NDIS Review:

Building a strong, effective NDIS

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About VALID

VALID is the peak organisation in the Victorian disability sector that represents adults with intellectual disability and their families. VALID has been run by and for people with disability and their family members for over 30 years. During this time, VALID has developed expertise in networking, information provision and project management to people with disability and families across Victoria. VALID has four program areas:

1. Self Advocacy

VALID's Self Advocacy team supports people with intellectual disability in a range of ways to become strong self advocates. One of these is working alongside VALID staff with intellectual disability to review group homes and report on self-advocacy practice to the provider and the Department of Families, Fairness and Housing (DFFH).

Their responses to this paper focus on **safeguarding for NDIS participants who live in group homes.**

2. Community Development and Engagement

VALID's Community Development and Engagement team works to build more inclusive communities so people with disabilities can live lives of their choosing. They take a multi-level approach to creating change in the broader community that works at individual, group and community levels. Community Development and Engagement is the only team within VALID whose work extends to people with disabilities other than intellectual.

Their responses to this paper reflect this broader focus and are based on **safeguarding in the context of the professional and lived experiences of VALID staff and volunteers with disability.**

3. Training and Consultations

VALID's Training and Consultations team runs courses for people with disability, family members and support staff. This team focuses on empowerment, accessibility and safety of people with disability. They also run focus groups that give people with disability and their families a chance to have their voices heard on different topics.

Their responses to this paper are focused on **the natural safeguarding that occurs when people have good support staff and are empowered to live a life of their choosing.**

4. Individual Advocacy

VALID's Individual Advocacy team is funded by the Victorian State Government to work with individuals to help solve a specific problem they are experiencing. Cases that involve abuse, neglect and human rights violations are prioritised.

Individual Advocacy helps people speak up about what they want, get the information they need to make their own decisions, and explore the choices they want to make. VALID also supports family members of people with intellectual disability as they advocate for or with someone.

Their responses to this paper are focused on **safeguarding in the context of their work with individuals who experience problems that often stem from systemic issues.**

Overview

In preparing this submission, VALID consulted each program area to capture some of the diversity of experiences and perspectives on safeguarding available to us. This submission is informed and structured by program areas with distinct voices and foci, and we acknowledge that such an approach has benefits and drawbacks.

One benefit is its demonstration that despite these distinctions, **every team in VALID is united by a focus on the genuine empowerment of every person with disability to live a life of their own choosing in peace, happiness and safety.** Another is that it demonstrates the **repetition of issues** with safeguarding that occur within group homes, Day Services and more.

The **Terms of Reference Objectives** this paper focuses on are from **Part 2: Building a more responsive and supportive market and workforce:**

> g. ensure the adequacy and effectiveness of the operation of the Quality and Safeguards Framework in ensuring quality, addressing conflicts of interest, and providing appropriate protection for participants;
>
> i. improve performance monitoring, compliance, reporting and responses to breaches, unscrupulous behaviour, including the detection of fraud and sharp practices.

The discussion and recommendations in this paper indicate that the scope of each problem is often wider than the suggested questions frame them.

However, we believe it is important for us to respond directly to these – even where our answers necessarily expand out from the question being asked. This is because it is critical to demonstrate the complexity of issues that exist for all people with disability around safeguarding that are further compounded for people with intellectual disability.

Self Advocacy

1. How can the regulation of providers and workers be used to improve the quality of services and supports for people with intellectual disability?

For the NDIS Quality and Safeguards Commission (NDIS Q&SC) to ensure quality and provide appropriate protection for participants, it needs to understand that **mandatory worker qualifications alone cannot be an effective safeguard** for the interests and safety of people with intellectual disability. The more important qualities are a value set that prioritises the human rights of people with intellectual disability and a commitment to doing the work that furthers these. These qualities are integral to the provision of quality support for people with intellectual disability.

A more pressing problem for the NDIS Q&SC to address is that when disability workers breach these human rights, **there has been a culture within services of 'moving the problem onto another house/service/etc.'** rather than the provider taking responsibility for ensuring a thorough and transparent investigation into the incident, and that appropriate action is taken. If an investigation shows a worker has breached human rights standards, the worker must be held properly accountable (including legal action where appropriate) and should not continue to work in the disability sector.

There is also a fundamental **disconnect between management of some disability services and support staff** in terms of management's understanding of what disability support staff are doing when working in people's homes. While it is questionable whether regulation might improve this situation, oversight would undoubtedly help – as would ensuring that people with intellectual disability themselves can speak up, including to managers, at a house level.

But the most pressing problem is that many people with intellectual disability are living in homes not of their choosing, and with housemates who often trigger and perpetuate further trauma for one another. **These environments could have all the regulation and high-quality staff they need to thrive, and they would still fail people with intellectual disability and staff.**

Recommendations

- When people are employed within the disability sector, make mandatory a trial period where they shadow experienced workers and need to demonstrate appropriate behaviour and attitudes towards people with intellectual disability before working alone
- To support the necessary culture shift within some services, NDIS Q&SC needs to continue to put a public spotlight on the disability services sector to do the right thing, follow regulations and not ‘sweep things like assault under the carpet’
- Ensure that workers are held fully accountable for human rights breaches and answer to criminal activity before the legal system – and that workers found to have breached people’s human rights and/or broken the law are removed from the disability service system instead of being ‘moved on’
- NDIS Q&SC needs to provide oversight in response to the disconnect between management of some disability services and support staff
- NDIS Q&SC needs to ensure that people with intellectual disability themselves can speak up, including to managers, at a house level
- All people with intellectual disability need to be in control of decisions, with appropriate supports, about where they live, who they live with, and who supports them

2. How can the NDIS build the capacity and natural safeguards of people with intellectual disability to support them to be safe and get good outcomes?

First of all, **we would like to acknowledge the significant gains** made around choice and control being made available to some NDIS participants with intellectual disability regarding where they live. We commend any high-quality support that works alongside people with intellectual disability to choose where they live in ways that are also available to people without disability in the community.

For the NDIS to ensure this occurs consistently, it needs to look at choice and control in the context of the lives of many people with intellectual disability who live in group homes. It then needs to **introduce measures to counteract the entrenched practices** that drive the complete lack of choice and control in many people's lives. For example:

- Not enough people are supported to handle as much of their own money as they can
- The day-to-day movements of many people with intellectual disability are too often determined by the activity of their co-residents and staff

In order to be safe and get good outcomes, people with intellectual disability need supporters around them who are aware of their own power. Supporters also need to be prepared to act decisively when needed. Therefore, staff in group homes need to understand choice and control, and the power imbalance that is inevitably present in all support worker-participant relationships. Additionally, they need to learn how to counteract these factors as much as possible.

Recommendations

- Provide high-quality support so all people with intellectual disability can exercise the same choice and control over where they live that is available to people without disability in the community
- The NDIS needs to introduce measures to counteract entrenched practices that drive the lack of choice and control in people's lives
- The NDIS needs to introduce measures to support staff in group homes to learn about genuine choice and control for people with intellectual disability, including about the power imbalance inherent within all support worker-participant relationships

3. What should the NDIS do to get the right balance between choice and control, the dignity of risk, and supporting people with intellectual disability to be safe?

It is easier for support workers to strike a better balance between choice and control, and dignity of risk, when they are providing 1:1 support. However, the balance between choice and control, and supporting people to be safe, ultimately comes down to individual support workers within the context of the organisations in which they work.

Another complicating factor is that **choice and control can be left for the NDIS planning process rather than the 'everyday' in people's lives**. For example, if an NDIS participant has a goal to make more friends, what we often see is that support staff become the participant's 'friend' and do not support the participant to make real (unpaid) friends within the community.

This is critical because choice and safety are far more effectively facilitated when people are not isolated from their communities and have more natural, unpaid supports.

Support Coordination needs to be clearly defined within the NDIS Practice Standards. This is because many staff do not appear to understand the scope of their role. To minimise this, **Support Coordinators need good, standardised training** on the support they need to provide so that support workers and others can strike a more effective balance between choice and control, and supporting people to be safe.

Another issue the NDIS needs to take into account when working to balance choice and control, and supporting people to be safe, is the issue of **building the capacity and safety of people with intellectual disability to share their thoughts, feelings and perspectives**. This means that people need to be given genuine opportunities to learn self advocacy skills, and staff should receive training to look for opportunities where they can support people to speak up in their daily lives.

Critical thinking is essential. There are many situations where the balance between choice and control, and supporting people to be safe, is legitimately complex. But what we find is that instead of working to find sensible, practical solutions, **some service providers tip the balance unreasonably toward supporting people with intellectual disability to be safe**. For example, we are aware that in some group homes where an individual has been medically diagnosed as having a risk of choking, that restrictions have been indiscriminately placed on all co-residents. This restricts the freedom of all other residents and demonstrates a lack of ability or willingness of staff to think through the issue in a deeper and more nuanced way to arrive at a more sensible conclusion.

It is also a systemic issue: if there aren't enough staff on a given day to support 1:1 service provision, then service providers such as Day Services are forced to decide between phoning families to let them know (which puts stress on families) or forces participants who are paying for 1:1 support into group activities. **It is difficult to demand excellence when the infrastructure is not there to support it.**

Recommendations

- The NDIS needs to understand and prioritise the provision of 1:1 support in people's NDIS plans instead of favouring the status quo of group support
- The NDIS needs to clearly define Support Coordination within its Practice Standards
- The NDIS needs to ensure that Support Coordinators have good, standardised training in supporting workers and others to strike a more effective balance between choice and control, and supporting people to be safe
- The NDIS needs to ensure that people with intellectual disability are given genuine opportunities to learn self advocacy skills
- The NDIS needs to ensure that staff are trained to look for opportunities where they can support people with intellectual disability to speak up in their daily lives
- The NDIS needs to ensure that its guidelines encourage and support service providers and staff to engage in critical thinking rather than default to 'easy', overly cautious solutions that unreasonably strip people with intellectual disability of choice and control
- The NDIS needs to examine systemic issues and identify drivers behind these in order to identify solutions that target the underlying problems – for example, people with intellectual disability not having a say in where they live or who they live with

4. How can all levels of government work together to prevent harm and promote quality in the supports people with intellectual disability receive?

The time for the NDIS and State Governments to **work together and acknowledge the harm experienced by people with intellectual disability** who fall between the gaps of services provided by different levels of government is well overdue.

Further, there are limited options for people with intellectual disability, their families or support providers to facilitate relationships between people with complex communication needs and people with and without disability in the community.

Recommendations

- All levels of government should acknowledge the harm they are causing people with intellectual disability by 'buck passing' between one another rather than filling the gaps between services provided by different levels of government. The disconnect between the Federal and State Governments causes harm and compromises quality and safety in the services people with intellectual disability receive.
- All levels of government should be in communication with one another about the work each is doing within the disability sector. For example, both State and Federal Governments must be accountable for issues that negatively impact people with intellectual disability as part of their duty to all Australian and Victorian citizens.
- All levels of government should work together to prevent harm and promote quality. For example, local government (Councils) could provide local services for NDIS participants living in group homes and other segregated settings for people with disability.
- All levels of government should fund proactive approaches to enable community members to engage with people with intellectual disability. For example, Choice Mentors was a pilot program run by VALID and the Victorian Office of the Public Advocate (OPA) to facilitate support for decision making, as well as the potential for friendships to develop, between people with intellectual disability and other members of the community.
- All levels of government should provide mechanisms to support the involvement of people with intellectual disability on Disability Advisory Committees

5. What can be done to make progress in reducing and eliminating practices that restrict the rights or freedom of movement of people with intellectual disability?

We have seen that **segregating people into homes not of their choosing** based on the nature of their additional support needs (e.g., medical, behavioural) results in an increase in practices that restrict the rights and freedom of movement of people with intellectual disability. This often occurs because it is seen as easier and more cost-effective to build housing that caters to a specific type of additional support need and then provide specialist staff to support 4-5 residents with that need. **The problems this creates are many and substantial**, especially for people who predominantly use their behaviour to express significant distress ('behaviours of concern').

We have also seen the impacts of a **lack of training and proper oversight over practices in, and the culture of, individual group homes**. One example[1] that might be avoided with such training and oversight is that of one group home in which a person who can only eat soft foods for medical reasons is only permitted by staff to drink smoothies instead of being supported to eat a variety of other unblended soft foods that are within medical guidelines.

Some parents who are requesting Supported Disability Accommodation (SDA) for their adult children would likely benefit from **support to understand the benefits of alternative options**. This is important in terms of making progress in reducing and eliminating practices that restrict the rights or freedom of movement of people because it gives them greater scope to:

- Choose where they live and who they live with
- Experience the benefits of supported decision making in general

Getting to know each individual and their needs is critical. One difficult example is around chemical restraint: at one end of this discussion, there are real, immediate concerns about the inappropriate medication (chemical restraint) of people with intellectual disability. At the other end, there are concerns that people with intellectual disability cannot trial medications for issues such as depression or insomnia in the same way other people in the community can unless these conditions are formally diagnosed.

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[1] Example has been anonymised for privacy reasons

Recommendations

- Provide the necessary support and infrastructure for people with intellectual disability to live in their own homes with people and supporters of their choosing
- Ensure that support staff training addresses, and that managers and the NDIS Q&SC have oversight over, the practices and culture of each group home
- Address people's individual needs rather than seeking to fit them into ready-made systems that do not work for them
- Provide support for families so they in turn can provide supports and environments in which they and their children can express themselves, think and dream big for their futures
- Provide support and training for Support Coordinators to find out and act on what school leavers with intellectual disability want to do and provide mainstream options rather than automatically placing them in Day Services after Year 12
- Ensure that the provision of 1:1 support has a strong focus on capacity building
- Facilitate and support a better interface between the disability, education and health sectors
- Continue to work to strike an appropriate balance between dignity of risk and duty of care by rejecting generic, all-encompassing rules around most issues, and getting to know each individual and their needs

Community Development and Engagement

1. How can the regulation of providers and workers be used to improve the quality of services and supports for people with disability?

- Providers sometimes **lack flexibility** in their times to visit: individuals are being told to work around the providers' own times and locations
- Staff have **low motivation** to do their job well, and **low job satisfaction** leads to poor quality work/service. Accountability of support workers often rests with vulnerable people (participants) who depend on their services.
- **Low staff numbers** – new staff continually entering the workforce who need training at the start of each shift

Recommendations

- For the NDIS and disability providers to **give more detail** in their own quality measures
- **More training** of providers and workers
- **Better understanding of policies and procedures** for all stakeholders
- Better policies and procedures
- **Better handover** of staff between shifts
- **Better understanding of the individual** person with disability
- More ways for participants to give **feedback** about support workers

2. How can the NDIS build the capacity and natural safeguards of people with disability to support them to be safe and get good outcomes?

- There are **not enough accessible versions of policies and rights** that people with intellectual and other disabilities can understand easily or at all
- It is **hard to keep up with changes** to the NDIS
- To build capacity and natural safeguards, **people need both peer and community networks**
- People cannot be safe or get good outcomes if their **mobility equipment is damaged** and repairs take a long time
- **Some participants feel judged** when they suggest ways to build capacity for themselves

Recommendations

- More **Easy English** versions of policies and rights
- **Better sharing of information** when changes are made to the NDIS
- **Increased capacity for peer support** – peers are a reliable source to share information about resources, connections, good providers, their experiences, etc.
- **Grow community networks**
- **Build the capacity of mainstream groups and organisations** to be more inclusive of people with disability
- **Faster turnaround** to get repairs done and/or reasonable and necessary adjustments installed/amended
- **Empowering individuals** to design ways to build their own capacity. ‘Building capacity’ options can be co-designed by people with disability.

3. What should the NDIS do to get the right balance between choice and control, the dignity of risk, and supporting people with disability to be safe?

- **People with disability do not feel listened to or understood**
- Some individuals need more support, whereas others are **less able to judge risk**
- Some people with high support needs choose low levels of support because **communicating is exhausting**

Recommendations

- For everyone who supports people with disability, or manages their supporters, to **listen to and understand** clients more, and to make extra effort for people with higher support needs
- **Consider the scale** of the individual's capacity
- **Better resources and better support** to interpret the risks
- **Respect participants' rights** – must not be unnecessarily restrictive
- If high risk, **suitable supports must be in place** – are risk assessments appropriate, or do they take away one's dignity of risk?
- The various staff who support people all need to have an **understanding of risks** being taken by participants they work with
- Understanding 'dignity of risk' – for participants, workers and supports – also needs input from allied health, psychology, social workers and supporters
- Provide **person-centred support** when providing higher levels of support, and **be mindful** of people's energy levels

4. How can all levels of government work together to prevent harm and promote quality in the supports people with disability receive?

- **The system feels messy**
- There are **too many low-quality service providers**
- There is **not enough collaboration** between different levels of government

Recommendations

- **Be clear about roles** and who is doing what
- **Have checks and balances** in place. Ask: are they doing a good job?
- Have **effective responses to reviews** at all levels of government
- **Use funding effectively**
- Have **more checking of service providers**. Standards should be sector wide.
- **More conversation and co-design** between levels of government
- The **Victorian Office of the Public Advocate (OPA)** needs to be better resourced

5. What can be done to make progress in reducing and eliminating practices that restrict the rights or freedom of movement of people with disability?

- It feels like participants are often **shut down, dismissed and ignored**
- Services can feel domineering because they don't listen. They have the power. If participants don't fit into their schedule, calls are not responded to. There is **very little real choice and control**, especially in rural areas.
- **Service providers give very little time** for supporters to understand participants' needs
- People with disabilities feel **commodified**
- Many **workers are short term**
- **Things are not explained well**
- Some Day Services are not allowing participants to **access community** in meaningful ways

Recommendations

- **More services**, carers, supporters, funds
- **Support** in troubleshooting issues
- Support Coordinators and/or Local Area Coordinators (LACs) to regularly assess whether participants are satisfied with how they are **participating in community**

Training and Consultations

1. How can the regulation of providers and workers be used to improve the quality of services and supports for people with intellectual disability?

- While regulation of providers and workers is essential, this is only one part of the issue – and therefore, **there is only so far regulation can go** in terms of improving the quality of services
- Many people enter the disability sector as a 'stop gap' job – i.e., it is the job they do while training to do something else. Many who work in the disability sector for this reason do not attach great importance to their job, **which reduces the quality of their work**.
- **Communication** between support workers and participants can be difficult for a range of reasons, and the complexity of this issue needs to be addressed

Recommendations

- A holistic approach should be taken to consider how to **boost the profile of disability support work** as a long-term profession
- **Training** is needed that addresses people's values base and respect for the work they do
- A nuanced approach is needed to **address the reasons behind communication issues** between support workers and participants – e.g. complex communication needs or one or both parties having English as a second language

2. How can the NDIS build the capacity and natural safeguards of people with intellectual disability to support them to be safe and get good outcomes?

Disability support staff need **incentives to build their skillset and continue to work within the sector**. These incentives include appropriate remuneration for qualifications and a personality suited to the role one is undertaking.

A person's training and qualifications are less important than the **qualities and characteristics** they bring to a disability support role. These should align with values of **empowerment** and a belief that the **human rights** of the person being supported are paramount, as well as values of **respect** and **kindness**.

These factors will build the capacity and natural safeguards of people with intellectual disability because if the values of a person's support staff fit the nature of their role, and if they have ongoing training, fair remuneration and love their job, they are more likely to **connect deeply with the people they work with**.

For this to work in practice, a **holistic infrastructure** is needed: the NDIS and other funding bodies need to support organisations to provide environments where **management and staff are rewarded for being genuinely person-centred in their work** with people with intellectual disability.

When there is a real shift from 'just doing a job' into **building the capacity of people with intellectual disability to live their best lives**, this is when people with intellectual disability will be supported to be safe and get good outcomes. This shift is not only needed at a support staff level, **but also at management, organisational and government levels.**

Recommendations

- A **personality assessment** for potential support staff to determine whether they have the values and qualities needed to properly undertake the role
- A **holistic infrastructure** that supports people with intellectual disability to be safe and get good outcomes through the prioritisation of person-centred support at all levels
- The NDIS and other funding bodies need to **support organisations to provide an environment where management and staff are rewarded for being genuinely person-centred** in their work with people with intellectual disability

3. What should the NDIS do to get the right balance between choice and control, the dignity of risk, and supporting people with intellectual disability to be safe?

If people are not given the funding to support them in the ways they need to be supported, **they will continue to be set up to fail and remain unsafe**.

Person-centred planning, thorough documentation of issues that arise around choice and control / dignity of risk / safety, and conversations about how to support a person the way they need to be supported are **critical factors in getting this balance right**.

Recommendations

- The NDIS should provide funding for **person-centred planning**, **thorough documentation** of issues that arise around choice and control / dignity of risk / safety, and for **conversations** about how to support a person the way they need to be supported
- **NDIS planners need to genuinely get to know people**. This needs to go beyond a 1-hour planning meeting, otherwise people are at risk of 'falling through the cracks'.

5. What can be done to make progress in reducing and eliminating practices that restrict the rights or freedom of movement of people with intellectual disability?

Recommendations

- Provide a holistic infrastructure that supports (financially and in terms of overall culture):
  - **Person-centred** planning
  - People being supported to **live lives of their choosing**
  - **Contact** with people's families
  - **Observation** and thorough **documentation** of how people respond in different environments, and what they like/dislike
  - **Staff meetings** where staff can have honest discussions about which staff are best suited to work with different clients

Individual Advocacy

VALID's Individual Advocacy team did not respond directly to **Q2: How can the NDIS build the capacity and natural safeguards of people with intellectual disability to support them to be safe and get good outcomes?**

This is because their answer is embedded in their responses to questions 1, 3, 4 and 5: When people with intellectual disability are supported to live lives of their choosing with the supports they need, this will naturally increase their safety and outcomes – as it does for all of us.

1. How can the regulation of providers and workers be used to improve the quality of services and supports for people with intellectual disability?

This question is an example of one that the Individual Advocacy team has necessarily expanded on its scope. This is because the inherent issue is far too complex for the solution to be better regulation of providers and workers.

There are real structural issues that make improving the quality of supports and services for people with intellectual disability hard to safeguard:

- **NDIS Q&SC**: Even if the NDIS Q&SC were better resourced, VALID's Individual Advocacy team is skeptical that more will be done when people complain. This is because:
  - **Big providers** are getting away with being dishonest to the NDIS Q&SC, and not nearly enough checking occurs on this front. VALID's experience of making a complaint to the NDIS Q&SC is that the wait time is substantial. When the complaint is dealt with, it is dismissed because the provider informs the Commission that 'everything is fine' when VALID knows that this understanding is not based on speaking to our clients and their families
  - **Big providers have a monopoly in some areas where the market is thin** and there is nobody else. This gives them more power in these areas.
  - **Communication issues between families and providers** are not easily addressed by the NDIS Q&SC. It will be problematic if work with families is not factored into how the NDIS works to improve the quality of services and supports for people with intellectual disability.
  - **Workforce issues** inhibit safeguarding measures, including within bigger providers
  - There is a **lack of responsible management**, and therefore management needs to be regulated. Just implementing more training and education in organisations for staff at the frontline level will not significantly change service delivery. There are already plenty of educational resources as well as workers who complete the NDIS Quality and Safeguards Training. Still, poor quality service is delivered, and abuse and neglect happen and are not always reported.

Recommendations

- **Regulation and enforcement** of quality service provision needs to be targeted at a high level in organisations: regulators need to hold executive teams responsible for poor service delivery
- **Structural issues need to be addressed. Families** need more support to handle issues and breakdowns in communication between themselves and providers.
- **Support providers** need further education to manage what are often high-conflict relationships between themselves and families
- **Further resources**, including time built into people's NDIS plans, are needed for providers who work with families and people with intellectual disability with 'behaviours of concern' to support relationships between providers and families

3. What should the NDIS do to get the right balance between choice and control, the dignity of risk, and supporting people with intellectual disability to be safe?

The root cause of the lack of balance between these factors is a broader social issue: ableism and a lack of social inclusion that makes it 'easy' for people to 'blame' someone's apparent lack of decision-making capacity on their disability, and then take away their choice and control.

While the NDIS is not solely responsible for this issue, it needs to acknowledge that one reason the balance referred to in this question is skewed is because people with intellectual disability are still not involved in the 'everyday lives' of many. This segregation results in a fundamental, widespread lack of understanding of the social nature of the challenges faced by, and innate capacity of, people with intellectual disability.

This issue extends to NDIS support providers and results in them exerting too much control that, while well-meant, appears to be rooted in the belief that people with intellectual disability cannot build decision-making capacity – or that the care teams supporting a person cannot build capacity to provide support for decision making.

Although the NDIA recently published their supported decision making policy, we still see NDIS planners taking away people's choice and control. It is especially important that this is fixed for people who have no family members or unpaid supports in their lives.

Recommendations

- **Education, in which advocacy can play a role,** around the importance of understanding the social nature of the challenges faced by, and innate capacity of, people with intellectual disability
- **NDIS to include funding for long-term supported decision making from Support Coordinators, allied health professionals, service providers and behaviour support practitioners**. VALID's Individual Advocates provide some supported decision making for people experiencing coercion, but a core tenet of effective supported decision making is knowing a person well. Therefore, if people who know and regularly support a person are paid to play a role in supporting their decision making, the person would benefit greatly. This means that supported decision making needs to be a mandatory part of these roles where it is needed.
- **NDIS planners** to assess whether a person needs supported decision making in their plan. Factors to take into consideration include whether a person uses verbal language to communicate or may need substantial additional support to make their own decisions.

4. How can all levels of government work together to prevent harm and promote quality in the supports people with intellectual disability receive?

VALID knows that if Support Coordinators describe to the NDIA people's involvement in the justice system and state the risk attached to the person through their offending, people do not always get the funding they need. This is because NDIS planners might say 'this person's issue belongs to the justice system and is not related to their disability', when we know that the person's intellectual disability is what landed them in trouble with the law in the first place – and that some people are kept on Supervised Treatment Orders (STOs) because they have an intellectual disability.

As a result of this inappropriate triaging of supports by the NDIA, the justice system is sometimes bound to keep people incarcerated or in treatment facilities for many years because they do not have enough disability support funding to be released into the community.

There are other examples of similarly inappropriate tensions between the NDIS and domestic and family violence services, the NDIS and Child Protection, and the NDIS and Health, that result in great harm and a lack of quality in supports as well as great financial cost to different levels of government. This can mean that **some people lose Support Coordination because a lifetime of engaging with services from a place of having been consistently traumatised means they may go through staff quickly.**

Support Coordinators, disability and other services are ill-equipped to work effectively with the many people with disability who have experienced, and are experiencing, trauma. This is because this work requires more resources: VALID's Individual Advocacy team knows that many Support Coordinators work in isolation, even within bigger organisations. Although the role of a Support Coordinator is to refer people to various services as needed, they still bear witness to and work alongside people in enormous distress. Without adequate supervision and support, Support Coordinators and disability services are unable to continue to support others, and are likely harmed themselves, in the long-term. In addition, further education and willingness on the part of some individual providers and organisations is required to mitigate this serious issue.

VALID's Individual Advocacy team has noticed a trend where people who continue to experience many layers of disadvantage and distress are 'given up on' by the NDIA. That is, VALID is not aware of any mechanism the NDIA has for checking in on people and alerting other services as appropriate (e.g., VALID, family violence services) that people are desperate, have seemingly 'voluntarily' disengaged from receiving NDIS services, and are at risk of further disadvantage, distress, and perhaps death.

This systemic failure perpetuated by NDIS processes, or lack thereof, embeds the labelling of people experiencing disadvantage and distress as 'difficult'. But as the Disability Royal Commission's report into restrictive practices highlights, '…perceived 'behaviours of concern' are distress, protest and resistance made in a context of maladaptive environments of concern.'[2] These environments can include engagement with NDIA staff, as people are not always treated respectfully by NDIS services, including call centre staff, Planners and LACs.

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[2] Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability – Research Report – Restrictive practices: A pathway to elimination, p. 9.

Recommendations

- **Better reporting and information-sharing** between all levels of government
- **NDIS planners to be alerted if funding is not being used** – for instance, if a person suddenly stops, or never begins to use, their Support Coordination funding, that should raise an alert. There should also be a mechanism by which professionals supporting people involved in the justice, domestic violence and other systems are informed when appropriate.
- **NDIA to maintain contact with participants that are 'hard to reach'** to periodically check in in respectful and person-centred ways as a means to keep the lines of communication open and build (or repair) trust
- **NDIS to be more vigilant around the potential for domestic violence** when participants consent to their partners, siblings or parents being their Nominee

5. What can be done to make progress in reducing and eliminating practices that restrict the rights or freedom of movement of people with intellectual disability?

It is critical to acknowledge that **when restraint is used, it is grievously harmful**. However, when supports are designed with the person in mind and followed consistently, **this harm can be reduced**. VALID sees some BSPs where restraints have been reduced due to a concentrated effort of services and behavioural support practitioners.

Unfortunately, **this does not occur in the majority of cases** seen by VALID's Individual Advocacy team.

We know from our work that there are gross violations of human rights in disability group homes, and in people's private homes where people live with family members and unregulated restrictive practice occurs.

NDIS service providers know about this.

Recommendations

- **Better management, education and staff supervision – including around the fact that lack of choice and control in people's lives is usually the problem**. Without better management and education, 'behaviours of concern' will inevitably increase when people are no longer sedated or otherwise restricted in order to mask environmental issues such as, potentially, living with people who abuse them.
- **Funding for Independent Advocates to review BSPs that state restrictive practices are to be used**. Reports submitted from previous reviews need to be accessible to the next independent person reviewing a plan to see if there were any concerns raised that have not been addressed. A well-described framework is needed to support and regulate the independent person's work.