SUBMISSION TO NDIS PROVIDER AND WORKER REGISTRATION TASKFORCE

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A research evidence informed perspective

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NDIS Provider and Worker Registration Taskforce Submission

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Who are we?

Carolyn Quinn is the parent/Nominee of two adult NDIS participants each with self-managed NDIS Plans. Carolyn's daughter is a post-grad qualified environmental scientist who is profoundly deaf and has very low support needs (assistive tech and some audiology). Carolyn's son is a music creative, retired micro-enterprise gardener and train enthusiast with severe-profound cognitive impairment, multiple interacting disability related health conditions and now has high intensity very complex 24/7 support needs. He has successfully lived in his own home with support for over 10 years (including prior to transition to the NDIS) achieving high quality integrated supports and positive outcomes through an individualised tailored model combining direct employment, directed regular contractor supports and fee for service specialist clinical supports.

Carolyn is also an experienced human services consultant in practice for over 35 years delivering specialised services to government and non-government across human services agencies at executive leadership and operational management levels. Her specialities are in personal safety (abuse, neglect, sexual assault, family violence, professional misconduct inquiries and organisational safeguarding review), evidence based leadership and professional development and outcome focused service model development, research informed service delivery implementation, service and program evaluation, and stakeholder engagement and inclusion.

Associate Professor Sue Lukersmith worked in Australia and UK across health and disability sectors as an occupational therapist, educator, consultant and then managing director of a multi-disciplinary rehabilitation practice for over 20 years. She worked internationally with the World Health Organization, based in Geneva and continues this part time from Australia on international reports and the WHO ICF Australia Interest Group. Her research is across academia and industry sectors. Her international research continued at University of Sydney, the Australian National University and now the University of Canberra. She has worked in real world industry-based research for 15 years including evidence-based practice advisor: on the panel for the NHMRC, and clinical guideline methodologist and developer for complex interventions for people with a disability. Her research focus is on best practice person-centred and integrated care, implementation research and complex interventions for people with disability and chronic conditions.

Luis Salvador-Carulla is the professor of mental health and the Deputy Director of the Health Research Institute, University of Canberra. He has previously been the head of the Centre for Mental Health Research at the Research School of Population Health, Australian National University (ANU) in Canberra (Australia) (2017-2021); and head of the Mental Health Policy Unit, at the Brain and Mind Centre of the University of Sydney (2014-2017). His main field of interest is decision support tools for the analysis of complex health systems and policy in public health with a special focus on mental health, ageing, disability and intellectual developmental disorders.

What are the issues with the proposed framework (Review rec 17)?

1. The framework proposed, based on provider accreditation and audit, is not supported by research evidence as an effective strategy for the stated purpose

Section 3.1.1 of the NDIS Review analysis document makes the statement "*Registration is a key preventative safeguard designed to ensure safe and high quality providers deliver fit-for-purpose supports to participants*"

The best available research evidence (see Appendix 1 for full summary of research evidence) overall shows:

- the accreditation and audit regulatory/quality improvement strategy can impact on internal organisation processes but that this does not translate to quality frontline practices, nor to outcomes for consumers (Hough 2021; Hussein et al 2021; Araujo et al 2020; Beadle-Brown et al 2008; Scott 2009; Shaw et al 2014;)
- the possible effect of accreditation and audit on organisation internal processes fades over time and with subsequent accreditation cycles (Bogh et al 2016; Pomy et al 2010;)
- Clinician/service consumer driven quality improvement strategies are associated with stronger evidence of efficacy and larger positive effect sizes than manager/policy-maker driven quality improvement strategies (external accreditation, risk and safety management systems, public scorecards and performance reports, and clinical governance) (Scott 2009).

Further there is concern that the accreditation and audit approach has potential negative effects by focusing organisation attention, resources and efforts on compliance process activities rather than frontline implementation of person-centred best practices and focus on outcomes for those being served (Hough 2021; Smith "Paper Safe: The Triumph of Bureaucracy in Safety Management 2018).

Governments and Public agencies have identified and aim to develop and implement evidence informed policy as best practice. Recent research involving a scoping review and affirmed by a RAND/UCLA consensus methodology identified a set of 39 unique evidence-based person-centred care quality indicators (Santana et al 2020). None related to provider nor worker registration. Through our own research we could not locate any evidence that does suggest that accreditation and audit of providers leads to person-centred best practice.

2. The proposed framework for whole of market provider registration and enrolment is service-centric.

The proposed framework is service-centric. It is about service organisations showing what they have in place as an agency and what they intend to do[1]. As discussed above it can be seen as more about agency intentions than actual practices. A focus on policies, procedures, processes, systems and management assumes these things translate into safe quality frontline delivery to participants, however this assumption is not supported by the research evidence (see Appendix 1).

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[1] Cortis, N., & Van Toorn, G. (2022). Safeguarding in Australia's new disability markets: Frontline workers' perspectives. *Critical Social Policy*, *42*(2), 197-219.

We recommend a person-centred approach to regulation for safety and quality in delivery of disability supports. A focus on service delivery to participants and their quality of life outcomes, not to be confused with a focus on agency systems and processes, is essential, because the frontline interface with the participant is what makes or breaks safety and quality from an individualised person-centred perspective[2]. The most important task is thus to design a regulatory model that is about proportionately monitoring the frontline service interface with participants and implementing evidence informed regulatory strategies which effectively influence that frontline interface with participants. Later in this submission we identify potential solutions for this.

3. **The NDIS regulatory system should focus on safety and quality in the frontline support interface with participants. It should not be a substitute nor duplicate for:**
    a. **other specialised systems with jurisdiction in safety including child protection system, family violence response system, criminal justice and law enforcement system, workplace health and safety system**
    b. **existing systems for individual professional registration or accreditation.**

The NDIS regulatory system should focus on the safety and quality of frontline service delivery to participants.

It is not appropriate for the NDIS regulatory system to leak into other jurisdictions and specialised areas of personal safety such as suspected abuse and neglect by family members or others outside the disability service system, nor domestic and family violence by current or past intimate partner. Likewise other criminal matters such as fraud investigation and prosecutions are the purview of criminal justice and law enforcement and the role of the NDIS is limited to reporting criminal matters where identified. It is not the role of the NDIS regulatory system to investigate suspected criminal activity.

Workers who provide NDIS supports vary widely from a one-off support for a specific time limited purpose or project (e.g. a book keeper supporting a participant to set up financial record keeping systems for self-management or a teacher contracted to create engaging visual supports for prompting home routines), peer support workers who themselves may be NDIS participants (e.g. a peer support worker coaching a participant in key word signing), personal care support workers, cleaners, musicians, nurses, allied health professionals, cooks (coaching safe cooking skills and healthy eating), teachers doing specific capacity building support (e.g. individualised coaching of an adult with intellectual disability in literacy for more independent daily living such as recognising destination on buses, reading a take away menu etc). NDIS participants and their families are using workers with diverse skill sets, and uniquely suitable capabilities to meet their individual needs and goals in creative innovative ways.

The concept of a traditional generalist Disability Support Worker is outdated in an individualised goal-oriented insurance model system (such as NDIS and also other systems such as CTP catastrophic injuries), and limits innovation and can be a more expensive option. For example, a local chef well known to a participant as she works at their favourite local café is approached to coach the participant with intellectual disability

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[2] Robinson, S., Graham, A., Canosa, A., Moore, T., Taylor, N., & Boyle, T. (2022). Ethical practice in disability services: Views of young people and staff. *Ethics and Social Welfare*, *16*(4), 412-431.

and his housemate in safely making five budget healthy dinners over weekly sessions for 5 weeks. The chef accepts because she knows and likes the participant, has some spare time in the afternoons and agrees upon a reasonable fee (tax invoiced) as it feels purposeful. . The chef did not seek to be an NDIS worker, is unlikely to identify as one and if she had to go through an administrative enrolment process as an NDIS worker would likely decline to do the requested coaching because she is not interested in being an NDIS provider. It is important that in designing a registration and enrolment system that such creative local community connected opportunities are not impeded. There are many examples of NDIS participants and families using an Assets Based Community Development[3] approach like this to achieve multiple individual goals simultaneously.

Where goal-oriented supports are delivered by workers with professional qualifications specific to their professional discipline, many are already registered or accredited with an oversight professional body (e.g. Book keeper registration; health professionals registration with AHPRA[4]). It is not appropriate for the NDIS quality and safeguards framework to try to capture all these diversely qualified people into a generic NDIS worker registration pool which is based on old models of generalist disability support workers. Such reductionism is likely to stifle goal-oriented creative solutions for individual needs by placing administrative burden or duplication that could become a disincentive to supporting NDIS participants.

Being clear on the scope and purpose of the NDIS regulatory framework developed is important to ensure the regulator does not fail to achieve its intended outcomes by trying to spread its resources too thin, attempting to be all things in all circumstances, stepping outside its expertise or inadvertently limiting creative solutions and cost effective alternatives to meet participant individual needs and goals.

4. The proposed framework for proportionate provider registration/enrolment focuses on service type as the single dimension of risk. This single dimension is not a research evidence informed approach to risk of abuse, neglect and exploitation of people with disabilities.

To be effective in influencing the safety and quality of the disability support frontline interface with participants it is important to understand what factors drive risk to participants in this interface between frontline provider and participants. This includes both risk probability and risk severity.

Although research shows children with disability are at increased risk of abuse and neglect comparative to children without disability[5], the portion of this involving abuse and

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[3] ABCD Institute | DePaul University, Chicago; 2-Module-2_Asset-Based-Community-Development_2.pdf (cswe.org)

[4] Australian Health Practitioner Regulation Agency Australian Health Practitioner Regulation Agency - Home (ahpra.gov.au)

[5] Fang, Z., Cerna-Turoff, I., Zhang, C., Lu, M., Lachman, J. M., & Barlow, J. (2022). Global estimates of violence against children with disabilities: an updated systematic review and meta-analysis. *The Lancet Child & Adolescent Health*, *6*(5), 313-323.
More, R. (2023) Inclusive child welfare services, disabled children, and their families: insights from a European comparison of social policy and social (work) practice in Austria, Iceland, and Ireland. European Journal of Social Work 2023 p1-12 https://doi.org/10.1080/13691457.2023.2219033
Mogens Nygaard Christoffersen. (2020) Sexual Crime Against Schoolchildren With Disabilities: A Nationwide Prospective Birth Cohort Study. *Journal of Interpersonal Violence* 37:3-4, pages NP2177-NP2205.
Jennifer Vanderminden, David Finkelhor, Sherry Hamby & Heather Turner. (2023) Victimization and abuse among children with disabilities: Age adjusted rates in a US national sample. *Child Abuse & Neglect* 146, pages 106495.
Brooke A. Thomas-Skaf & Angelique Jenney. (2021) Bringing Social Justice Into Focus: “Trauma-Informed” Work With Children With Disabilities. *Child Care in Practice* 27:4, pages 316-332.

neglect by family members, friends and trusted adults outside the disability support system etc is the responsibility and jurisdiction of the child protection systems (including mandatory reporting in some states), and law enforcement and criminal justice system. Research on prevalence of abuse neglect and exploitation of adults with disability has produce highly variable rates depending on methodological issue and again a portion relates to abuse, neglect and exploitation under the jurisdiction of non-NDIS authorities [6]. For example:

- Malihi et al. (2021 cited in Collins et al 2022) when comparing the prevalence of physical and sexual violence against people with disabilities in New Zealand, found that more people with disabilities (including physical, intellectual and psychological) reported higher non-partner physical and sexual violence experiences, compared to those without disabilities.
- Beadle-Brown, et al. (2011 cited in Collins et al 2022) conducted an audit of adult protection monitoring data in England. Among the 6148 referrals, 1857 were for individuals with an intellectual disability. Sexual abuse was subsequently confirmed in just over 26% of this sample and in two-fifths of referrals for alleged sexual abuse related to abuse in residential services.
- Results from the National Crime Victimization Survey of the American Bureau of Statistics (Harrell 2017 cited in Mailhot Amborski et al 2022) indicated that certain types of disabilities (e.g., hearing defect) are significantly less associated with violent crime victimization than others (e.g., intellectual disability).
- Seppälä et al (2021) found poly-victimization played a significant role in maltreatment of children with disabilities. Children's hearing impairment, physical disability, and mental health problems increased the odds of poly-victimization more than other forms of abuse[7].
- Mailhot Amborski et al (2022) meta-analysis found individuals with disabilities were at significantly higher risk of sexual victimization than persons without disabilities (odds ratio = 2.27). The risk of sexual victimization among individuals with a disability was significantly higher in adult participants compared with the risk in child participants. Sensory impairment was the type of disability associated with the highest risk of sexual victimization[8]. This is important as it indicates that disability type is not a reliable single dimension definer of risk across abuse types.

The focus of the NDIS regulatory framework needs to be on abuse, neglect and exploitation in the provider frontline interface with participants. Like all effective prevention and responses to abuse neglect and exploitation it needs to be based on evidence based understanding of the factors driving risk in the frontline interface with participants, as well as the points of potential influence to reduce and manage those risks. Service type as the single dimension of risk for determining a proportionate registration and enrolment approach is not supported by the research evidence.

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[6] Collins, J., & Murphy, G. H. (2022). Detection and prevention of abuse of adults with intellectual and other developmental disabilities in care services: A systematic review. *Journal of Applied Research in Intellectual Disabilities*, 35(2), 338–373. https://doi.org/10.1111/jar.12954

[7] Seppälä, P., Vornanen, R., & Toikko, T. (2021). Multimorbidity and polyvictimization in children—An analysis on the association of children's disabilities and long-term illnesses with mental violence and physical violence. *Child Abuse & Neglect*, *122*, 105350.

[8] Mailhot Amborski, A., Bussières, E.-L., Vaillancourt-Morel, M.-P., & Joyal, C. C. (2022). Sexual Violence Against Persons With Disabilities: A Meta-Analysis. *Trauma, Violence, & Abuse*, *23*(4), 1330-1343. https://doi.org/10.1177/1524838021995975

Risk factors for abuse and neglect of people with disability identified in research evidence[9] include:

- **Isolation**. As is the case for everyone, people with disabilities are more vulnerable to abuse neglect and exploitation when they are excluded, and isolated with lack of or limited meaningful personal safeguarding relationships in their lives [10]
- **Congregate care and closed support settings;** institutionalised practices; isolated environments; lack of visits by people outside the service and poor monitoring of participants living away from family and community networks
- **Involvement in an individual behaviour management program**; being in receipt of a drug to control behaviour; escalation of behaviours that challenge which is an indicator the participant feels unsafe or is unsatisfactorily supported
- **Unsupported communication difficulties or previous abuse victimisation**
- **Intersections with other forms of social and economic disadvantage and marginalisation**. For example a global review and meta-analysis (Fang et al 2022) found children with disabilities in economically disadvantaged contexts were especially vulnerable to experiencing violence[11].
- **Perceptions of, or attitudes towards disability and people with disability**. For example, beliefs that adults with intellectual disabilities are fundamentally different, they are 'too disabled', and 'have no skills' were a risk factor for abuse (e.g., Bigby & Beadle-Brown 2016 cited in Collins et al 2022). 'Such beliefs may underlie experiences of inequality between staff and service users characterised by distortions of power and control' (Manthorpe & Martineau 2015 cited in Collins et al 2022). Perceptions and attitudes of service leadership, workers and the regulator need to be understood within the wider context of reinforcing societal attitudes and how they frame vulnerability and create barriers to safety of participants[12]
- **Gender** with males more likely to be the abuser than females
- **Managerial practice weaknesses** (e.g. lack of managerial support for frontline staff, lack of team meetings and reflective practice, poor implementation of policy, resistance to change and inadequate monitoring of frontline service delivery, high turnover, poor communication with staff and families)
- **Organisation staff culture** (e.g. organisational norms of 'confrontation and criticism', 'compete rather than co-operate', 'never making a mistake', absence of relational caring values, paternalistic beliefs, service isolation, ineffective staff

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[9] Paddy McNally, Laurence Taggart, Mark Shevlin, The development of a trauma informed care framework for residential services for adults with an intellectual disability: Implications for policy and practice, Journal of Policy and Practice in Intellectual Disabilities, 10.1111/jppi.12457, **20**, 3, (232-248), (2023).
Paddy McNally, Mandy Irvine, Laurence Taggart, Mark Shevlin, John Keesler, Exploring the knowledge base of trauma and trauma informed care of staff working in community residential accommodation for adults with an intellectual disability, Journal of Applied Research in Intellectual Disabilities, 10.1111/jar.13002, **35**, 5, (1162-1173), (2022).
Collins et al (2022);
Royal Commission into Violence Abuse Neglect and Exploitation of People with Disabilities (2022)
James I. Charlton, Nothing about us without us: Disability oppression and empowerment, University of California Press, 2000, 53.

[10] Davy, L., Robinson, S., Idle, J., & Valentine, K. (2024). Regulating vulnerability: policy approaches for preventing violence and abuse of people with disability in Australian service provision settings. *Disability & Society*, 1-22.

[11] Fang, Z., Cerna-Turoff, I., Zhang, C., Lu, M., Lachman, J. M., & Barlow, J. (2022). Global estimates of violence against children with disabilities: an updated systematic review and meta-analysis. *The Lancet Child & Adolescent Health*, *6*(5), 313-323.

[12] Clifton, S. (2020). Hierarchies of power: Disability theories and models and their implications for violence against, and abuse, neglect, and exploitation of, people with disability. [Hierarchies of power: Disability theories and models and their implications for violence against, and abuse, neglect, and exploitation of, people with disability (researchgate.net)]
Thomas-Skaf, B. A., & Jenney, A. (2021). Bringing social justice into focus:"Trauma-informed" work with children with disabilities. *Child Care in Practice*, *27*(4), 316-332.

supervision, a punishing regime, institutionalised practice, inexperienced leadership, a culture committed to preserving the status quo).

Protective factors identified in research include[13]:

- **Empowering participants and their families** with knowledge and skills around rights, speaking up and assertiveness; effectively implemented supported decision-making; enabling choice and control
- **Positive culture** characterised by positive attitudes towards participants, acknowledgment and attendance to difference, recognition and respect for participant preferences, staff intrinsic motivation, confidence to challenge bad practice and positive relationship with senior colleagues, whereby staff feel listened to and valued; shared responsibility for practice quality; caring culture characterised as coherent, respectful, enabling of participants (as against 'looking after') and motivating for staff.
- **Effective frontline leadership** including supervisors who worked alongside staff (e.g., modelling, monitoring and correcting practice), good communication, shared decision making, the embracing of new ideas and external visitors, good connections with the community, good relations with the safeguarding team, regular staff training, independent staff appraisal and supervision, a consistent use of disciplinary procedures for staff, support for whistleblowers, reflective practice, enabling teamwork and person-centred working practices.

Understanding the points of potential influence to reduce and manage risks requires consideration of:

- **The culture surrounding participants** that supports respect, empowerment, dignity of risk, structurally embedding choice and control of people with disability and their families; and where competing interests arise prioritises the interests of people with disability over those of the provider organisations and workers. This also includes creating a sector culture that actively lives out and enables the rights in the UNCRPD.
- **Inclusion and personal safeguarding relationships**[14]. **"**Like vulnerability, autonomy is necessarily relational, and the level of autonomy and vulnerability a person experiences and is exposed to in their lives depends on the scaffolding and support of the people, relationships and systems around them" (Davy et al 2024).
- **prevention** of abuse neglect and exploitation (e.g. ensuring people with known history of abuse neglect or exploitation of people in any context, do not have access to NDIS work roles in contact with participants or managing those in contact with participants; cross-system information sharing so for example workers banned under the Working With Children Check system are automatically banned for NDIS roles as well; capacity building including UNCRPD and Protective Behaviours learning for participants and their families[15])

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[13] Collins et al 2022; Davy et al 2024

[14] Robinson 2015; Hutchison and Stenfert Kroes 2015 cited in Davy et al 2024

[15] United Nations (2006) Convention on the rights of persons with disabilities (CRPD) UN General Assembly
Robinson, S., & Graham, A. (2021). Feeling safe, avoiding harm: Safety priorities of children and young people with disability and high support needs. *Journal of intellectual disabilities*, *25*(4), 583-602.
Schmidt, E.K., Brown, C. & Darragh, A. Scoping Review of Sexual Health Education Interventions for Adolescents and Young Adults with Intellectual or Developmental Disabilities. *Sex Disabil* **38**, 439–453 (2020). https://doi.org/10.1007/s11195-019-09593-4

- **early identification/detection** of abuse neglect and exploitation (e.g. participant and their families understanding of what is abuse, neglect and exploitation and what quality service looks and feels like; Code of Conduct with supporting application material clarifying how it applies in complex aspects of practice; capacity building for people with disabilities, families and workers on indicators of abuse, neglect and exploitation; ensuring all participants have personal safeguarding relationships, that are outside the services, that have frequent contact and 'eyes on the ground'; Community Visitors forming direct relationship with participants without provider gatekeeping of the relationship, with participants in congregate support settings and making visits unannounced to the service workers)
- **early disclosure** by people with disabilities and their families of abuse neglect and exploitation (e.g. expectation that the default position is to believe participants and their families when they report abuse neglect or exploitation; capacity building on UNCRPD and Protective Behaviours learning for participants and their families and speaking up about concerns or abuse; personal safeguarding relationships; Community Visitors forming direct relationships with participants; multiple easy accessible ways to tell someone who will act upon the information for the person's safety)
- **prompt response to disclosures, complaints and concerns**
  This includes for example independent initial investigation by a professional skilled in investigation of the relevant abuse type where there is disclosure or complaint of abuse, neglect and exploitation of a participant/s by service worker/s, and prompt referral to police and other relevant authorities and specialist services. Where a matter is reported or otherwise comes to the attention of the NDIS safeguards regulator the relevant disability provider should be directed as to how the matter is to be investigated, by whom and what actions to take in the interim to safeguard any participants from the alleged source of harm.
- **prevention from re-abuse and systems abuse**
  This includes ensuring the source/s of harm is removed and that the victim of abuse neglect or exploitation is not systemically abused by being disadvantaged, removed or dislocated from their chosen connections and other supports and that they receive equitable access to mainstream safeguarding systems.
- **Trauma-informed support for and communication with participants and their families**[16].

Brown, M., McCann, E., Truesdale, M., Linden, M., & Marsh, L. (2020). The design, content and delivery of relationship and sexuality education programmes for people with intellectual disabilities: A systematic review of the international evidence. *International Journal of Environmental Research and Public Health*, *17*(20), 7568.
Araten-Bergman, T., & Bigby, C. (2023). Violence prevention strategies for people with intellectual disabilities: A scoping review. *Australian Social Work*, *76*(1), 72-87.

[16] Paddy McNally, Mandy Irvine, Laurence Taggart, Mark Shevlin, John Keesler, Exploring the knowledge base of trauma and trauma informed care of staff working in community residential accommodation for adults with an intellectual disability, Journal of Applied Research in Intellectual Disabilities, 10.1111/jar.13002, **35**, 5, (1162-1173), (2022).

What do we recommend the Taskforce advise to government?

Advice the government:

1. **That investment in an expanded registration system (provider organisation accreditation and audit approach) is not supported by the research evidence and is unlikely to achieve the stated aim of ensuring safety and quality, in frontline practice service delivery to participants.**
   It is important that the framework does not over emphasise or over-invest in the arms length service-centric accreditation and audit compliance approach that can inadvertently lead to "paper safe"[17] organisations that pass compliance audits, focus attention and efforts on risk and safety system activities, but fail to meaningfully implement safety and person-centred quality in frontline practices with participants.

2. **To adopt a quality and safeguards framework weighted primarily towards person-centred individualised approach to safeguarding, and capacity building.**
   The person-centred individualised approach to safeguarding should include:
   a. Individualised quality and safeguard planning, capacity building and review
   b. Preserving participant right to the dignity of risk, and enabling choice and control in their own lives including in directing their supports
   c. Capacity building for participant/nominee for self-directing of supports – understanding of what safe quality individualised service looks like and rights to direct their supports; how to speak up and where to get help to speak up; building consumer expectations of services
   d. Readily accessible independent advocacy for individuals particularly those with limited natural safeguarding supports
   e. Peer mentoring on self-management in the first 1-2 years of self-managing.

3. **Investing in research evidence informed strategies for improving quality and safeguarding in frontline practices with participants** including:
   a. Focus on, and accountability for individual participant quality of life outcomes
   b. Individual participant safeguarding planning build into all NDIS initial Plans and Plan reviews. This could include identifying participants at risk through isolation who may require additional safeguarding support.
   c. Individual advocacy allocated for participants without their own natural safeguarding relationships in their lives, until such time as natural safeguarding relationships are well established through capacity building focused on developing a circle of support or similar. This individual advocacy needs to be relationship based so that over time the advocate becomes known and trusted by the participant. The relationship is vital for the advocate to be someone to tell about concerns or worries about the safety and quality of supports/services.
   d. Community Visitor programs – relationship based, known, trusted consistent person with eyes on the ground (that can drop in unannounced) to visit and contact the participant/s, particularly those is congregate care and closed service settings.

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[17] Gregory Smith (2028) The Triumph of Bureaucracy in Safety Management, Wyland; Hough et al (2024)

    e. Capacity building around Supported Decision-making and how it can be meaningfully implemented in various real world contexts
    f. Accessible evidence informed low/no cost core training for frontline generalist disability support workers on the evidence based Active Support approach and how it can be meaningfully implemented in various real world contexts
    g. Capacity building for frontline practice leadership and coaching, particularly in delivering support to people with high complex support needs and people in congregate and closed service settings such as group homes. There are currently two NDIS funded demonstration projects on two versions of frontline practice leadership undergoing evaluation. Frontline practice leadership is also being applied in varied ways by some self-managers and this could inform diverse applications of frontline practice leadership and coaching as a quality improvement strategy.
    h. Capacity building programs for self-managers on quality and safeguarding in their context
    i. Research to practice translation and practice improvement (e.g. similar to the functions of the Centre for Community Child Health Victoria[18] that accessibly translates research to practice applications in the early childhood development and early intervention sector. It also guides quality improvement frontline coaching approaches with features similar to frontline practice leadership. It offers a practical, step-wise approach to understanding problems and designing and testing possible responses. It empowers those on the frontline to work out how to solve the issues they face.)
    j. Mechanisms for accessible no cost/low cost ongoing development for frontline best practice e.g. live online practice focused learning circles around particular areas of practice. NDIS support hourly rate costing models will need to accommodate reasonable time consideration for learning and development.

4. **Ensure that if a graduated risk proportionate system is created that it is designed around the research informed key drivers of risk probability and risk severity and is tailored according to the risk probability and risk severity profile including**:
    a. **Participant isolation** (regardless of disability type isolation is a key driver of vulnerability and risk of abuse, neglect and persisting service quality deficits):
        i. Lack of or low frequency contact (would need to be defined) with safeguarding relationships with family/close friends/well known community allies from outside the service
        ii. Closed service settings – e.g. where specialist disability housing and daily living support is provided by the same or affiliated providers; or daily living support and allied health supports are provided by the same or affiliated providers;
        iii. Congregate care settings – e.g. group homes; boarding houses, congregate group day programs; congregate respite accommodation services.
    b. **Large number of participants serviced by the service provider organisation**.

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[18] Centre for Community Child Health -Centre for Community Child Health : Publications and resources (rch.org.au); Centre for Community Child Health : Policy Brief (rch.org.au); The practices of an effective quality improvement coach | Centre for Community Child Health (rch.org.au);

This is important because if the organisation has inadvertently engaged a predatory offender or has systemic safeguarding risks or management inadequacies (e.g. high staff turnover, reliance on one-off agency contractors to fill support roster gaps; limited on-site supervision/practice observation of frontline staff, poor culture etc) or unresolved frontline safeguarding failures (e.g. repeat medication errors etc) the pool of participants potentially impacted is greater in organisations with larger numbers of participants supported. In these circumstances the risk probability is higher.

c. **Unsupervised direct supports to children with disability delivered outside the family home**
   This includes the following unsupervised direct supports for children delivered outside the family home and is a similar risk dimension used in state based Working With Children regulation in NSW:
   i. 1:1 or in groups without the child's parent/in loco parentis delegate being directly involved, observing or supervising, or
   ii. by one support worker without a responsible adult from outside the worker's service directly involved, observing or supervising on site (responsible adult might be for example the child's teacher observing therapist support delivered in school).

d. **Behaviour supports delivery that includes any restricted practices**
   As restrictive practices by definition breach the person's rights these carry significant risk. We support the recommendation of the Royal Commission of working towards elimination of restrictive practices.

To provide ongoing NDIS support involving direct face to face support, where any of the above in a, b, d apply the provider organisation must be a registered provider with the NDIS Quality and Safeguards Commission and for c the worker must have undergone a screening check (see 5 below). Providers supporting participants in isolating higher risk service models including congregate care (group homes, boarding houses, multi-dwelling on single site SDA) and closed service settings (multiple support categories delivered by the one provider) must undergo advanced registration. To be effective:

- the quality standards need to have additional requirements tailored to these higher risk isolating service models
- each site (each group home; each boarding house etc) be separately accredited on these additional requirements. This is vital given the culture and safety dynamics can be site specific and thus can impact differently on participants at specific congregate care sites. Organisation level registration is not sufficient.
- a suitably experienced auditor be assigned by the NDIS Quality and Safeguards Commission from a panel of pre-approved auditors, in relation to these higher risk isolating service models. It is important to ensure the provider does not select and directly pay their own auditor so that the auditor does not hold a potential or perceived conflict of interest. Those organisations seeking registered provider status could pay a fee to the Commission that funds the payment of auditors by the Commission. This process will also aim to create a desirable disincentive for providers to persist with higher risk isolating service models and promote adaption over time, particularly for next generation participants towards more

innovative service models and phasing out of congregate care as recommended by the Disability Royal Commission.

- The auditor has direct access to the Community Visitors, and to directly invite participants and their families/circles of support to communicate with the auditor in the person's preferred way, about safety or quality improvement issues. To be effective it is important that the provider is not in a position nor able to act as gatekeeper regarding who communicates with the auditor. Participants/nominees would retain the right to ignore the invitation, decline the invitation or accept the invitation on their terms.

5. **Screening of workers in ongoing unsupervised direct face to face NDIS support roles, either a Working With NDIS Participants Screening check or a state based Working With Children Check, but not both.**
   The requirement for this worker screening at the point of employment/engagement and then regularly renewed needs to be proportionate to the risks so should include criteria:
   - The work role is ongoing. Those engaged for one-off support or short time-limited projects are exempt, except if it will involve personal care support such as toileting, showering, dressing, medication support. AND
   - The work role involves substantial face to face support directly with the participant/s. Roles with only incidental contact with the participant e.g. gardener are exempt. AND
   - The face to face support with the participant/s is not directly supervised by the participant's parent/guardian/person responsible or the participant has legal capacity in their own right. AND
   - A verified state-based Working With Children Check has not been provided.

   Workers who provide NDIS supports to children in unsupervised working with children roles already must undergo a state-based Working With Children Check. Also as many adult NDIS participants who do volunteering and the workers who support them in doing so must have a state-based Working With Children Check, it is important not to create unnecessary administrative and cost burden by duplication of screening. The NDIS Quality and Safeguards Commission could simply agree to accept the verified state-based Working With Children Check as a sufficient screening for NDIS roles.

6. **Develop and implement a separate strategy for equitable NDIS payment claims transparency and accountability**, **for all NDIS plan management types** (e.g. upload invoices approved and signed by participant/Nominee/Person Responsible/Guardian prior to claim payment; random claim invoice audits, targeted audits of suspicious claims, educative corrective approach to claim errors or misunderstandings particularly for self-managers). The strategies for effective NDIS claim transparency and accountability, and prevention of provider overcharging and claim fraud are different to what is required for personal safety and other aspects of service quality in practice and should not be conflated.
   To be effective, inclusive, and fair this will need to include:

a. A fully accessible inclusive co-designed claim transparency and accountability system that includes options so as not to create barriers or disadvantage (e.g. not assuming everyone has quality internet connectivity etc)
b. Plain language accessible information and capacity building support for self-managers on the claim transparency and accountability systems and what/how they can get set up to make it easier for them to meet requirements.
c. Funding approved for self-managers for oncost components incurred for meeting claim transparency and accountability requirements (e.g. costs of book keeper to set up systems; cost gap difference between personal use internet plan and reliable small business internet plan etc)

The authors of this submission would be happy to provide further input to the NDIS Provider and Worker Registration taskforce.

Appendix 1.

Reflection in Light of Key Messages from Published Peer Reviewed Research and Evidence.

The NDIS Review "Working together to deliver the NDIS" report released in December 2023, made 26 recommendations with 139 actions to change the system that supports people with disability in Australia. The analysis document accompanying the Review report suggests little reference was made to the research evidence in shaping the recommendations which is concerning if the revised NDIS is to be an evidence informed scheme. Of particular concern and consideration in this paper are the following:

- Recommendation 17: "Develop and deliver a risk-proportionate model for the visibility and regulation of all providers and workers, and strengthen the regulatory response to long-standing and emerging quality and safeguards issues":
  - Action 17.1 "design and implement a graduated risk-proportionate regulatory model for the whole provider market".
  - Action 17.3 "remove the link between a participant's financial management of their plan and the regulatory status of their support providers."

  Section 3.1.1 of the NDIS Review analysis document makes the statement "*Registration is a key preventative safeguard designed to ensure safe and high quality providers deliver fit-for-purpose supports to participants*" but the Review fails to provide any supporting research evidence for the view that registration as a strategy works to achieve this. It appears to be an unfounded assumption which warrants further exploration.

There appears to be a trend in Australia for use of registration (accreditation and audit approaches) in human services systems (e.g. health, early education and care; aged care) as the go to strategy for quality, so exploration of research on the effectiveness of the strategy in wider human services systems is of pertinent interest, if we are to be evidence informed in regard to the Review recommendation.

As commented by Cortis et al (2021) based on the work of Hough (2021) on the NDIS regulatory approach, "The work provides an unsettling reminder of the ways the formal regulatory architecture now in place was developed, not out of careful theorisation or evaluation of evidence, but rather from a series of inherently political design choices and trade-offs." Dru Marsh (2021) further comments in relation to Hough's work (Hough 2021) and calls for "further exploration of the interaction between the NDIS and other regulatory systems, notably Work Health and Safety schemes. Doing so may help to assess an observation made recently at the Royal Commission (19 December 2019) that worker safety may be prioritised over quality of life of people with challenging behaviours by using restricted practices as a form of Work Health and Safety risk control (National Dis ability Services 2019) …. It highlights a putative tension between accommodating both worker rights and the rights of people with a disability to live an "ordinary life" under the separate regulatory schemes."

Further the social commentary around these issues appears to be based more on opinion or potentially vested interest bias rather than on the research evidence base. Yates et al 2024 state "while no evidence exists to suggest that participants purchasing services from unregistered providers are more at risk….. some commentators have raised concerns about the use of unregistered providers and suggested that this may be contributing to cost 'blowouts' and mistreatment of 'vulnerable' clients (Burton 2022; Per Capita 2022)".

The basis for the concern comes into question when facts are considered as stated by Yates et al (2024) "Registered providers tend to be larger agencies who receive high amounts of NDIS funding. For example, NDIA figures indicate that 9% of providers paid through plan managers are NDIS registered, but they represent 59% of total payments in the relevant quarter (NDIS, 2022b, p. 96)."

To aid in avoiding a repeat of ill-informed politically oriented design, the purpose of this paper is to ask important questions and reflect upon what the research evidence tells us relevant to consideration of the Review recommendation 17.

Is registration/visibility to government regulators, of service provider organisations an effective strategy for ensuring safety and quality services?

The research literature distinguishes between registration of service provider organisations, often described as the accreditation and audit approach, and registration of individuals in a professional discipline (e.g. individual occupational therapist registration with the Australian Health Practitioner Regulation Agency APRHA). Here we focus on what the research tells us about the service organisation accreditation and audit approach as it is the approach recommended by The NDIS Review (Rec 17).

Although the "NDIS Quality and Safeguards Commission has considerable power, including the right to issue infringement notices, to apply to courts for the imposition of civil penalties, or to ban staff members and providers from providing disability supports" (Hough, A., McEwen, J. 2024), in the decade since the NDIS began these powers have not been significantly used for ensuring safety of NDIS participants and quality of services received. Commission data for the period 2022-2023 shows:

- There were 16,378 registered NDIS providers
- 16,305 complaints to the Commission about providers, an increase of 44% in comparison to the previous year. No data is provided on the number/percentage of complaints about registered providers/non-registered providers. No data is provided on the total number of providers subject of complaint, which would show if there are multiple complaints about some providers. No data is provided on the risk rating of the complaints, nor the nature of complaints (fraud, overcharging, participant safety, failure to delivery etc)
- 34% of participant survey respondents indicated that the quality of services and supports from their NDIS provider(s) had improved over the previous 12 months. All participants and representatives that responded to the survey had finalised a complaint with the NDIS Commission in the previous 9 months. This data indicates a low rate of quality improvement even where a complaint had been made.
- 92 Banning Orders were made for individuals or providers (no breakdown data is provided); 11 Infringement Notices issued; 608 Corrective Action Requests and 104 Revocations of Registration; 15 Suspended Registrations, and 48 Warning Letters. No data is provided about the number of providers subject to one or more actions, which would show whether multiple actions are taken with some providers. No data is provided on whether the actions taken were in relation to registered /non-registered providers.
- 3 proceedings for imposition of civil penalties, all relating to deaths of NDIS participants while in/under the care of the registered provider. No civil proceedings were taken for circumstances less than death. These cases highlight that services'

registered status does not keep participants safe even from the most extreme abuse/neglect.

Preventable deaths of people with disability while under the care and support of providers occur despite the services being funded, registered and visible to government regulators (Royal Commission into Violence Abuse Neglect and Exploitation of People with Disability 2022, NSW Ombudsman 2018, Salomon & Trollor 2019, Hough 2021) shedding doubt on the NDIS Review assumption that "registration is a key preventative safeguard…":

- In the year 2017-2018 in Victoria 83% of the deaths were people with disability living in shared supported accommodation.
- In the period 2014- 2017 in NSW of the 592 deaths of people with disability reviewed 95% were people living in government funded shared accommodation disability services; 4% lived in assisted boarding houses and 0.6% (3 deaths) were living in private or community housing.

Failure of NDIS strategies for quality and safety that are based on the external accreditation and audit approach, is not surprising given the research evidence. Given the scarcity of research relevant to this in disability service systems specifically we also turn to lessons from other complex human service systems that have invested in research and evidence in this area.

Hough (2021) states "Scandals about abuse and neglect in disability service provision abound. For example, in Britain there have been the Winterbourne View and Whorlton Hall scandals (Flynn & Citarella, 2013; Murphy, 2020b; Parish, 2013). Both scandals raised important questions about regulatory processes, including the adequacy of regulatory oversight and the processes of quality audits (Murphy, 2019, 2020a, 2020b; United Kingdom Parliament Joint Select Committee on Human Rights, 2019). In Australia, numerous government inquiries have documented instances of abuse and neglect (e.g., Robertson, 2020; Safeguarding Task Force, 2020; The Senate Community Affairs References Committee, 2015). One of the responses to the continued abuse and neglect of people with disabilities has been stronger regulation of disability service providers and workers. Despite the move to stronger regulation, there is a surprisingly limited literature on the topic of regulating disability service provision. Of the literature that exists, some articles have described single systems: that of England (Behan et al., 2016); one aspect of the New Zealand system (Diesfeld et al., 2020); and the systems in the United States in the late 1980s (Bradley & Bersani, 1990). Cunningham et al. (2020) and McEwen et al. (2014) focused on standards. McEwen et al. (2020) added to the literature by comparing three systems for measuring process and outcomes... In all of the studies, there are limited links to the broader literature on regulation." Hough (2021) describes "The NDIS regulatory system is a polycentric system, with target audiences including people with disabilities, workers (including frontline support workers and allied health professionals), and disability service providers. It explicitly embraces developmental, preventative, and corrective elements (Department of Social Services, 2016). To give examples of each domain and the application to each target audience, development of participants includes encouraging self-advocacy. Preventative elements include screening out workers who have particular classes of criminal convictions or other backgrounds that suggest that they are unsuitable to support participants. At the provider level, this preventative domain includes the publication of Rules and Practice Standards to set the bar about quality service delivery. In the corrective domain, there are requirements about reportable incidents and complaint management, and compliance powers applying to providers." See Hough (2021) for a thorough description of the existing polycentric regulatory system of the NDIS.

The focus of this paper is the provider level registration of NDIS providers (an accreditation and audit approach) and queries whether there is value in this approach being mandated and expanded as recommended in Recommendation 17 of the NDIS Review.

Hough (2021) assists in considering the motivations for current recommendations "Public interest arguments are that regulation results from the State acting to protect consumers, some of whom may be vulnerable in the general marketplace. An alternative explanation is that regulation can be a response to the power of interest groups, seeking to protect their interests. A third explanation advanced by some micro-economists is that regulation can be understood as a tool to restrict access to markets and to enable regulated entities to engage in what economists call "rent seeking" (i.e., the seeking of excess profits by regulated entities)." With the advent and likely influence of large provider lobby groups such as AbilityFirst and Alliance20, Hough's analysis is particularly notable and worth consideration as is the view that having the current competition option to use unregistered providers (as is current) may curtail "rent-seeking". If registration is mandated there may be an unintended consequence of "rent-seeking" behaviour by registered providers.

Key research and evidence relevant to our question includes:

- Hough (2021) in a research informed analysis of the current NDIS regulatory approach states "Legally-binding regulation both sets standards for all and creates the basis for enforcement action against those providers and workers who lack the motivation or the knowledge to provide quality and safe supports (Baldwin et al., 2012). However, this approach can have the disadvantage of creating a compliance mindset, with the potential for providers and workers doing the bare minimum to meet the externally-imposed requirements. At its worst, the command-and-control style of regulation can result in the attention of workers and providers being on the *system* of policies and procedures, losing sight of the intended *purpose* of the system (Gaventa, 2008; Hart & Buiting, 2018)…. Of course, one of the dangers of either command-and-control regulation or self-regulation is ritualism in implementation (i.e., that the required processes are implemented in form but not in substance [Braithwaite et al., 2007; Power, 1997]) In relation to the external accreditation and audit approach Hough states "a regulator must attempt to assure that accurate data are collected, by a competent auditor, in a context where the provider and workers might be motivated to game the system. The importance of the issue is highlighted in cases where audit processes found a provider satisfactory but subsequent reports demonstrated that the service provision in fact violated human rights, was of poor quality, or was unsafe (e.g., Behan et al., 2016; Carnell & Paterson, 2017; Murphy, 2020a, 2020b; United Kingdom Parliament Joint Select Committee on Human Rights, 2019)." Hough highlights that unlike accreditation auditors, Community-visitors "can have an important window on the quality-of-service provision via their unannounced visits to service sites (Safeguarding Task Force, 2020; Westwood Spice, 2018)." Hough (2021) concludes "policy makers should consider the issue of whether regulatory requirements are supported by empirical evidence, or whether they are engaging in what might be considered evidence-free policy-making. In that regard, the study by Beadle-Brown et al. (2008), which demonstrated poor correlations between auditor ratings and the lived experience of people with intellectual disabilities in residential care, is a reminder of the importance of research into the effectiveness of regulatory processes. It is possible that regulatory design is often due to forces of institutional isomorphism rather than due to evidence of effectiveness (DiMaggio & Powell, 1983). The recurring scandals of abuse and neglect of people with disabilities suggest that disability service provision can have profound effects on people's quality of life; indeed, it is a matter of life and death importance for some."

- Perceived compliance with regulator service standards is only marginally correlated with quality-of-life measures for service users (Beadle-Brown et al. 2008).
- Scott (2009) conducted a metareview of systematic reviews of controlled trials (gold standard of evidence) in determining effect sizes for specific quality improvement strategies (QIS) and found:
  - "Clinician/patient driven QIS were associated with stronger evidence of efficacy and larger effect sizes than manager/policy-maker driven QIS"
  - "manager/policy-maker driven QIS including continuous quality improvement programmes, risk and safety management systems, public scorecards and performance reports, external accreditation, and clinical governance arrangements have not been adequately evaluated with regard to effectiveness"
  - Institutional accreditation uses external evaluators to assess agency performance against standards. "Although frequently cited as a quality accountability mechanism, a scoping review of reviews found that the direct effect of institutional accreditation on quality of care is uncertain".
  - "Based on current best available evidence, clinician/patient driven QIS appear to be more effective than manager/policy-maker driven QIS"
- A systematic review of voluntary accreditation schemes in hospitals (Hussein et al 2021) summarised the mixed results on the impact of voluntary accreditation in hospitals. There was effect of accreditation on healthcare workers and particularly on job stress, and results indicate a positive effect of hospital accreditation on perceived safety culture, process-related performance measures, efficiency, and the patient length of stay (for two specific accreditation systems), whereas employee satisfaction, patient satisfaction and experience, and 30-day hospital readmission rate were found to be unrelated to accreditation.

'Accreditation positively affects perceived patient safety culture [56], safety climate and attitude toward medication error reporting [57], and organizational culture as manifested by a less hierarchical culture and more group and developmental culture [58]. On the contrary, a recent study did not detect changes in the safety management culture from the nurses' perspective after accreditation [59]. Reviewed research found negative or no impact of accreditation at the professionals' level. Studies reported a consistently negative impact of hospital accreditation on professionals' perceived job stress. Despite the widely held belief that accreditation contributes to improving patient satisfaction and experience, most findings provide little evidence of this. Multiple studies that compared accredited with non-accredited hospitals or accredited hospitals at different accreditation levels did not find any association. For instance, Sack et al [77, 78] did not find a link between accreditation and patients' perception of better quality'.

- Shaw et al (2014) investigated the relationship between ISO 9001 certification, healthcare accreditation and quality management in European hospitals. Accreditation and certification are positively associated with clinical leadership, systems for patient safety and clinical review, but not with clinical practice. Both systems promote structures and processes, which support patient safety and clinical organization but have limited effect on the delivery of evidence-based patient care.

- Araujo et al (2020) conducted a systematic review on the impact of voluntary hospital accreditation on healthcare quality indicators, as classified into seven healthcare quality dimensions. They focused on synthesizing pieces of evidence from studies that quantitatively examined differences in health quality indicators before vs. after hospital accreditation or among accredited vs. nonaccredited hospitals. Overall results suggest that accreditation may have a positive impact on hospital processes but there is no consensus regarding the impact of accreditation on hospital outcomes. They found a further complication is that it is not clear if the improvements observed in accredited hospitals are related to the accreditation itself or if accreditation merely reveals hospitals that are more motivated to comply with healthcare guidelines and to implement quality improvements.
- A study of accreditation of health organisations in Canada (Pomy et al 2010) found that while the first time accreditation process may stimulate organisational activity for internal process changes such as spirit of cooperation, introducing quality improvement programs, creating new leadership roles for quality, fostering links (impact on patient outcomes was not tested in this study), this outcome of stimulating internal process change fades over subsequent accreditation cycles. They found motivation to introduce accreditation-related changes dwindled over time. Others have shown a post-accreditation fade or slump (Bogh et al 2016)
- The Bigby et al (2018) research review states research “points to discrepancies between inspectors’ ratings of supported accommodation services (based either on UK minimum standards or a different rating of quality) and research measures of the quality of support and quality of life (Beadle-Brown et al. 2008; Netten et al. 2010). For the most part, inspectors’ ratings were more likely to reflect the management, environment, staff training, systems and processes than observed outcomes for service users.”
- Studies show mixed evidence concerning staffing, mix, and turnover and aged care quality. The psycho-social work environment appears to matter for care quality. The way aged care facilities are designed is critical for employee wellbeing and care quality. (Taylor 2024). Bigby et al (2018) research review states “Larson et al. (2005) propose that workforce conditions imposed by external conditions such as labour market conditions and wage agreements that lead to higher costs and rates of staff turnover have a negative impact on the quality of services. They suggest that, in addition to a number of other initiatives to improve recruitment, addressing wage and compensation issues are critical; however, there is as yet no research evidence that such strategies have a direct impact on the outcomes of those supported or on the care practices of staff.”
- Extensive research has highlighted the importance of implementation science considerations when setting out to effect change in complex human service systems (Braithwaite et al 2018). Knowledge pipeline linear thinking (ie. the path from knowledge creation, through knowledge products, to knowledge use) has shaped past processes for change aimed at implementing evidence based practice, however, “We now know that this straight-line thinking was naïve at best, and little more than an idealization, with multiple fractures appearing in the pipeline.” Combining lessons from implementation science and “complexity science offers a radically different set of considerations to those interested in systems change. As a paradigm, it denies over-simplification, and is conceptually

transformative, adding a much richer set of understandings to the task of systems improvement." (Braithwaite et al 2018).

- Hough et al (2024) explore the complexity of genuinely achieving quality in disability support service delivery. They explore "How do service providers ensure high-quality and safe support is delivered to every person they support, in every type of service, in every location, by every staff member, and on every occasion? This is the challenge that disability service providers face". They argue:
  - "High-quality support and services are key safeguards against abuse and neglect. What constitutes good quality varies by each individual, stakeholder group, and type of service".
  - "strategies for achieving high-quality and safe supports should be integrated into standard ways of working, rather than approached as a box-ticking exercise disconnected from day-to-day practice."

Is professional registration an effective strategy for quality in practice?

Professional registration is the strategy of individual professionals in a discipline (e.g. health professionals; teachers) being registered with an approved professional body and generally has set criteria for registration which are intended to align with professional competence or scope of practice the professional is allowed to do. While there is a lack of evaluation research specific to disability support worker registration or scope of practice of disability support workers there is research on registration for other human service disciplines.

Some key messages from research relevant to our question include:

- Moore et al (2021) describe and compare varied approaches to registration of health professionals used in four countries including Canada, UK, USA, Australia. They state "Fundamentally, the goal of health professional regulatory regimes is to ensure the highest quality of care to the public. Part of that task is to control what health professionals do, or their *scope of practice*. Ideally, this involves the application of evidence-based professional standards of practice to the tasks for which health professional have received training. There are different jurisdictional approaches to achieving these goals." The results show "in some cases, 'tasks' or 'activities' are the basis of regulation, whereas in other contexts protected 'titles' are regulated, and in some cases both." They developed a table of leading practices related to regulating scopes of practice that match specific regulatory principles (see below):

Regulatory principle	Description related to scopes of practice	Leading practices
Definition	Clear definitions of professional scope that advance regulators' mandate of protecting public safety	Uniform legislation and regulatory authorities operating nationally provide consistent and clear practice standards and regulatory frameworks (Australia)
Flexibility	Regulation sufficiently flexible and responsive to allow for timely innovation and optimization in scopes of practice	Umbrella frameworks that offer regulatory flexibility and loosen the restrictiveness of scopes of practice (many Canadian jurisdictions)

Regulatory principle	Description related to scopes of practice	Leading practices
Accountability	Scope of practice regulation is transparent and contributes to high-quality and safe patient care	Transparent and publicly accountable risk-based processes with separate oversight body (UK)
Efficiency	Optimizing coherence, coordination, and communication while maintaining focus on public safety	Licensure compacts allowing licensure recognition and sharing of regulatory data across jurisdictions (US)
Collaboration	Legitimate stakeholder perspectives included in scope of practice consultations and definitions	Increased public engagement in regulatory processes such as community reference group (Australia)

- (Fenech et al 2023) “Teacher registration is increasingly utilised as a governance mechanism to audit teachers’ work and drive professional practice. There is limited and mixed empirical evidence, however, as to whether registration drives teaching quality.” “Findings problematise[19] the need for, and benefits of, teacher registration. That early childhood teachers’ practice and development was most driven by intrinsic motivation and, to a lesser extent, being employed in high-quality, not-for-profit, and preschool settings where other early childhood teachers are employed, suggests that more effective and progressive policy approaches to support quality early childhood education require an addressing of the contexts and conditions in which early childhood teachers work.”
- The Bigby et al (2018) research review states “Searching to improve the quality of services and outcomes for service users, researchers have identified a ‘bewildering array of variables’… For example, staff qualifications are often thought to affect outcomes, but neither type of qualification or direction of effect are articulated.”

Taking account of this research, should registration of professionals in disability support (other than those already doing so such as teachers, nurses, psychologists and other allied health professionals), then there would first need to be significant work defining the scope of practices in the various roles.

What is likely to work for driving quality in human services generally and disability services in particular?

Hough et al (2024) describe the need for three levels of action for quality service, the individual level (individual worker interaction with individual participant); organisation level (codesign of services, individualisation, organisation implementing evidence-based practice, investing in training etc); whole-of-system such as inclusive employment, affordable housing etc. and workers’ knowledge of systems. Hough et al (2024) set out six core components underpinning high quality and safe support:

1. **The human rights approach**
   human rights approach should inform a provider’s objectives and methods of service delivery. For example, Article 19 of the UN Convention on the Rights of Persons with Disabilities declares:

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[19] to ‘problematise’ means to critically consider how an object or concept like ‘teacher quality’ has come to be constructed as a problem, and how purported truths and solutions like ‘teacher registration’ reinforce the problem construction. Problematisation is fundamental to critical policy sociology (Ozga, 2021 cited in Fenech et al 2023).

‘*the equal right of all persons with disabilities to live in the community, with choices equal to others, and [that nations] shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community’*. (United Nations, 2006, Article 19)
A human rights approach stands in stark contrast to historical approaches to disability service delivery, sometimes called the ‘charity’ model, where supports were provided in ways where human rights were optional (Office of the High Commissioner for Human Rights 2010). Under the charity model, people with disabilities often reported that service delivery was controlling rather than offering choices equal to others in the community.”

2. **Concern for quality of life**
“Service providers need to ensure that they are providing good quality and safe supports during service delivery while also acting to promote the person’s overall quality of life. A person does not have a good quality of life if their needs are met during support delivery but not at other times or if their needs are met in one of the domains of quality of life but not others. In Australia, some of the National Disability Insurance Scheme (NDIS) Practice Standards are framed as whole-of-life outcomes, not just outcomes from the support provided. Despite the emphasis in Australia’s NDIS Practice Standards on whole-of-life outcomes, the NDIS is in many ways designed as a transactional system based on the hours of support provided. However, service providers should provide support in a way that helps the people they support to achieve quality-of-life outcomes. For example, a person with intellectual disability might ask for help with shopping and accessing community venues. If, in providing this help, the service provider supports the person to build their skills in shopping and assists in building relationships in the community, then the person’s quality of life is also likely to improve over time.”
3. **Person centredness**
“Being person centred means focusing on the person being supported, understanding that different individuals will have different needs and preferences, and ensuring that processes start and end with the person being supported rather than with the organisation. A consistent theme in case studies in Australia’s Disability Royal Commission has been service providers thinking about quality and risk management in organisation-centric ways and being less focused on the needs of the people being supported (Royal Commission into Violence Abuse Neglect and Exploitation of People with Disability 2022)”.
4. **A commitment to evidence-based support**
“In the last decade there has been substantial progress on building evidence around what constitutes good support in disability service provision. For children with disabilities, there is now a strong evidence base to support family-focused practice, with the professional supporting the entire family in order to provide the best support to the child (McCarthy & Guerin, 2022). For adults with intellectual disability living in a group home setting, research has demonstrated that Active Support is associated with an improved quality of life. For people with psychosocial disabilities, recovery-oriented practice is associated with improved outcomes (Winsper et al., 2020).”
5. **A balanced approach: purpose driven balanced with a management system approach**
“When purpose driven, the organisation seeks to embed core concepts such as human rights and person-centred approaches and to ensure that the design of the quality management system reflects the needs of people supported and staff members, not just those of the organisation. However, management systems typically aim to standardise processes and practices to ensure consistency in the support provided. What is needed

is—ironically—the standardisation of individualisation. For example, when planning service delivery, the service provider works with the person supported in a systematic way to understand the person, their needs and preferences, and potential risks to the person"; "organisations should not place too much emphasis on management systems for the following reasons:

- An excessive emphasis on standardisation can be contrary to the third key concept of being person centred, as the needs and preferences of individuals will vary,
- What is important is what happens in practice, not the management system itself: the quality management system is the 'means' to the 'end' of good quality and safe supports—it is not an 'end' in its own right, and
- Perceived compliance with standards is only marginally correlated with quality-of-life measures (Beadle-Brown et al., 2008). Paperwork may be compliant, but the people supported may have a poor quality of life."

6. **A commitment to continuous improvement**

   "This philosophy recognises that achieving quality and safeguarding is not a 'set and forget' process (Braithwaite et al., 2007). New people being supported, changes in a person's circumstances, new staff members, changes in the external environment, and evidence about new risks to quality and safe service delivery create new challenges. Further, expectations of organisations and staff members will continue to increase over time in response to new and emerging evidence about what works."

Make outcomes for the people being served the primary focus of quality:

In considering this question we first need to refer to the research body of knowledge on what quality is and how it is assessed. The Young et al (2023) review highlights the complexities of achieving valid approaches to quality oversight and regulation in health care. They describe, derived from the work of Donabedian, that the assessment of healthcare quality has often been separated into three primary buckets:

- "Structure: resources required to supply healthcare, including human and inanimate physical resources
- Process: methods, behaviours, and strategies
- Outcome: measurable results for patient-customers, which are more of a gold standard barometer than structure or process."

It is notable that the NDIS registration system is based on structure and process, without reliable monitoring and accountability for delivering participant outcomes.

Van Loon et al (2013) describe how evidence-based outcomes (EBOs) can be used to improve clinical, managerial, and policy decisions in systems and organizations providing services and supports to persons with intellectual disability.

Young et al (2023) describes the goals of healthcare quality systems as:

- Achieving uniformity in desired results for patient-customers health (ie. interventions used achieve positive results for patients and do so consistently),
- Reducing waste/Increasing efficiency (e.g overtreatment, failures of care coordination, pricing failures, fraud and abuse),

- Preserving patient safety (with preventive actions - prioritise patient safety over business issues, leaders promote, reward, and 'champion' the attitudes and behaviours that create a culture of safety), and
- Person-centred care. Focusing service whenever ethically possible on the desires of those being served. Patient-customers are better served by learning their objectives, aligning business goals with patient/customers' goals when it is ethically and legally appropriate to do so, and by 'activating' patient-customers (Hibbard et al 2013 cited in Young et al 2023) Activating customers means enabling them to manage their own service transactions by increasing their knowledge, skills, and options for self-management of services. Activated patients have been found to achieve better clinical outcomes than patients with similar characteristics who were not 'activated.' (Fors et al 2015; Pirhonen et al 2020 cited in Young et al 2023).

Bigby et al (2018) research review concluded that the propositions with strongest or most promising evidence about what makes a difference to quality-of-life outcomes for service users in supported accommodation are:

- Staff practice reflects Active Support Staff practice compensates, as far as possible, for inherently disadvantageous characteristics of service users, particularly severity of disability and challenging behaviour
- Front-line management uses all aspects of practice leadership
- Service culture is coherent, enabling, motivating and respectful There are strong organizational policies and practice in the area of HR (that support front-line leaders and recruitment of staff with the right values) There are processes to assist staff to focus their practice on engagement of service users
- Staff are trained in Active Support, and training has both class room and hands-on components There are adequate resources for sufficient staff with the rights skills to enable people to participate in meaningful activity and relationships but not too many that they obstruct participation
- Supported living options offer services users more choice and control
- Ordinary housing that is small, dispersed in community, homelike.

Beadle-Brown et al (2021) study of outcomes and costs of support for people with severe-profound intellectual disability found “people who received consistently good active support experienced better outcomes in terms of several quality of life domains. Good support did not require significantly more staff time, and there was no evidence of higher total costs for those receiving good support” and concluded “the inclusion of active support in government guidance and local commissioning practices related to people with severe intellectual disabilities is likely to improve user outcomes. Observation should be an important element in measuring service quality.” Beadle-Brown et al (2021) state “over many years, research has shown that one of the key determinants of quality of life, and in particular whether people spend their time meaningfully engaged (apart from severity of disability), is whether the support they receive is enabling and empowering—helping people to do as much as possible themselves and then, when support is needed, doing *with* people rather than doing *for* or *to* people (see Mansell, Beadle-Brown, Whelton, Beckett, & Hutchinson, 2008 for a review). This approach is usually referred to as “active support” (see Beadle-Brown et al., 2016; Bigby & Beadle-Brown, 2018; Mansell & Beadle-Brown, 2012; Stancliffe, Jones, Mansell, Lowe, 2008). Core to the slightly different approaches to active support that exist is the fact that those who provide support are enabling and empowering those they support to successfully participate in a range of meaningful activities and relationships with the aim of improving quality of life. Mansell and Beadle-Brown (2012) describe active support as an enabling relationship by which staff and other carers provide graded assistance to ensure success—assistance that is tailored to the needs, pace and preferences of the individual delivered in a person-centred, warm and respectful way and making the most of all the opportunities available at home, in school, in the community and at work…. Engagement in meaningful activity and relationships is considered a particularly important outcome in that it is the vehicle by which many aspects of quality of life are realized." Beadle-Brown et al (2021) detail concrete observations that can be used to determine whether a person is receiving support for quality of life outcomes:

Emotional well-being	• Level of challenging behaviour • Score on the SPELL framework elements in particular whether the environment contains structure to make it predictable and it is low arousal
Physical well-being	• Whether or not people engaged in any physical activity during the visit • Was the available meal relatively balanced nutritionally
Material well-being	• Whether or not people had a paid job • Was the accommodation well kept and homely
Personal development	• Whether the person attends college or work placements • Whether people are participating in a range of activities at home and in the community and therefore experiencing opportunities to develop (IPDL and ICI)
Social relationships	• Whether or not people receive contact from staff (for facilitating engagement) and others they live with • Whether they are in contact with their family and how often • Whether they have friends (outside the service) and how often they see them • Whether they have contact with neighbours and are known by name by neighbours
Social inclusion	• Whether people have accessed community-based activities and facilities in the past month (ICI) • Whether people have interacted with others that are not staff and people they have lived with when out in the community
Self-determination	• Opportunities for choice (CMS) • Whether people are observed to make choices and have those choices respected • Whether people have an advocate • Whether people are able to effectively communicate

Rights	- Whether people encountered any barriers, or negative interactions or discrimination when out in the community

Beadle-Brownet al (2021) found “significant differences in terms of quality of life outcomes between those who were receiving consistently good active support and those who were receiving mixed, weak or non-existent active support, even when there was no significant difference between the two groups on level of ability (the only other factor that has been found to consistently predict levels of engagement in other studies)” and “those in the good active support group experienced better outcomes in terms of overall engagement in meaningful activities and relationships and in terms of emotional well-being and personal development, interpersonal relationships, social inclusion and self-determination”.

Empower service users to make choices and build their expectations of quality:

Hough et al (2024) focuses consideration of how to genuinely build quality not simply satisfy a regulator at one point in time stating “some people with disabilities and especially people with intellectual disabilities have become used to poor quality support and thus their expectations may be inappropriately low. Numerous reports by parliamentary committees, commissions of inquiry, and regulators have documented poor quality support resulting in people being harmed in service delivery. Historically, even when the supports delivered were safe, supports were often centred around the convenience of service providers or staff rather than being centred on the individual being supported.”

A Cochrane Database systematic review (Stacey et al 2014 cited in Young et al 2023) of 115 controlled studies reported that providing patients with decision support tools:

- Improves patients' knowledge regarding their medical care options,
- Improves the accuracy of their perception of possible benefits and harms,
- Increases the degree to which they engage in decision-making,
- Reduces health practitioner-patient decision conflicts, and
- Increases the likelihood that patients choose treatments that are consistent with their value (ie value of treatments).

Race (2007 cited in Bigby et al 2018) concluded a factor influencing service quality included pressure for better quality services exerted by service users’ families.

Most importantly, service-users themselves should be given more control and feel empowered to direct their own safeguarding by providing clear information to them about what constitutes abuse and the safeguarding referral process (Hollomotz, 2012). For example, findings Detecting and Preventing Abuse: A Review highlighted the importance of providing sex education and assertiveness training to people with intellectual disabilities to help with prevention and early detection of sexual abuse (Cambridge et al., 2011a; Turk & Brown, 1993). Additionally, service users should have an independent advocate who can notice and raise concerns on their behalf (Bright et al., 2018).

Recent research takes empowerment further looking into co-production of services and co-regulation for safeguarding (Yates et al 2024). The Yates et al (2024) study explored “why clients choose to use unregistered providers, and what actions they take to improve the quality and safety of services purchased in this way." They explain "Unregistered providers are still regulated by the Quality Safeguards Commission in that they are required to comply with the NDIS Code of Conduct and can be sanctioned and banned from providing NDIS services, although the mechanisms for monitoring and enforcement are more limited (Hough, 2021). The QSC can also receive and investigate complaints regarding unregistered providers and may support NDIS participants to make complaints directly to unregistered providers (NDIS QSC, 2022b)."

Yates et al (2024) state "As the NDIS has evolved, many studies have explored how and whether principles of choice and control have been achieved in the scheme (e.g., Gavidia-Payne, 2020; Perry et al., 2019; Warr et al., 2017). However, an area that has received less attention is individualised funding participants' role in the regulation of services…. While no evidence exists to suggest that participants purchasing services from unregistered providers are more at risk, the current national Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability has focused attention on the safety and quality of disability services." Yates et al (2024) found NDIS participants (with or without support eg. from their Nominee) conduct numerous co-regulation activities during hiring, training/onboarding and ongoing arrangements with providers….. many felt there was no difference in risk between the two types of providers, and some felt less safe with registered providers. Feelings of safety were instead underpinned by such factors as the ability to choose from a wide range of providers, hiring people embedded in communities or with the right expertise irrespective of registration status, and direct relationships formed with workers and providers in the absence of company 'bureaucracies'." They (Yates et al 2024) concluded "our findings show that for some NDIS participants, what was intended as a marker of quality and safety has in fact become the opposite. In contrast, many interviewees spoke of how much they appreciated and valued their unregistered services, including the increased autonomy and opportunity to co-produce that these arrangements afforded. Interviewees demonstrated extensive use of various risk assessment mechanisms and showed capacity to evaluate and reduce risk in service delivery. They argued that no service provision arrangements could be risk free, and it was important for inclusion and citizenship to be allowed the 'dignity of risk' in choosing between registered and unregistered providers. Along with interventions to the registration process aimed at improving the quality and safety benefits of provider registration, we recommend capacity development of NDIS participants to understand their options, rights and obligations with regard to scheme operation. Supporting choice and control in this way is likely to have positive implications far beyond the unregistered provider space and promote better outcomes with regard to the scheme as a whole."

Capacity building of leadership and management for a genuine safety and quality culture, and evidence informed frontline practice leadership:

- Poor service culture has been identified as a risk factor for the occurrence of abuse of people with intellectual disability (Hutchison & Kroese, 2016 cited in Collins et al 2022)
- An extensive research review was commissioned by the Australian Association of Gerontology (Taylor 2024) in relation to aged care work, environment, processes, staffing and job quality. The review included a large body of literature that addressed human resources/worker-related topics: effective leadership, worker motivation, wellbeing, voice, bullying, workplace incivility and workplace violence, employee development, labour turnover, aspects of equality and diversity; the feminised nature of aged care work, work-family conflict, shift work and staffing levels and skill mix. The literature commonly relates the quality of management and leadership to the psycho-social environment in aged care, suggesting that this influences workforce and care quality.

Taylor concluded that “effective management and leadership in aged care are essential for effective aged care worker performance, which, in turn, enables high-quality care”. “Competent workers and good care are the products of skilled managers. Managing the aged care workforce demands a wide range and high level of skills.” On the basis of the extensive research review Taylor recommends consideration to “establishing a National Taskforce on Aged Care Management and Leadership”.

- Kersten et al (2018) conducted a systematic review to identify which organisational factors are enabling and/or disabling in stimulating the sharing and application of knowledge (application of good practices) in the care and support of people with intellectual disability. The application and sharing of knowledge are indispensable in optimising the quality of care and support for people with intellectual disability (Schalock et al. 2008; Reinders & Schalock 2014).
  Organisational factors were categorised into three main clusters: (1) characteristics of the intervention (factors related to the tools and processes by which the method was implemented); (2) factors related to people (both at an individual and group level); and, (3) factors related to the organisational context (both material factors (office arrangements and ICT system, resources, time and organisation) and immaterial factors (training, staff, size of team)). An overall analysis of the retrieved factors indicates that they are related through the pre-conditional role of the management of the organisations. Management seems to provide the identified material and immaterial factors, such as time, resources and training. In addition, management is usually guiding in the choice of the method, tool or ICT system; whether user-friendliness and suitability for the professionals are considered as criteria is up to the management. Moreover, the selection of professionals, the composition of teams and policymaking is performed by managers. In this way, management is able to influence the organisational culture in terms of being more or less supportive of knowledge processes. In this way, management has a key position in facilitating processes of sharing and application of knowledge. These results are in line with the (included) study of Beadle-Brown et al. (2014), in which management quality is indicated as a facilitator of knowledge application when combined with practice leadership.

- A research review aimed to expose variables influencing quality of life outcomes of people with intellectual disability living in supported accommodation, found evidence was strongest for the presence of staff practices (use of Active Support), front-line management practice (use of practice leadership), culture (enabling and motivating), human resources policies and practice (that support front-line leaders and recruitment of staff with the right values), adequate resources, and small, dispersed and homelike settings (Bigby et al 2018)

- Bigby et al (2020) found “senior leaders in organisations where at least 71% of services delivered good Active Support prioritised practice; understood Active Support; and strongly supported practice leadership. In these organisations practice leadership was structured close to everyday service delivery, and as part of frontline management” and concluded “patterns of coherent values, priorities and actions about practice demonstrated by senior leaders were associated with successful implementation of Active Support, rather than documented values in organisational policy or procedures”.

- Hough (2022) states “Demands of commissions of inquiry, legislators, and regulators that disability service providers’ boards of directors have greater involvement in the governance of quality and safeguarding have been increasing, both in Australia and overseas. However, there is no empirical literature on how disability service provider boards might govern for quality and safeguarding. In contrast, there is a substantial literature on the impact of boards on the quality of care in the hospital sector and a small but developing literature on board influence on work health and safety". The Hough review examines what might be learnt from both literatures and considers what findings might – and might not – be hypothesised to be transferable to the governance of disability service providers. It is noteworthy that the three review articles do conclude that there are small but statistically significant relationships (Brown, Citation2020) between board governance and quality and patient outcomes. Jiang et al (2009) "demonstrated correlations with both process of care measures (for heart attack, heart failure and pneumonia), and risk-adjusted mortality, and:

- provision of clinical quality data, including national benchmarks
- provision of patient safety data, including national benchmarks
- provision of patient satisfaction data, including national benchmarks
- most board meetings having a specific agenda item on quality
- chief executive officer and executive performance evaluation including measures for clinical improvement and patient safety
- establishing strategic goals about quality, and
- board involvement in setting the organisation's quality agenda."

Hough concludes that further research is needed on how disability service provider boards in particular might influence quality and safeguarding.

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