Submission to the National Disability Insurance Scheme

Proposed Quality and Safeguarding Framework for the NDIS

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About the Chair in Intellectual Disability Behaviour Support

The Chair in Intellectual Disability Behaviour Support (IDBS) was established at UNSW in April 2014 through funding provided by the NSW Department of Family and Community Services, Department of Ageing, Disability and Home Care (ADHC). The Chair forms part of the NSW Government's efforts at providing better services that meet the individual needs of people with intellectual disability with complex support needs. The Chair oversees a program of work which aims to develop capacity in the Australian context to ensure that people with intellectual disability and complex support needs have a framework of service supports that enable them to fulfill their potential as equal citizens in an inclusive Australian society.

The work of the IDBS program centers on the following:

- Collaborative relationships with key academic, government and sector agencies both nationally and internationally;
- Development and delivery of courses in support for people with intellectual disability who have complex support needs and behaviours of concern;
- Research programs contributing to the development of improved support practices for those with intellectual disability and complex support needs across the sector; and
- Address knowledge deficits within the Australian and international context.

The IDBS Program Team is made up of the following personnel:

Associate Professor Leanne Dowse – Chair

Dr Michele Weise – Consultant

Dr Angela Dew – Research Fellow

Dr Louisa Smith – Lecturer

Dr Susan Collings – Research Associate

Dr Aminath Didi – Program Manager

1. INTRODUCTION

The team comprising the Intellectual Disability Behaviour Support (IDBS) Chair at the University of New South Wales appreciates the opportunity to offer comment on the *Consultation paper for a Proposal for a National Disability Insurance Scheme Quality and Safeguarding framework*.

The comments offered in this submission are made with particular reference to individuals with intellectual disability and complex support needs who may require positive behaviour support. People with complex support needs are understood as those who have multiple interlocking experiences and factors that span disability, health/mental health, behavioural and social issues over the life course. Individuals with complex support needs face significant vulnerability to marginalisation and disadvantage within the service system and in the community.

The response is based on the following key premises:

- Quality and safeguarding for vulnerable people is a human rights issue. Cost-saving arguments should not be a deciding factor in any decisions regarding the content and operation of the framework.
- The aim of a quality and safeguarding framework should be to enhance service quality, maximise safety, optimise professional behaviour and ensure freedoms of human rights.
- The sector needs national consistency in quality and safeguarding data collection.

The response provided in the following pages corresponds to the sections comprising the consultation paper.

2. GLOSSARY OF TERMS

2.1 The definition of "challenging behaviour" utilised in the proposed framework is outdated. Emerson's definition of challenging behaviour might be replaced by a more contemporary and frequently used reference in the international literature; that offered by Banks, co-chair of the Royal College of Psychiatrists: "behaviour…of such an intensity, frequency or duration as to threaten the quality of life and/or physical safety of the individual or others and is likely to lead to responses that are restrictive, averse or result in exclusion" (Royal College of Psychiatrists British Psychological Society and Royal College of Speech and Language Therapists, June 2007, p. 10).

2.2 No definition is provided as to what constitutes "behaviour support". We propose that this is critical as it offers a benchmark for practice, not least because it underpins the key aim of the framework in the reduction and elimination of restrictive practices. Any definition should include the recognition that behaviour support is qualitatively different in nature from the ways other support types are conceived in the NDIS. Specifically the recognition that behaviour support is not a single product (as exemplified by the Behaviour Support Plan), nor a service (such as clinical consultation) but rather is an outcome focused support comprising a range of actions and products. Importantly, there is the need for a clear understanding of the continuum of behaviour support practice, which varies in degree and intensity from fundamental to complex, the aim of which is to facilitate safety, quality of life and social inclusion. The articulation of this framework for behaviour support as it applies to both the NDIS catalogue of supports and in the Information Capacity Building and Linkages framework is currently a significant shortcoming.

2.3 The definition of "positive behaviour support plan" utilised in the proposed framework is very general and therefore its utility in guiding and benchmarking practice is tenuous. In order to ensure the definition is fit for purpose it would need to make specific mention of the key features of the behaviour support planning process which has been identified to include: functional assessment, educational procedures, system change, multi-component, ecological validity, long-term sustained support, social validity (Carr & Horner, 2007; Dunlap et al., 2010; Emerson & Einfeld, 2011; Luiselli, Bass & Whitcomb, 2010; McVilly, 2002). Further, the current definition suggests that only adults have challenging behaviour, when the research is clear that behaviours of concern can occur across the life span.

2.4 No distinction is made between restrict*ive* and restrict*ed* practices. This may be important given the evidence that policy and research literature also use these terms interchangeably (NSW Government Human Services Ageing, June 2010). If not addressed, there is potential for confusion in the longer term. Our understanding is that *restrictive* is the umbrella term, and *restricted* is used to refer to those procedures which have clearly defined parameters around their use (e.g. physical restraint, PRN psychotropic medication) (Office of the Senior Practitioner Ageing Disability and Home Care Department of Family and Community Services NSW, March 2012). We

suggest that the framework document should clearly enunciate the distinction, or at least acknowledge that there is confusion, and then clarify a position.

3. RESPONSE TO PART ONE: PROPOSED QUALITY AND SAFEGUARDING FRAMEWORK FOR THE NDIS

3.1 The framework rightly emphasises developmental and preventative domains (pp. 11-12), and is also responsible in recognising the need for a corrective component (p. 12). The sector's reliance on the disability workforce as the change agents means inevitability that human error is a key contingency and that mistakes will be made. Therefore, a safeguard that provides corrective action is imperative. The role of independent advocacy in this domain is a key un-articulated issue.

3.2 While we understand the logic of premising a quality and safeguarding approach on a risk-management model, we remain wary that this results in continued de-emphasis of positive behaviour support and its central importance as a key support type for people with intellectual disability and complex support needs. In real terms, the absence of a clearly articulated framework of the continuum of 'behaviour support' which itself traverses developmental, preventative and corrective domains risks a continuation of the current approach, wherein risks are managed by precipitous resort to restricted practices (where these are currently applied routinely rather than as a last resort), with limited due diligence to the real work of positive behaviour support (Chan, Webber, & Hayward, 2013; Webber, McVilly, & Chan, 2011). The ways these are articulated and benchmarked in behaviour support plans themselves requires consideration as an oversight function of the NDIA.

Response to developmental domain

3.3 Achievement of developmental aspects relates to the participant's capacity to access information. The developmental domain aims to provide structures so that NDIS participants can build knowledge and their own ability to safeguard (p. 11). This capacity may be compromised for people with intellectual disability and complex support needs who often experience marginalisation within their families and communities and within the service system itself. For this

group particular attention needs to be paid to the way this domain is built and the key role of independent advocacy as an element of its function more clearly articulated.

3.4 We remain concerned about the quality and safeguarding framework's lack of acknowledgement of the very particular needs of those with intellectual disability and complex support needs. The developmental domain, perhaps naively, places great emphasis upon the use of mainstream and natural supports (p. 15). Those who, "may be isolated and have no natural supports" (p. 15) *are* those with complex support needs, and they are often isolated without natural supports *because* of their complexity. As well the reverse is true - isolation and lack of natural supports *exacerbates* complex support needs. Reliance on connecting these participants to mainstream and natural supports denies the nature of their complex support needs. It also ignores the reality that a) there is very little mainstream or natural supports available, and b) mainstream and natural supports have little expertise in assisting participants with intellectual disability and complex support needs. Further, the research suggests that although the presence of natural supports correlates with increased opportunity for social inclusion (Randell, 2009), and are therefore an important ingredient, they cannot be relied upon as a fundamental structural support (Mansell & Beadle-Brown, 2009). Instead natural supports should be treated as augmentative and the need for access to independent advocacy should be recognised as a very likely contingency for this group.

3.5 Given the above there is a clear implication and relationship to the NDIS Information, Linkages and Capacity Building Framework. It cannot be assumed that mainstream and natural supports are present for, or currently inclusive of, people with intellectual disability and complex support needs. Indeed evidence suggests that this group (including people with mild intellectual disability) will more likely be accessing mainstream than specialist services, but very often unsuccessfully. This points to the need for efforts directly targeted at building capacity within services including those related to health, mental health, housing, child protection, criminal justice, drug and alcohol and other aspects of social care provision in engaging and responding to those with intellectual disability and complex support needs. This would include both awareness of the continuum of behaviour support practice and the need for clear guidelines and pathways for referral to specialist support services as a key mechanism for addressing safety of individuals and quality of service.

Response to preventative domain

3.6 Similar to the developmental domain there is continued limited understanding of the needs of those with complex support needs. There is evidence of continued heavy reliance on the mainstream and natural support structures (see *3.5* previously), and those with intellectual disability and complex support needs are potentially very vulnerable with this reliance.

3.7 An important feature of the preventative domain is the reduction and elimination of restrictive practices (see also our response to Part 2: Detail of key elements of the Quality and Safeguarding Framework). While we fully support the aim of eliminating restrictive practices, to do so without commensurate workforce up-skilling in quality positive behaviour support would be both unethical and difficult to achieve. Evidence from the UK experience is instructive here – whereby post-Winterborne View there have been moves to re-regulate, particularly in terms of making training in Positive Behaviour Support compulsory for all direct support workers in adult disability services. This is very different to the relatively ad-hoc approach to workforce capacity building, skill development and benchmarking in behaviour support planning and practice currently operating differently in the various jurisdictions in the Australian service landscape. Since there is strong research evidence that restricted practices are being implemented not as the intended last resort, and in the absence of positive behaviour support plans (Wastell, Skirrow, & Hare, 2015; Webber et al., 2011) we strongly advocate that the sector must address the latter before removing the former.

3.8 We suggest that achievement of preventative aspects will only be accomplished with a co-occurring commitment to workforce development and maintenance; i.e. the sector can only deliver "high quality supports" (p. 12) if it has a quality workforce. This would include attention to developing and maintaining a skilled specialist behaviour support practitioner workforce who are trained and supported to develop and implement behaviour support plans, as well as a strategy to ensure that direct support workers have foundational skills and capacity in behaviour support practice. An additional dimension here is the benchmarking of behaviour support plans themselves. We suggest that establishing this framework is a significant foundational undertaking in ensuring quality and safe support provision for people with intellectual disability and complex

support needs. Currently such training and support is predominantly tied to State Government clinical governance functions, which will likely disappear in many jurisdictions with the advent of full Scheme rollout. The inconsistency and inadequacy of the current approach to developing, supporting and monitoring a 'behaviour support ready' workforce remains a significant outstanding challenge to the quality and safeguarding endeavour and to the responsiveness and effectiveness of the Scheme overall for people with intellectual disability and complex support needs.

Response to corrective domain

3.9 We were gratified to note the challenge identified around the application of universal safeguards (p. 22), in which the proposed framework acknowledges that "…not all supports are covered by industry regulation or self-regulation" (p. 22). Currently there are no nationally consistent requirements around universal safeguards of personal supports (an example might be police checks). This leaves many participants vulnerable, particularly those with the highest or most complex support needs. Benchmarking behaviour support across providers, practitioners and plans is a key component of an overall quality and safety framework that takes account of the specific issues for those who require behaviour support.

3.10 The document is unclear about how people with intellectual disability and complex support needs might be informed about using complaints mechanisms or reporting serious incidents (pp. 22-23). In the consumer-driven NDIS model it will be especially important that these mechanisms are clear to the participant, and that they feel empowered to use them if necessary. Three considerations are critical to addressing this issue: a) People with intellectual disability and complex support needs may be unlikely to have the means to access the complaints avenues due to low levels of literacy, lack of access to technology and a lack of support persons or advocates to assist them in recognising and articulating the nature of their complaints, b) Many people with intellectual disability and complex support needs have a history of unsatisfactory engagement with services and may not be aware that their experiences warrant complaint and so an emphasis on educative functions which make accessible to this group knowledge and expectations around service standards will be necessary, c) Many people with intellectual disability and complex

support needs experience significant social isolation and their service engagement may be the only, or one of very few, connections to social support they have. As a result many may be reluctant to complain or report for fear of loss of service (p. 46 & p. 71). These three points underscore the critical role of independent advocacy around support for complaints for this group.

3.11   A nationally consistent data monitoring system would seem imperative in the corrective domain. The disability sector currently has no national monitoring of universal safeguards, complaints or serious incident reporting. This means that we do not know the extent of potential problems, cannot map the topography of states and territories, or identify pockets of poor (or good) practice.

3.12   We endorse the recognition of "thin markets" and "market failure" as challenges (p. 25). Those with intellectual disability and complex support needs will likely be particularly vulnerable to these. The framework document rightly recommends market oversight functions so that these can be identified early. The authors also note the UK government plans to introduce a market oversight function with exactly this purpose, and to particularly monitor "the business failure of difficult-to-replace adult social care provider organisations" (p. 26).   Similar functions will be central to efforts to safeguard people with intellectual disability and complex support needs as this group will likely be among those most exposed to 'thin markets' and therefore be more heavily reliant on such a mechanism.

4. RESPONSE TO PART TWO: DETAIL OF KEY ELEMENTS OF THE QUALITY AND SAFEGUARDING FRAMEWORK

Response to NDIA provider registration

4.1 While strong advocates for flexibility we are wary that without a system of formal registration for all providers, both organisational and for individual behaviour support practitioners (on the continuum from neighbour to formal service), people with intellectual disability and complex support needs may be vulnerable to poor quality service delivery with limited redress, to

decreased likelihood of quality outcomes, and, in the worst case scenario, to abuse. Two key principles underpinning this framework should be a) keep it simple to maximise workforce entry to the market, and b) encourage maximum flexibility of choice by the participant.

4.2 There is a clear need for a system of regulation for providers in the behaviour support domain. This should include an accreditation system for agencies and for the individual practitioners they employ to deliver behaviour support. Accreditation/registration requirements should be set against a specified set of competencies/proficiencies at both the organisational and individual level. This presents a significant challenge in the current landscape in which there is no one recognised system of accreditation for behaviour support practitioners, who are in reality drawn from a range of professional disciplines (including psychology, speech pathology, social work and occupational therapy) or from the ranks of experienced direct support workers who have learnt their craft through the disparate jurisdictional 'on the job' training and supervision schemes. The development of such a system of accreditation/certification should be nationalised and could be operated by a suitably equipped education provider such as a University or RTO. The addition of a certification structure for those providing training in Behaviour Support Practice would also be required. The development of this framework is a significant outstanding responsibility of the NDIA and will require a comprehensive national effort to achieve.

4.3 Registration requirements may be staged on a continuum according to the level of complexity (rather than risk - see 3.2 above) but in this context the framework will need to guard against unintended and adverse impacts on market capacity and willingness to provide supports for people with intellectual disability and complex support needs. Specifically, a mechanism to counter any perceived or real disincentive for services to take high-risk clients if doing so means more complex and onerous regulatory requirements should be a central concern. In addition, due to the complexity associated with specialist behaviour support provision, new entrants into the market should be required to achieve certification prior to the delivery of any service.

4.4 An NDIS Code of Conduct is an imperative, irrespective of which option for provider registration is adopted. This Code would provide the spine for all expected provider behaviour

4.5 Who would bear the costs associated with mandated evaluation of some providers is unclear (p. 41). The extent to which the findings would be made public to participants would also require consideration.

4.6 In addition to registration of providers and practitioners there is a need to consider the mechanism through which Behaviour Support Plans are themselves monitored for efficacy and quality. This additional dimension should figure in consideration of an overall accreditation/certification framework.

Response to systems for handling complaints

4.7 Although there is considerable rhetoric in the quality and safeguarding document about accessible complaints mechanisms, there is actually no available empirical research about the extent to which accessible documents are indeed actually accessible. We propose that the NDIS has to be careful to not presume that, for example, easy read is the solution to accessibility. We simply do not know the extent to which so-called accessible mechanisms truly are accessible. To this end accessibility considerations should include a full range of accessibility options and could include for instance audio or visual recording of a complaint on a secure site.

4.8 The need for a formally appointed independent complaints body is especially acute when considering the "thin markets" to which people with intellectual disability and complex support needs will potentially be vulnerable. In the absence of viable alternative providers, participants may be less inclined to complain about poor quality service.

Response to ensuring staff are safe to work with participants

4.9 With increased numbers of providers coming in to the NDIS marketplace there will be increased risk of unsafe staff. The key guiding principle should be that safe staff is a non-negotiable for all vulnerable people. The NDIA therefore has a responsibility to maintain high levels of scrutiny.

4.10 A system of the removal of proven persons who pose a risk to participants relies primarily on the recognition and monitoring of specific individual incidents. Care should be taken to provide

the capacity within this system of monitoring to recognise and capture lower level incidents which together make up a pattern of frequent poor support practice.

4.11   National consistency to ensure safe staff is an imperative. Bitter experience has shown us that even those settings where there is assumed high level of client and staff monitoring, abuse occurs. This concern is intensified for those people with intellectual disability and complex support needs who may be residing in a less closely monitored environment such as a licensed or an unlicensed boarding house. Therefore, judgements regarding when a clearance is reasonable should be made not only based on the nature of the person seeking clearance, but should also include consideration of the nature of the role and the type of support provided.

4.12   The idea of aligning staff vetting processes with aged care and working with children checks (p. 62) seems sensible. This would require a cross-agency and nationally consistent approach.

4.13   The danger in a system which focuses primarily on excluding or barring persons from service delivery roles is that concentration on procedures for managing who should be 'in' or 'out' of the system risks obscuring assessments of quality and safety 'during' the support. Considerations of quality monitoring of support should be given similar prominence in any system of quality management.

4.14   Repeat or intermittent screening of staff safety should be required. The current South Australian model mandating three-year repeats is instructive (p. 64).

Response to safeguards for participants who manage their own plans

4.15   A key consideration here is developing a safeguard that would prevent less reputable providers from targeting participants with intellectual disability and complex support needs to self-manage their own plans, when they might not have the capacity to do so. This points to the clear need for independent advice and advocacy services, particularly for those with intellectual disability and complex support needs who have limited natural supports.

5 RESPONSE TO REDUCING AND ELIMINATING RESTRICTIVE PRACTICES IN NDIS FUNDED SUPPORTS

5.1 Behaviour support planning and practice are identified as the key to reducing 'challenging behaviours' and thereby fundamental to the approach embodied in the push to eliminate and reduce restrictive practices. However, as already detailed (see points 2.2, 2.3, 3.2, 3.5, 3.7, 3.8 and 4.2) there are currently under-developed, ad-hoc and variable approaches to developing, supporting and monitoring workforce and agency capacity to deliver high quality behaviour support. To re-iterate – there is an urgent need for a national review of behaviour support which captures issues of the continuum of behaviour support practice, organisational and individual practitioner capacity assessment, and workforce development with specific attention to the framework for training and accreditation. Such a review should make evidence-based recommendations to the NDIA regarding the preferred model of a national framework for registration and accreditation of behaviour support providers, practitioners and plans.

5.2 A key challenge will be how to maintain individual responsibility to 'do the right thing' with the collective responsibility to ensure that human rights are protected. Where possible it is preferable to avoid litigation as the 'go to' response. Current restricted practice approaches, which rely upon the individual to ensure proper procedure, are, however, poorly implemented (p. 77). Restricted practices are implemented routinely (Wastell et al., 2015) and not as the intended last resort, and in the absence of behaviour support plans (Webber et al., 2011).

5.3 The guiding principle about whether to have legal requirements for registration and monitoring of restrictive practices should be based on a human rights and safety protection rationale. If this thinking is adopted, then legislative reform is likely to be one part of the restricted practices solution in the NDIS era.

5.4 The research reminds us that legislative reform does not guarantee practice change (Rickard, Chan, & Merriman, 2013; Søndenaa, Dragsten, & Whittington, 2015). Despite the implementation of checks and balances, reduction in the use of restricted practices has proven difficult (Rojijn &

Frederiks, 2012; Søndenaa et al., 2015; Wastell et al., 2015), adding weight to the argument for workforce skill development and maintenance.

5.5 If the NDIA were to adopt a national model, then consideration about where the oversight function should sit would be required. Further research would be required to confirm whether this function should sit within NDIA, or an NDIA appointed independent third party, akin to an Ombudsman's model.

5.6 Consent is a critical feature of current restricted practices protocols (NSW Government Human Services Ageing, June 2010). In the quality and safeguarding framework document, consent is addressed mainly from the perspective of others' consent (e.g. p. 76 and p. 77), with limited attention to self-consent (p. 79). Collective clinical experience suggests that efforts to explain and gain consent from the participant are regularly tokenistic. A safeguarding structure would be required to ensure that efforts to explain the restricted practice and gain the informed consent of the affected participant are undertaken and documented.

5.7 The quality and safeguarding framework document implies that restricted practices are limited to accommodation settings (p. 78). Monitoring of restricted practices must be extended to all service settings, including day programs and respite.

5.8 In a thin market (to which people with intellectual disability and complex support needs will be vulnerable) there is increased risk of the use of restricted practices. While restricted practices use can be prevented by a) mandatory provider registration, b) repeat staff safety checks, c) mandatory professional development activities and accreditation, and d) mandatory supervision and mentoring (p. 81), these activities may initially result in an even thinner market, with the exit of some providers. This could mean a period of limited service availability to people with intellectual disability and complex support needs, which should be a recognised contingency planned for in the development of any new framework.

5.9 A fundamental benefit of a national mandatory reporting mechanism around restricted practices is the monitoring of systemic trends and repeated use with individuals over time (p. 84).

5.10   Addressing the problem of restricted practices will require clear definitions. Currently, there is no nationally accepted definition of restriction or infringement of liberty, and the defining boundaries of each type of restricted practice remain unclear. Lack of clarity around definitions then results in a number of questions. For example, is freedom of movement a restriction on civil liberties and how is this balanced with duty of care? Is placement in care, resulting in denial of access to ongoing personal relationships, a restricted practice? When does a restriction become a deprivation (Williams, Chesterman, & Laufer, 2014)?

6. SUMMARY

6.1 Any proposals agreed upon in the quality and safeguarding framework around behaviour support which addresses issues for providers, practitioners and plans cannot be achieved without proportional commitment to professional training, accreditation and ongoing monitoring of workforce practice across the country.

6.2 If there is to be reliance upon the mainstream and natural supports, then there needs to be commitment to building the capacity of these. Lessons from the intellectual disability sector suggest that reliance on these supports has produced negligible outcomes for those with intellectual disability and complex support needs. Further, recent evidence suggests that the mainstream and natural supports marketplace is "thin" for those with intellectual disability and complex support needs. The sector can only build the capacity of those who are present in the marketplace. The sector may have to first *build* the marketplace.

6.3 The NDIA, or an appointed separate party, should take carriage of development and implementation of a national data collection system that allows oversight of quality and safeguarding activities.

6.4 Legislative reform will be necessary if the proposed options recommended in this response were to be taken up.

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