarding

at the level of the community, family and friendships. Natural social networks including families and the local neighbourhood are important. Social network development for many persons requires a targeted and specific focus.

- 3.1.5.2 Yooralla customer feedback demonstrates that families (e.g., “mum” as mentioned at a customer forum), key workers and friends form an important network to raise concerns when they do not feel safe.
- 3.1.5.3 Yooralla customer feedback emphasises the importance of a peer support model, particularly in complaints management and to structure a complaints system through a peer support model. Feedback from this group reiterates the need for stronger representation of natural safeguards via funding of individual advocacy. According to this group, there is a willingness to pay for advocacy services. They also indicated that usually they would speak to staff directly if they have a complaint to make. However, they recommended a peer support model of giving feedback and complaints. That is, peers supporting peers in feedback and complaints.
- 3.1.5.4 Promote and increase disability rights awareness and positive social attitude towards disability in a more targeted manner through neighbourhood renewal and inclusion, and working with urban planning in the design of public spaces that foster inclusionary practices, and accessibility to mainstream services. For example, working with urban planning and local councils to provide more accessible public toilets with hoist, social hubs etc.
- 3.1.5.5 It is particularly crucial to undertake public campaigns focussed on educating and changing community attitudes and behaviour on disability as an aspect of human diversity consistent with the CRPD. This should drive the move away from a charity model or social exclusion to one of social equity.
- 3.1.5.6 Increase the initiatives in developing peer mentoring/support and leadership, particularly for people with cognitive disability. Victoria’s VALID advocacy organisation’s work on “My Rights Training” and Victoria’s Reinforce are great examples of the development and benefits of self-advocacy. Yooralla’s Lifeskills Speaking Up program on abuse prevention has a focus on building a support network and this has led to the establishment of a community of practice of people with and without cognitive disability to meet on a regular basis to discuss feedback and complaints. Yooralla also has a customer rights and empowerment team that provides peer support and leadership development, case management and that also responds to matters such requests for counselling or external referrals.
- 3.1.5.7 Furthermore, when information is shared, face-to-face, as cited in Yooralla’s experience of delivering rights training and speaking up programs; it can lead to a positive outcomes. Yooralla

developed and implemented the Lifeskills Speaking Up program<sup>10</sup> which was delivered to more than 200 participants across Yooralla service sites. The Speaking Up program used an action learning methodology to teach participants about self-protective behaviours, how to make complaints, how to form a support network and to identify and keep safe from potential abuse. After delivering the Speaking Up program, many of Yooralla's customers decided to initiate and establish a community of practice. They meet on a regular basis; the group is independently chaired by a person with cognitive disability. Yooralla supports the group in practical ways such as facilitating meeting rooms or supporting the members to develop the 'next steps'. This community of practice group now independently call themselves the "YES" Group (Your Enquiries Solved) to listen and support each other in making complaints or to problem-solve day-day concerns.

3.1.5.8 Yooralla has also partnered with Victoria's VALID advocacy organisation to deliver "My Rights" training to people with disabilities, families and staff. This training is in tandem with the Lifeskills Speaking Up program. In addition, Yooralla partnered with Deakin University and VALID to secure a modest grant, from the Transport Accident Commission of Victoria, to develop a train-the-trainer module on rights training for people with acquired brain injury. This project is called "My Life Keys" and has just commenced.

3.1.5.9 There is increasing research on the loneliness and social isolation experienced by people with a cognitive disability due to the continued stigmatisation of disability<sup>11</sup> and where disability is not perceived as an aspect of human diversity. The suggestions highlighted above emphasised the criticality of targeted intervention to promote friendship and belonging as a means of preventing abuse and neglect.<sup>12</sup> Friendships and belonging are an important focus for health and well-being for people with cognitive disability, in particular, and they occur mainly in public domains.<sup>13</sup> Therefore, friendships and activities to promote social belonging must be actively pursued as a policy agenda within NDIS.<sup>14 15</sup>

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<sup>10</sup> Harris, C., Price, J., & Chan, J. (2013). "Speaking Up program: Empowering people with a disability to exercise their rights to make complaints and prevent abuse. Paper presented at the Australian Society for Intellectual Disability 48th National Conference: Our Time, 6 – 8 November, Sydney, Australia.

<sup>11</sup> Gilmore, L., & Cuskelly, M., (2014) Vulnerability to loneliness in people with intellectual disability: an explanatory model. *Journal of Policy and Practice in Intellectual Disabilities*, 11(3), pp. 192-199

<sup>12</sup> Fitzsimons, N.M. (2009). *Combating violence and abuse of people with disabilities*. Baltimore: Paul H. Brookes.

<sup>13</sup> Emerson, K., & McVilly, K. (2004). Friendship activities of adults with intellectual disabilities in supported accommodation in Northern England. *Journal of Applied Research in Intellectual Disabilities* 2004, 17, 191–197.

<sup>14</sup> McVilly, K., Stancliffe, R., Parmenter, T.R., & Burton-Smith, R. (2006). 'I Get by with a Little Help from my Friends': Adults with Intellectual Disability Discuss Loneliness." *Journal of Applied Research in Intellectual Disabilities*, 19(2), 191–203,

<sup>15</sup> McVilly, K., Stancliffe, R., Parmenter, T.R., & Burton-Smith, R. (2006). Self-advocates have the last say on friendship. *Disability & Society*, 21(7), 693-708.



- 3.1.5.10 It will be useful to put in place measurement of a person's belonging in terms of a loneliness index to measure outcomes for that person.<sup>16</sup>
- 3.1.5.11 In addition to the above, it is useful to develop financial advisory support groups for people with disabilities, particularly for people with cognitive disability. These groups are already in place for people without disabilities.
- 3.1.5.12 Actively promoting health and well-being of people with disabilities is a health and social equity program at Yooralla. For example there is a dedicated health and well-being team in Yooralla. There is also an NHMRC Grant with the University of Melbourne to develop a cost effective and sustainable health-care model that a non-government service can deliver. Active promotion of health is important to prevent social isolation and to actively respond to disclosure of abuse and neglect.
- 3.1.5.13 Provide incentives to non-disability specific services such as fitness gyms, leisure and recreational activities; or local clubs to promote greater social cohesiveness. Incentives do not have to be monetary but ones that create patronage and/or increase brand prestige.
- 3.1.5.14 Establishment of customer advisory reference groups to include families and individuals with disability. For example, in Yooralla there is an Independent Advocacy Advisory Committee (IAAC) made up of people with disabilities, parents and advocacy organisations. Briefly, the role of the committee is to provide systemic advocacy advice. This advice includes feedback on organisational policies or initiatives. The Chair of the committee has direct contact with the Chair of Yooralla's Board. The role the IAAC adds a further level of transparency and scrutiny to the policies and initiatives at Yooralla.
- 3.1.5.15 Another Yooralla initiative is Speak Tank; this is a project to develop and promote people with disabilities to speak up on a range of topical issues and in varied forums (such as blogs, the Big Issue, etc) as part of a wider stakeholder engagement strategy. Another aim is to promote positive images of people with disabilities and to promote the voice of the person with disability.
- 3.1.5.16 Yooralla has a small peer support program. Peer support projects include supporting parents to network and a mentoring program. Through Yooralla's initial support and facilitation, the Parents with Disability Network is now an independent group. Through our peer mentor program, many of the participants now play an active role in promoting self-advocacy; one person is now employed, full-time, at Yooralla and has a conjoint adjunct Research Fellowship with Deakin University.

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<sup>16</sup> McVilly, K., Stancliffe, R., Parmenter, T.R., & Burton-Smith, R. (2006). 'I Get by with a Little Help from my Friends': Adults with Intellectual Disability Discuss Loneliness." *Journal of Applied Research in Intellectual Disabilities*, 19(2), 191–203,

3.1.5.17 Recognition of gender and disability, sexual orientation and gender identity is important in quality standards and safeguarding rights. Similarly, attention should also be focused on indigenous people and people from culturally linguistically diverse communities. Women and children with disabilities are particularly vulnerable to abuse and violence.<sup>17</sup> A Code of Conduct, policies and an organisational action plan to address the equity of access for these groups of people with disabilities is very important in order to reflect the diversity of the Australian population and to ensure that providers are taking proactive measures to ensure the safety and well-being of these groups of people.

3.1.5.18 Similar to the National Disability Abuse Hotline, the development of a “safeguard technology app” will be particularly useful for persons with communication disability, literacy limitations or for those who may not have a support network. This can be linked to an independent oversight body or a provider, in order for the person to send a message on matters of disclosure of abuse and/or to seek help on such matters.

### **3.1.6 Question 5: What can be done to support people with a limited number of family and friends**

3.1.6.1 Please see examples above Nos 3.1.17; 3.1.5.14 and 3.1.5.15.

3.1.6.2 Funding to target development and establishment of peer support and leadership mentoring programs and courses; these do not have to be provided by disability specific organisations.

3.1.6.3 Offering “community connections” services such as programs that are primarily aimed to link the person with local neighbourhood. Funding services that provide these social connections will be important.

### **3.1.7 Question 6: What kind of support would providers need to deliver high quality supports?**

3.1.7.1 Providers are often subject to diverse regulatory mechanisms, each with its own distinct requirements and standards. This is in addition to an independent accreditation process. A “one stop shop” approach for providers in terms of ensuring delivery of high quality supports with a single point of accountability will be productive in reducing red tape and regulatory burden.

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<sup>17</sup> United Nations’ “Some Facts on People with Disabilities”. Retrieved on April 15, 2015  
<http://www.un.org/disabilities/convention/facts.shtml>

- 3.1.7.2 Yooralla proposes that a service level of safeguards could be reduced to three standards, that is, (a) focus on governance at the organisational level; (b) equality and decision-making of the person at the individual level; and (c) a focus on community level of participation and community connectedness. And there could be sub-sets under each standard.
- 3.1.7.3 Yooralla has implemented many of the examples noted in this consultation paper. Many of the supports and initiatives are in addition to and/or above the funding provided for the person.
- 3.1.7.4 Yooralla proposes a benchmarking project in the varied domains of support delivered to the person, such as shared services; quality of behaviour support plans; critical incident data and the use of restrictive interventions to name a few. Incentives ought to be provided to providers that reach a 'gold standard' of delivery.
- 3.1.7.5 It would be very beneficial if NDIS promulgates a set of evidence based standards. Currently, there are "treatments" that have no scientific basis and, potentially, may cause harm to the person. Many of these treatments are usually in the area of autism, such as magnet therapy; rose coloured lens and facilitated communication.
- 3.1.7.6 Specific learning and development support in key areas such human rights analysis, and mandatory training on gender equity and disability, graduate courses in Positive Behaviour Support, mental illness and cognitive disability and forensic disability are critical in ensuring a qualified and experienced workforce.
- 3.1.7.7 Appropriate level of pricing and outcome-focussed costing in specialist areas such as dual disability, individuals with high and complex health-care support needs, and youth with cognitive disability at risk of criminal offending.
- 3.1.7.8 Feedback from Yooralla customers indicated that providers should be employing trustworthy people with whom a customer feels safe; there was a preference for customers being able to choose their own support people.

### **3.1.8 Question 7: Should there be an independent oversight body for the NDIS?**

- 3.1.8.1 Yes there should be an independent oversight body for the NDIS.
- 3.1.8.2 The Victorian model of Disability Services Commissioner and/or the Health Care Services Commissioner is an important starting point to consider. An independent oversight body is strongly supported by Yooralla customer feedback.

### **3.1.9 Question 8: What functions and powers should an oversight body have?**

- 3.1.9.1 The legislative functions and powers that have the ability to instigate investigations and reviews, award penalties, assist in complaints resolution and mediation, determine decisions on particular complaints, evaluate research and, most importantly, instigate positive change for health and social equity for people with disabilities.
- 3.1.9.2 It would be important that complaints resolution has a tiered approach, where, for example, a complaint, in the first instance, ought to be addressed within the provider's internal processes before it being escalated to the oversight body. The "reasonableness" test must be applied, bearing in mind the funding or pricing provided to deliver a service to the person.
- 3.1.9.3 It is crucial that the oversight body has a human rights function and the ability to undertake investigations and reviews using the CRPD and NDIS Act as the basis for the reviews.
- 3.1.9.4 The oversight body ought to have capacity to address provider's complaints, such as failure to pay for services offered.
- 3.1.9.5 The oversight body should also have oversight of the management and response of critical incidents by providers and setting the quality of assurance and evidence-base practice standards.

## **3.2 Part 2: Detail of key elements of the Quality and Safeguarding Framework**

### **3.2.1 Question 1: Considering the options described above, which option would provide the best assurance for; - Providers? – Participants?**

- 3.2.1.1 In light of evidence-based practice and within a framework of practice excellence, Yooralla supports Option 4, that is, where the registration requirement as outlined in the consultation paper in the following areas is mandatory - basic legal requirements; code of conduct; additional conditions, quality assurance and industry certification. Disability service providers already fulfil the requirements of Option 4. Other human services such as health or children services have to meet a high degree of standards. Yooralla customer feedback also supports registration of providers.
- 3.2.1.2 To reduce the level of requirements as proposed in the consultation paper will potentially diminish the quality of service provision.
- 3.2.1.3 In considering the notion of quality assurance, Yooralla proposes that quality is outcome-focussed with the emphasis on "rights, well-being and safety".

- 3.2.1.4 The suggested focus (in 3.2.1.3) articulates the possibilities and life opportunities of people with a disability, thus acting as an agenda for social change agenda in the community.
- 3.2.1.5 There is, therefore, a sharper focus on inclusion, equity and self-determination – all values that are consistent with the CRPD and contemporary models of service delivery.
- 3.2.1.6 It guides practice and quality improvement.
- 3.2.1.7 It assists the organisation in assessing its effectiveness of and accountability for the practices, services and strategies it delivers.
- 3.2.1.8 Outcomes are multi-dimensional and are similar to quality of life indicators. These outcomes have subjective (e.g. “self-report”) and objective components (e.g. “direct observation”). Objective measures of life circumstances and experiences results in better predictors of outcomes related to choice, constructive activities, social and community well-being.<sup>18</sup>

Outcome	Domain - examples	Indicators to measure- examples
<b>Rights</b> (e.g. To have control and choice, and make decisions)	Self-determination	<ul style="list-style-type: none"> <li>• Personal control</li> <li>• Attainment of personal goals</li> <li>• Choices and decision-making</li> </ul>
	Personal development	<ul style="list-style-type: none"> <li>• Education status</li> <li>• Personal skills, including optimal communication.</li> </ul>
	Access to justice	<ul style="list-style-type: none"> <li>• Awareness of legal rights</li> <li>• Legal access</li> <li>• Respect, dignity and equality</li> <li>• Political contribution</li> </ul>
<b>Well-being</b> (e.g. To be healthy and lead a fulfilled life)	Emotional well-being	<ul style="list-style-type: none"> <li>• Contentment and positive experiences</li> <li>• Self-concept and identity – including choice and control</li> <li>• Prevention from stress</li> <li>• Family stress reduction</li> <li>• Family cohesion</li> </ul>

<sup>18</sup> Schalock, R.L., Gardner, J.F., & Bradley, V.J. (2007). Quality of life for people with intellectual and developmental disabilities: Applications across individuals, organisations, communities, and systems. Washington, DC: AAIDD.

	Physical well-being	<ul style="list-style-type: none"> <li>• Health-care and nutrition status</li> <li>• Leisure and recreation</li> <li>• Social participation in activities of daily living</li> </ul>
	Material well-being	<ul style="list-style-type: none"> <li>• Financial status, income protection</li> <li>• Employment status</li> <li>• Housing status and residential setting</li> <li>• Personal possessions</li> <li>• Transport availability</li> </ul>
<b>Safety</b> <b>(e.g. To feel safe and participate meaningfully in the community)</b>	Interpersonal relationships	<ul style="list-style-type: none"> <li>• Family and social networks</li> <li>• Friendships, and relationships</li> <li>• Neighbourhood interactions</li> <li>• Sense of security</li> <li>• Prevention from abuse</li> </ul>
	Social inclusion	<ul style="list-style-type: none"> <li>• Community connectedness, e.g. social participation, social contribution</li> <li>• Local and family supports</li> <li>• Social supports</li> </ul>

3.2.1.9 The research suggests that certain characteristics, environmental variables and service provider characteristics significantly predict better quality of life outcomes.<sup>19 20</sup> Some of these characteristics are:

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<sup>19</sup> Schalock, R.L., Bonham, G.S., & Verdugo, M.A. (2008). The conceptualization and measurement of quality of life: implications for program planning and evaluation in the field of intellectual disabilities. *Evaluation and Program Planning*, 31, 181-190.

<sup>20</sup> Schalock, R.L., Gardner, J.F., & Bradley, V.J. (2007). *Quality of life for people with intellectual and developmental disabilities: Applications across individuals, organisations, communities, and systems*. Washington, DC: AAIDD.

- 3.2.1.9.1 Personal characteristics – health status, communication ability and the support needs level.
- 3.2.1.9.2 Environmental variables – perceived personal supports, type of residential setting, participation in household activities, transportation availability, income and integrated activities.
- 3.2.1.9.3 Service provider characteristics – leadership, work stress score, satisfaction working with client, staff attention, and job satisfaction.
- 3.2.1.10 **For providers, consideration for quality assurance should emphasise on**
- 3.2.1.11 how we can enhance health and support needs, and be sensitive to the changing support needs of a person, such as a person with a progressive neurological condition
- 3.2.1.12 developing or facilitating social supports, more independent and productive environments
- 3.2.1.13 increasing community involvement = collective impact strategy
- 3.2.1.14 maximising work environments – happy and healthy staff = better outcomes for clients.

**Some simplified examples of items within a particular indicator:**

- 3.2.1.15 **Rights: self-determination – choices**
- 3.2.1.16 Subjective (self-report): “Are you offered choices everyday (e.g. what to wear, what to eat, places to visit) on a scale of “yes, not sure, no” or a four or five point likert scale.
- 3.2.1.17 Objective (direct observation): “To what degree is the person offered choices as to what to eat etc” or “To what degree is the person offered choices as to how the person exercises choice” or “Do you have and operate the technological aids, communication devices and equipment to make choices?” This could be assessed on a scale of “considerable, some, little or none”.
- 3.2.1.18 **Well-being: material well-being indicator**
- 3.2.1.19 Subjective (self-report): “Do you have personal possessions such as a radio, TV, etc?” On a scale of “yes, not sure, no”.
- 3.2.1.20 Objective measure (direct observation): “How many personal possessions does the person have?” On a scale of “considerable, some, little or none”.

### 3.2.1.21 **Safety: interpersonal relationships – friendships**

3.2.1.22 Subjective (self-report): “Do you have friends (other than your housemates)?” On a scale of “yes, not sure, no”.

3.2.1.23 Objective measure (direct observation): “Has the person identified persons as friends and refers to them as such (other than the housemates)?” On a scale of “yes, not sure, no”.

## 3.2.2 **Question 2: Should the approach to registration depend on the nature of the service?**

3.2.2.1 No. It is important to maintain a level of uniformity and consistency, and a fundamental set of expectations. Regardless of the nature of the service, there ought to be consistent standards and requirements. Current topical issues such as poor practices of financial planners, trade professionals and in the building industry show that a minimum requirements for registration can potentially lead to a negative or at worst, a deleterious effect.

3.2.2.2 The research literature of treatment for persons with autism is a good example of how individuals and families can be susceptible to practices and services that are not grounded on research evidence, and most importantly, exposes the person to harm and/or causes harm to the person. Furthermore, many of these practice and treatment approaches breach the rights of the person.

3.2.2.3 The suggestion for Code of Conduct compliance has merit, however it is limiting. The examples used pertain to personal assistance. People with disabilities have health related support needs that can require intrusive procedures. This is one of the many types of support needs that have not been given sufficient attention in this consultation paper.

3.2.2.4 The underlying assumptions of a ‘market economy’ are that there is a wide range of choice offered for services in every regional area, a constant supply of professionals and direct support workers in the workforce with experience and knowledge, and that the population of people with disabilities are homogenous. These assumptions are not correct.

3.2.2.5 As such, Yooralla reiterates the importance of registration for all providers.

## 3.2.3 **Question 3: How can the right balance be reached between providing assurance and letting people make their own choices?**

3.2.3.1 It is not necessarily the case that providing assurance and letting people make their own choices are mutually exclusive goals. People can make choices but not within a vacuum. For example, it



should be assumed that people with cognitive disability can make decisions and be supported to make decisions. The more important question is how they are supported to make decisions and the development of their capacity and capability. And whether the right skills, values and contemporary practice are in alignment with the NDIS Act and CRPD.

- 3.2.3.2 As such, an immediate and considerable focus must be given to workforce development to ensure there are professionals and support workers who can meet the requirements of rights, well-being and safety.
- 3.2.3.3 A fundamental starting point is to reiterate the right of the person to have the mental capacity to make day-to-day decisions; especially for persons with a severe level of cognitive disability and/or multiple disabilities.

#### **3.2.4 Question 4: How important is it to have an NDIS complaints system that is independent from providers of supports?**

- 3.2.4.1 It is very important to have an NDIS complaints system that is independent from providers of supports. However, it is important to ensure providers are not burdened with layered and excessive regulation in responding to complaints. For example, providers in Victoria are subject to several layers of oversight and scrutiny. These are usually resource intensive and, at times, fosters duplication of effort. For example, there are the provider's own internal audits, accreditation processes with its mid-term cycle reviews, departmental site visits, reporting of critical incidents and "quality of service" reviews. These are in addition to responding to reports from Community Visitors, conducting internal investigations into complaints and responding to the Disability Services Commissioner's enquiries and formal complaints process.
- 3.2.4.2 As mentioned before, it is recommended that complaints are tiered and focussed on the customer experience to achieve immediate resolution.
- 3.2.4.3 Yooralla customers promote the notion of a tiered peer support model in identifying and reporting complaints, and promptly resolving complaints.

#### **3.2.5 Question 5: Should an NDIS complaints system apply only to disability-related supports funded by the NDIS, to all funded supports, or to all disability services regardless of whether they are funded by the NDIS?**

- 3.2.5.1 It should apply to all funded services. This is important in ensuring consistency and uniformity of quality standards. An unintended implication and perception of the different application of an

NDIS complaints systems to one group versus another (i.e., disability-related) is the notion of segregation; this is contrary to inclusion and this same principle should be applied to all supports.

- 3.2.5.2 Yooralla customer feedback emphasises the importance for not-for-profit and for-profit providers to be registered and insured, as they strongly believe that registration will enhance the quality of service and improve the ease of access. Registration should also apply to advocacy groups.

### **3.2.6 Question 6: What powers should a complaints body have?**

- 3.2.6.1 The Victorian Disability Services Commissioner is a very good model that could be adapted.
- 3.2.6.2 It is reasonable to consider the oversight body of NDIS merging with a complaints body.
- 3.2.6.3 The Victorian Health-Care Services Commissioner has particular functions that can be adapted, such as being able to mediate and/or call for the provider to take immediate action or determine the complainant's issues as closed or without merit. In the current complaints handling system, providers are often burdened with on-going complaints from a small group of complainants whose issues are on-going and who are unlikely to be satisfied even with the offering of another provider. Some of these issues relate to funding, an issue that a provider is not going to be able to address.

### **3.2.7 Question 7: Should there be community visitor schemes in the NDIS and, if so, what should their role be?**

- 3.2.7.1 Yes. The Victorian Community Visitors and the Office of the Public Advocate is a very good model that should be adapted for the NDIS framework.
- 3.2.7.2 It is important to maintain the voluntary nature of Community Visitors.
- 3.2.7.3 Community Visitors have a role in safeguarding rights at the community level. Their independence acts as another measure of safeguarding rights. An important characteristic of the Community Visitor (CV) scheme is that the CV is a 'lay-person' and as such, adds the additional lens of viewing issues and monitoring issues as an ordinary citizen. Yooralla's experience of the Community Visitors in Victoria has been positive, transparent, collegiate and outcome-focussed on the person(s).

### **3.2.8 Question 8: Who should make the decision about whether employees are safe to work with people with disability?**

- 3.2.8.1 The Queensland state Positive Notice Card and the Victorian Disability Workers Exclusion Scheme are good models. Such a scheme will benefit from a legislative framework. As it is mainly administrative, this function can be within an administrative body.
- 3.2.8.2 It should also apply to temporary staffing agency providers.
- 3.2.8.3 Yooralla customers stress the importance of such a scheme.

### **3.2.9 Question 9: How much information about a person's history is required to ensure they are safe to work with people with disability?**

- 3.2.9.1 All the information required for a police check and working with vulnerable persons checks should apply.
- 3.2.9.2 It is particularly important to add that the information should be similar to the Victorian Disability Worker Exclusion Scheme that assists providers to exclude the employment of persons based on serious allegations raised, prior to any formal charges being laid. The serious allegations should include allegations of sexual assault, severe physical assault resulting in medical attention and financial abuse that are also reported to the Police.

### **3.2.10 Question 10: Of the options described above, which option, or combination of options, do you prefer?**

- 3.2.10.1 Police check and working with vulnerable persons check should apply if supports and services are from a provider or an individual providing support. See 3.2.11.1.

### **3.2.11 Question 11: 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?**

- 3.2.11.1 The international research evidence on abuse (whether it is in the context of elder abuse, child abuse or disability abuse) highlights that perpetrators of abuse are most likely the person(s) most

familiar or in close contact with the individual receiving support. The perpetrators can be both paid and unpaid carers.<sup>21</sup>

- 3.2.11.2 Therefore, the issue of safeguarding at recruitment is important but is effective only when the potential perpetrator has a criminal record; as such police checks have limited effect and value at recruitment. Hence the Queensland and Victorian models of working with vulnerable persons check are important at the point where allegations should be made known to providers.
- 3.2.11.3 Much of the literature in abuse indicates abuse usually occurs over time. Therefore the more effective consideration is on monitoring of the workers and focus on building and developing a rights-based workforce culture. The research literature in abuse prevention indicates that the most effective models are at the level of primary level of prevention, such as self-advocacy; power and control in their lives and speaking up; eliminating social exclusion and isolation in the community; and a stronger network of belonging (like families and friends).
- 3.2.11.4 At the organisational level, providers have to create and maintain a positive workforce culture that respects, protects and fulfills the rights of people with disabilities. There ought to be accompanying and appropriate governance structures and systems to be able to identify and report, and respond to disclosures of abuse.
- 3.2.11.5 Yooralla customer feedback reiterates the importance of police checks and similar safeguarding mechanism to ensure that the staff employed are safe, particularly in residential services.

### **3.2.12 Question 12: What kind of assistance would be most valuable for people wanting to manage their own supports?**

- 3.2.12.1 At the developmental level, fundamental life skills such as budget management; leadership and negotiation; and speaking up programs are important for people with cognitive disability. A support service that people with disabilities can go to for advice or problem-solving on day-day issues would be valuable.
- 3.2.12.2 Brokerage to manage administrative and/or financial assistance may be beneficial.
- 3.2.12.3 Yooralla customers feedback recommends having a written guide and a program to teach people entering the NDIS scheme on how to manage their funds. They are of the view that NDIS should not assume people know how to manage their funds and that NDIS should have systems and processes that seek to protect them from financial abuse.

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<sup>21</sup> Fitzsimons, N.M. (2009). Combating violence and abuse of people with disabilities: A call to action. Baltimore: Paul H. Brookes.

3.2.12.4 Customer feedback also comments that individuals and small businesses should have the same safeguards as larger providers, and there should be a guide for the employment of staff. They also indicated that self-managed funds should be goal-oriented, have capacity to track the goals and for the goals to be monitored. This is to ensure that they are getting value for their money.

### **3.2.13 Question 13: Who should decide when restrictive practices can be used?**

3.2.13.1 The Victorian Senior Practitioner model is a very good model to emulate. However, the independence of the practitioners ought to be strengthened as an independent Governor-in-Council appointment. The focus on legislative compliance, promoting practice change, treatment and research are critical for its effectiveness. Yooralla customer feedback strongly endorses the Victorian model or some similar model.

3.2.13.2 Yooralla strongly advocates for a national approach to the safe elimination of restrictive practices, including reporting; monitoring and undertaking reviews. As such, Yooralla proposes a national role of Chief Practitioner to oversight the compliance, practice change, clinical oversight and research in the area of restrictive interventions.

3.2.13.3 It is reasonable to consider the merger of a national Chief Practitioner role with that of a national disability complaints body, as many of the complaints and incidents do relate to restrictive interventions.

3.2.13.4 The success of the Victorian model has been well-researched.<sup>22 23 24 25 26 27</sup>

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<sup>22</sup> Chan, J., Webber, L., & French, P. (2014). The importance of safeguarding rights and the role of legislation: The Australian perspective. In S. Karim, (Ed.). *A human rights perspective on reducing restrictive practices in intellectual disabilities and autism spectrum disorders*. Birmingham: British Institute of Learning Disabilities.

<sup>23</sup> Webber, L., Chan, J., & French, P. (2014). Best practices in Australia in the use of restraint reduction practices for people with intellectual disabilities and autism spectrum disorders. In S. Karim, (Ed.). *A human rights perspective on reducing restrictive practices in intellectual disabilities and autism spectrum disorders*. Birmingham: British Institute of Learning Disabilities.

<sup>24</sup> Chan, J., LeBel, J., & Webber, L. (2012). The dollars and sense of restraints and seclusion. *Journal of Law and Medicine*, 20, 73–81.

<sup>25</sup> Rickard, E.D., Chan, J., & Merriman, B. (2013). Issues emanating from the implementation of policies on restraint use with people with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 10(3), 252-259.

<sup>26</sup> Chan, J., & Webber, L. (2013). Key strategies that lead to restraint and seclusion reduction: A four year study of the use of restrictive interventions in Victoria, Australia. *Journal of Policy and Practice in Intellectual Disabilities*, Abstracts for the 3rd IASSIDD Asia-Pacific Conference, 10(2), 110.

<sup>27</sup> Webber, L., McVilly, K., & Chan, J. (2011). Restrictive interventions for people with intellectual disability exhibiting challenging behaviours: analyses of a population database. *Journal of Applied Research in Intellectual Disabilities*, 24(6), 495-507.

3.2.13.5 There are few key elements that are the hallmarks of the Victorian model, namely; (a) the person with a disability can appeal against the use of restrictive intervention, (b) guardianship is not the appropriate role to approve and consent to restrictive interventions and that this is best done by the provider in the form of an authorised program officer so as to ensure the provider takes ownership in eradicating the use of restrictive interventions; (c) mandatory reporting of use of restrictive interventions and the use of data to inform practice change and reform; (d) legislative power to declare “other restrictive practices/interventions”; (e) the role of the chief practitioner having the ultimate clinical decision-maker role and (f) annual reporting of the data to inform reform and practice change.

### **3.2.14 Question 14: What processes or systems might be needed to ensure decisions to use restrictive practices in a behaviour support plan are right for the person concerned?**

3.2.14.1 See the Victorian Senior Practitioner model. The National Framework for Reducing and Eliminating the use of Restrictive Practices in the Disability Service Sector is another pertinent model to consider, though it is very similar to the Victorian model.

3.2.14.2 Ensure that the quality of behaviour support plans is at best practice standard based on the research evidence.<sup>28 29</sup> Yooralla instigated an independent review of the quality of behaviour support plans of persons subjected to restrictive interventions using the international best practice tool called the Behaviour Support Plan, Quality Evaluation Tool II<sup>30 31</sup>. The review was undertaken by Deakin University. Recommendations of the review led to a series of actions such as the establishment of the Practice Excellence Group to monitor the quality of behaviour support plans and advise on restrictive intervention reduction strategies. The results have now led to an increase in the quality of the behaviour support plans. The monitoring of restrictive interventions data in March 2015 showed that the restrictive practice of seclusion has been

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<sup>28</sup> Webber, L., McVilly, K., Fester, T., & Chan, J. (2011). Factors influencing the quality of behaviour support plans and the impact of quality of BSPs on the use of restrictive interventions in disability services in Australia. *International Journal of Positive Behavioural Support*, 1(1), 24-31.

<sup>29</sup> Webber, L., Richardson, B., Lambrick, F., & Fester., T. (2012). The impact of the quality of behaviour support plans on the use of restraint and seclusion in disability services. *International Journal of Positive Behavioural Support*, 2(2), 3–11

<sup>30</sup> McVilly, K., Webber, L., Paris, M., and Sharp, G. (2012). ‘Reliability and utility of the Behaviour Support Plan Quality Evaluation tool (BSP-QEII) for auditing and quality development in services for adults with intellectual disability and challenging behaviour’, *Journal of Intellectual Disability Research*, DOI: 10.1111/j.1365-2788.2012.01603

<sup>31</sup> McVilly, K., Webber, L., Sharp, G., and Paris, M (2013).The content validity of the Behaviour Support Plan Quality Evaluation tool (BSP-QEII) and its potential application in accommodation and day support services for adults with intellectual disability’, *Journal of Intellectual Disability Research*, DOI: 10.1111/j.1365-2788.2012.01602.x

eliminated across the organisation. Furthermore, a few individuals have also ceased the need for PRN chemical restraints and mechanical restraints.

- 3.2.14.3 Yooralla partnered with the Victorian Senior Practitioner to initiate an independent comparative analysis (benchmarking) on the use of restrictive interventions against the state data. The independent review by Deakin University indicated that Yooralla provides services to people with high and complex support needs (such as those with psychiatric disorders, communication impairment and people with autism) higher than the state average (including the Department of Human Services and non-government service providers). This initiative has the potential to be expanded to a national benchmarking project.

### **3.2.15 Question 15: Are there safeguards that we should consider that have not been proposed in these options?**

- 3.2.15.1 At the developmental level (at the individual level), it would be useful to include primary level of interventions on safeguarding rights at the level of the community and to promote social inclusion. This suggestion has already been discussed in this submission.
- 3.2.15.2 A focus on building communication ability, confidence and competence would be another suggestion. Technology now enables people who have never had independence in communication to develop that ability. The self-advocacy programs can now incorporate a much wider range of views if people are given access to and training and support for the use of appropriate communication technology.
- 3.2.15.3 Yooralla suggests the following oversight body and positions for consideration.
- 3.2.15.4 The establishment of a national Commissioner of Safeguarding Rights in Disability. The statutory body will have the full legislative functions and powers similar to the Disability Services Commissioner and that of the Victorian Health-Care Services Commissioner. The body will have the powers to investigate a disclosure of abuse and have carriage of abuse prevention strategies, including research in this area.
- 3.2.15.5 The establishment of a national Chief Practitioner and Deputy Commissioner as a single role in the area of reporting, monitoring and leading positive change for the elimination of restrictive interventions; and oversight of critical incidents. The role will carry similar legislative functions and powers, including mandating research in this area. Another function that is important for this role would be the oversight of providers' management and response to critical incidents, and the monitoring and reporting of national data on restrictive interventions and critical incidents.
- 3.2.15.6 The establishment of a national Chief Advisor, Quality and Standards. This role will be part of the office of the Commissioner of Safeguarding Rights in Disability. It is critical that this role leads

and sets the standards, based on the research evidence, to determine what services and products should be funded. The role will lead evidence-based research and set the agenda for innovation in the sector. In other industries, there is significant investment in quality and standards, and research. Examples include CSIRO, National Institute of Clinical Excellence in the UK and other similar established offices or bodies. There is a gap in disability services in Australia in a national approach to quality assurance and research investment.

- 3.2.15.7 Yooralla has invested in a significant ICT strategy and implemented the RiskMan reporting system. Yooralla has further developed the 'off-the-shelf' RiskMan system to include root cause analysis and development of action plan strategy, and on a real-time response capability to every single incident.
- 3.2.15.8 A greater focus on persons who present with high and complex support needs, particularly for those who are at risk of being in contact with the criminal justice system, those who require justice-based diversionary supports and those who are in the criminal justice system.
- 3.2.15.9 There are also many people with mild cognitive disability who may not identify themselves as having an intellectual disability.<sup>32</sup> Often these individuals are not identified when they come in contact with the criminal justice system and many may not seek disability services. As such, many of these individuals fall between the 'safety net'. It is important for NDIS to give direction in this area.
- 3.2.15.10 The development of a national qualification and credentialing 'passport' to demonstrate evidence of specific experience and skill competencies (e.g. Vulnerable Person Police Checks, First Aid, Positive Behaviour Support, Safe Lifting etc) for direct support workers that can be shown to providers and persons with disabilities who self-manage.
- 3.2.15.11 It is recommended that the Australian Human Rights Commission and each State and Territory Equality & Human Rights statutory body be collectively commissioned to report, biannually, on indicators of inclusion and empowerment of people with disabilities against the Convention that the NDIS legislation has a key foundation.
- 3.2.15.12 It is recommended that the role of the Public Advocate be maintained and strengthened.
- 3.2.15.13 It is recommended that NDIS could provide leadership by promoting the sharing of best practice and evolving evidence amongst and within providers.

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<sup>32</sup> <http://wwild.org.au/families-carers-support-workers1-2/legal-professionals/identifying-intellectual-disability-or-impairment.html>



**3.2.16 Question 16: For providers, what kinds of support are you receiving now from state and territory departments that you think would be helpful if it was available under the NDIS?**

- 3.2.16.1 Clarification on funding for specialist services that include disability nursing and advocacy functions. There is a disconnect between mainstream services such as health and mental health that are augmented by certain providers, such as health and well-being nursing for those individuals with high health-care support needs.
- 3.2.16.2 Urgency for a determination regarding changing support needs, particularly individuals with progressive neurological conditions or those with a fluctuating health-care status.
- 3.2.16.3 Current receipt of DHS and DSS funding for contribution toward the cost of the yearly and three yearly Independent Reviews and Accreditation.
- 3.2.16.4 Current State funding for the clinical assessment and support for admission into a new residential service.
- 3.2.16.5 State funding being allocated for particular services such as therapy, advocacy, staffing, rehabilitation, prevention and monitoring of physical health status (e.g. contractures), and day-to-day essential services for persons using a wheelchair.
- 3.2.16.6 One-off project grant to promote disability awareness, for example, the ACE DisAbility Network.
- 3.2.16.7 Funding for advocacy services.

**3.2.17 Question 17: Would you support mandatory reporting on the use of restrictive practices? Why/Why Not?**

- 3.2.17.1 There ought to be mandatory and legislative reporting of restrictive practices as this is a requirement in Articles 13, 14, 15 and 16 of the CRPD. Furthermore, if a restrictive practice is being used; it should be authorised by law. Hence it is important to have a legislative framework.
- 3.2.17.2 As mentioned before, abuse does not occur in a vacuum. Restrictive practices, in the form of seclusion, chemical restraints or psychological restraints are abuse in its most basic form. While it is not envisaged that such practices should be immediately reportable; it is very important to focus on a positive culture that prevents the development of poor practice. These poor practices can escalate.

3.2.17.3 The CRPD mandates the use of data to inform and monitor the application of the CRPD. The Victorian Senior Practitioner model has a significant population-based data that should be continued and enhanced so that Australia can report on its compliance with the CRPD.

**3.2.18 Question 18: If you support mandatory reporting on the use of restrictive practices, what level of reporting do you believe should occur (based on one, or a combination of, the options above?)**

3.2.18.1 All three options as per the current practice in Victoria should be applied. To “water it down” is to diminish the safeguarding rights of people with disabilities. Australia cannot afford to wind back the significant measures implemented in Victoria, Queensland and Tasmania, as these approaches are consistent with the CRPD and the NDIS Act.

3.2.18.2 In fact, these safeguarding approaches in Victoria and Queensland ought to be strengthened and sharpened.

3.2.18.3 Victoria has population data in this area of reporting and to cease or limit its continuity will be a backward step in rights protection of people with disabilities.

3.2.18.4 More importantly, Australia is signatory to the CRPD and the Optional Protocol, hence Articles 13, 14, 15 and 16 should be enlivened within an NDIS context.

3.2.18.5 Australia has led the way internationally in the area of reduction of restrictive interventions in disability services. This momentum should continue in light of the CRPD.

## 4 Conclusion

4.1 Yooralla supports in principle the general framework of the NDIS consultation paper on quality and safeguarding rights. The consultation paper provides pertinent quality and safeguarding recommendations. There are areas in this consultation paper that require clarification and aspects of the framework that can be strengthened and enhanced.

4.2 This consultation paper will benefit from a further clarification that is more inclusive of the voice of people with cognitive disability and/or with multiple and complex support needs. It is also important that there are many people with disabilities who present with changing support needs due to their progressive medical condition and/or deteriorating health condition. From Yooralla’s experience, more than 80 percent of Yooralla customers present with high and significant levels of support needs.

- 4.3 There should be investment in building and strengthening self-advocacy, and empowering individuals to exercise their rights and speak up for themselves. Empowerment of the person must be matched with effective oversight and monitoring bodies, independent of NDIS.
- 4.4 The roles of families and advocacy, at the individual level, are important in developing and maintaining natural support networks.
- 4.5 Yooralla has provided some practical suggestions to many of the questions posed in this consultation paper, such as streamlining and simplifying registration and accreditation process; objective and subjective measures of quality of life and strengthening self-advocacy at the organisational level. Yooralla has also provided some examples of its own experiences in building self-advocacy and disability abuse prevention, improving the quality of behaviour support plans and the implementation of strategies to reduce restrictive interventions.
- 4.6 Yooralla proposes an independent body with oversight of complaints management and resolution, providers' management and response to critical incidents, and the leading and setting up quality assurance and standards. Yooralla proposes the following roles to meet these core functions: a Commissioner of Safeguarding Rights in Disability, a Chief Practitioner and Deputy Commissioner, and Chief Advisor, Quality and Standards.
- 4.7 Yooralla will be keen to share our learning and assist in the significant work of the NDIS in this landmark Australian social reform.
- 4.8 Yooralla wishes the NDIS to recognise the costs associated with putting in place quality and safeguard measures and hopes that implementation of such measures is supported by the availability of adequate resources. ■