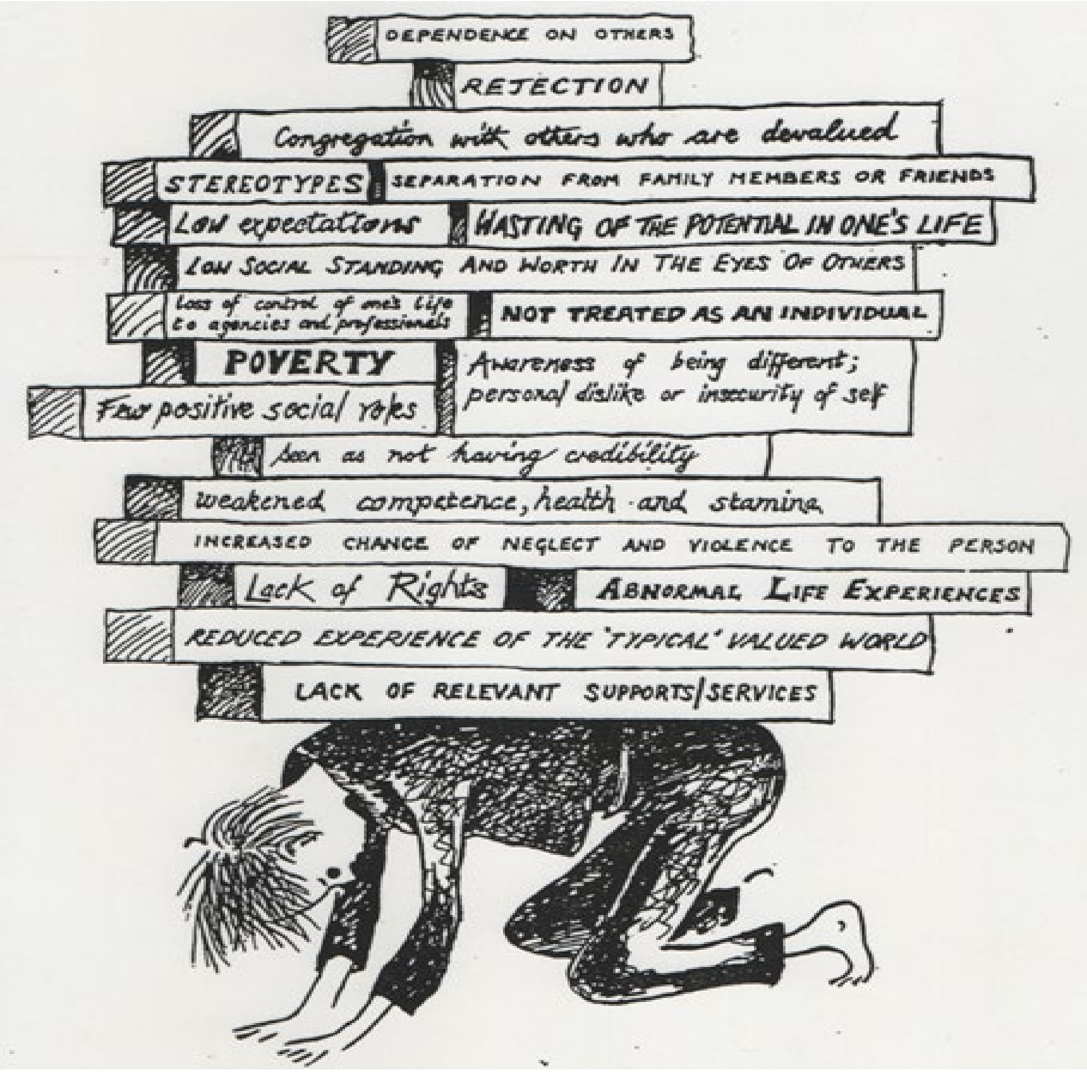
family ADVOCACY

Submission in response to the Proposals Paper on NDIS Participant Safeguarding, July 2023



The Impact of Devaluation (Image courtesy of Training Institute, Syracuse University, NY)

> *"The safest place for Mac is to be respected as a member of his community, to be engaged as a member of his community and to actually be in his community. The most dangerous place is for him to be an outsider and not part of the community."*
>
> *Gina, Mac's mum and disability advocate*

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Introduction

Family Advocacy is an independent disability advocacy organisation that works across NSW to safeguard the rights and interests of people who have developmental disability[1] through individual and systemic advocacy and building the capacity of families to advocate with, or at times, on behalf of, their family member. We were founded 32 years ago by the families of people with disability and continue to be governed by families, are values and rights based, and work to end the discrimination against people with disability, so that full and empowered lives can be experienced.

Family Advocacy appreciate the opportunity to provide a response to the Australian Government's Proposals Paper on NDIS Participant Safeguarding as part of the Independent Review of the NDIS. We applaud the Australian Government for identifying "that building strong natural safeguards is important, that risk and safeguarding processes need to be fit-for-purpose for participants, and that more intensive safeguards may be needed where participants might have more difficulty accessing or building natural ones."

Broadly speaking, we agree with the issues identified about safeguarding in this paper and the three complementary ideas being proposed. To strengthen these three ideas for safeguarding, we strongly recommend the following concepts be adopted and interwoven into them:

- Safeguarding and The Model of Family Advocacy
- Safeguarding by Creating Socially Valued Roles
- Safeguarding by Monitoring for Service Quality via Service Model Coherency
- Other Recommended Safeguards

Through these concepts, there is much scope to achieve the three draft proposals such as capacity building for advocacy development, supported decision making and self-advocacy, as well as mitigation from the impacts of devaluation and protection for the heightened vulnerability which many people with disability face on a daily basis in all areas of their life.

Our comments and recommendations are premised on over three decades of experience hearing from and working together with families who advocate with, or at times on behalf of, their family member with developmental disability in NSW, our widespread knowledge of national and international research in the field of safeguarding, the human rights-based principles espoused in the UNCRPD.

With this in mind, we also refer to and recommend the NDIS Review team read our previous submissions that are relevant to the Proposals Paper, namely those for the Australian government and the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (Disability Royal Commission):

Submission in response to the NDIS Quality and Safeguarding Framework Issues Paper

Submission No. 7 to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability: The important role of family and the Family Advocacy model

Submission to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability - Submission No.6: Response to Promoting Inclusion Issues Paper

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[1] Developmental disability is a disability that occurs in the developmental period of a person's life (in the period from conception to adulthood) and includes but is not limited to: autism, intellectual disability, cerebral palsy, spina bifida, and any combination of physical, intellectual or sensory disability.

Submission to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability - Submission No.5: Response to Restrictive Practices Issues Paper

Submission to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability - Submission No.3: Response to Rights and Attitudes Issues Paper

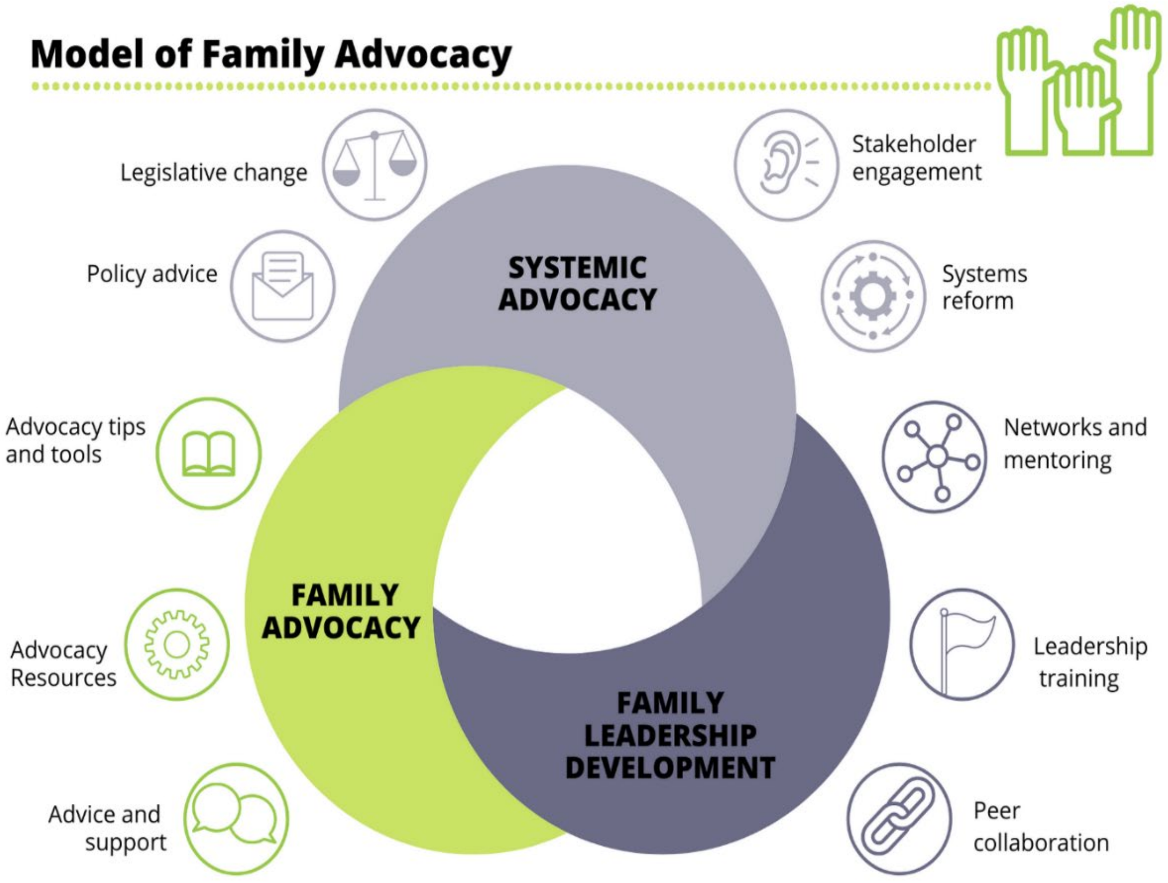
Endorsement of Disability People's Organisation of Australia's (DPOA) Segregation of People with Disability is Discrimination and Must End Position Paper

Safeguarding and The Model of Family Advocacy

As the Proposals Paper states, "60% of adults in the NDIS have conditions that could affect their decision-making capacity and 42% are less than 15 years old and will likely need support to be heard in decision-making or may not be old enough to make decisions on their own."

This means many people in the NDIS will need support to adequately self-advocate and/or make informed decisions. Whilst we acknowledge there are people who do not have family, in the majority of cases, it is the family that provides this support, especially for their child with disability, and this will be the focus of our submission.

The infographic illustrates the Model of Family Advocacy. A comprehensive study has been undertaken by UNSW, Social Policy Research Centre's (SPRC), see Family Advocacy Model Research report.



Below is an extract from Family Advocacy's Theory of Change from the 2023 Strategic Plan, Change, to illustrate the paths followed to safeguard the person with disability.

Family Advocacy's theory of change

- We deliver advocacy advice and support, workshops and mentoring to shift expectations and create a strong vision for an inclusive life.
- Families become agents of positive social change and support their family member to live a full life embedded in community.
- The rights of people with disability are recognised and upheld and they live in inclusive, accessible communities with natural and formal supports, connections and relationships.
- Everyone in the community expects to share the same environments as people with disability and understand, uphold and safeguard their rights.

Advocacy support, resources and skills
Families are empowered to strive high and learn about the rights and interests of people with disability. Family supporters develop skills, vision and confidence to speak up alongside or at times on behalf of their family member with disability and in doing so seek out and create opportunities for them to lead valued and inclusive lives.

Leadership development and leadership roles
Families are supported to participate in leadership training, mentoring, they connect with one another in leadership development opportunities, through peer networks and advocacy related events. The strengthening of vision, capabilities and connections, over time, help families to influence change to broader communities and systems themselves. They become agents of positive social change through leadership within families, communities and systems.

Changes in leadership, protection and progression of rights
Family leaders across NSW volunteer to advocate for system change together with grassroots organisations (e.g., have input into policy development). Families act as a safeguard so that an inclusive life can be realised by their family member with disability – where the rights and interests of people are upheld, equal opportunities to participate are created, and the community and policymakers expect people with disability to lead inclusive lives.

People with developmental disability lead lives embedded in community through the focus on the attainment of socially valued roles
People with disability realise their goals, contribute socially and economically and lead inclusive lives through the support of families. The rights and interests of people are protected and safeguarded through the advocacy leadership development of families
In many cases, family advocacy is undertaken when their family member with disability

We fully support the notion the advocacy undertaken by families is the greatest safeguard. Indeed, the Family Advocacy model is built on the premise to fulfill a need for advocacy development, so that family members could conduct the most potent and effective advocacy possible, with, and at times on behalf of, people with developmental disability. This includes building the capacity of the person with disability and their family member around understanding devaluation and how to mitigate this through creating socially valued roles (Theory of Social Role Valorisation), understanding right relationships, how to support decision making, self-advocacy and self-determination.

It is important to note that where this model of advocacy differs from some other forms of advocacy is in the advocacy undertaken. For many advocacy organisations, for example, the formal advocate 'takes on' an issue and works to remediate it. Taking the person impacted out of the equation whilst the matter is being resolved. This model of 'doing for' forms a major part of the Australian disability advocacy landscape.

The Family Advocacy model, however, is truly person-centred, working to invest in people with disability and their families so they are well equipped with the knowledge, skills and confidence to take on the issue at hand. Our advocates are there to support at every point in the journey to advise and support, however, we do not undertake the advocacy required. The very nature of this approach naturally builds the confidence and resilience to take on the required advocacy around the person in their life. It also acts to alleviate pressure points that may build into a more critical issue. As people become more familiar with their child's rights, and their confidence in interacting with mainstream systems increase, often issues are alleviated much earlier on, thereby mitigating critical issues/barriers.

In many cases where advocacy is required, and the family member with disability has identified a significant issue or barrier, the person may not be able to address the issue without significant support of the family unit. Therefore, providing advocacy advice and advocacy leadership development to this group forms a critical component to protecting and safeguarding vulnerable citizens with disability.

Informal advocacy undertaken by families is both cost effective and provides an ongoing safeguard for the person with disability. If advocacy is undertaken, it is rarely a once off and so the development of advocacy skills is essential. Relying on professional (paid) advocacy to take up important issues as they arise in a person's life, will always be fraught as there will never be enough professional advocates to deal with the number of people needing advocacy.

There is also the risk of the easy and quick issues being dealt with in a system where little professional advocacy is available, simply as a means to get through the numbers. This is problematic as we know that many advocacy issues facing people who are extremely vulnerable and marginalised, can take years to reach any real conclusion.

A contemporary example of the recognition of the legitimacy of family, friends and allies in the life of a person with disability, is the number of people now acting as 'nominee' or the person responsible, for children and adults within National Disability Insurance Scheme (NDIS). They are representing the interests of the child or adult with disability ('by whom' is the advocacy being conducted and 'for whom' is the advocacy being conducted), putting forward the case for necessary supports (the 'what' that is being advocated for), by attending meetings, writing letters, providing reports from others, making phone calls, informing themselves via research and talking to others (the 'how' advocacy is being done).

Indeed, the acknowledgement and respect of the role of family in the lives of people with disability is one of the general principles listed to guide the actions of the NDIA. Family, in whatever shape or form it may have, has a critical and vital role in the care and support of any individual. For many people with disability, this reality can be lifelong.

We highlight that this type of advocacy is freely given by the family member but does require investment in the family member to build their advocacy capacity. Family Advocacy, as well as through one of our initiatives, Resourcing Inclusive Communities, aims to build capacity by assisting families to develop skills and confidence so that they make informed decisions around supports that facilitate inclusive individualised lifestyles for their family member with disability, such as:

- attending mainstream schooling (One of the Kids Workshops),
- gaining employment (School to Work Project) or
- individualised housing arrangements (My Home My Way)

- Inclusive Lives: Possibility to Reality
- a resource booklet called Developing Community Connections, Strategies for assisting a person with disability to connect with people around shared interests and experiences.
- Conversations for Collaboration – A student centred approach to parent educator collaborative engagement.

Case study – Penny (Parent) supports Al (Son), to live independently

After finishing his Inclusive Education in the regular class at his local high school, Al communicated to his family his desire to live independently. His mum, Penny, advocated at many points alongside Al to enable this to happen, from advocating around ensuring her son to the right information and level of supports, and navigating the barriers of the NDIS.

All their efforts paid off, and Al moved into his own home where he lives independently with supports in place, for one year now. He was delighted to host brunch at his place for Christmas. Unfortunately, too often, when people with disability face similar barriers, the end result is living in a group home that is not of your choosing and with people who are not of your choosing. If the family had not stepped up to advocate, this might not have been the case for him. Utilising this knowledge of and their relationship with the person, enables options to be explored that are sustainable in the long term.

We hear of many successful inclusion stories that highlight how key it is for a parent to hold a clear Vision for their child, thinking ordinary and typical, being included in mainstream society, high expectations in the long term, and good collaboration. Accordingly, it is essential the NDIS Review team recommends the investment in the advocacy leadership development of families and we suggest the Family Advocacy Model be expanded nationally.

Similarly, there needs to be an investment in building the capacity of providers and workers in the disability sector to provide disability competency training which could include knowledge and information, how to build supported decision-making skills, understand impacts of devaluation, the importance of creating socially valued roles for the person with disability as a safeguard, right relationships and service model coherency (discussed later in this submission).

Balance between the dignity of risk and safety

The Proposals Paper questions getting the balance right between dignity of risk and supporting people with disability to be safe.

Family Advocacy believes it can be dangerous to move too swiftly to self-determination and citizenship for the person with disability and overlook the potency of family in supporting the person to get there. It also acts as a means to make a vulnerable group even more vulnerable by removing informal safeguards. Family Advocacy understands that many families, like others in the broader eco system that surrounds the person with disability, may need capacity building to understand their role in contributing to the development of supported decision making and self-determination. However, it must be acknowledged that, for some people with disability there will always be a level of supports needed to see this lived out.

We also feel it's important to acknowledge that many people with disability (due to many factors such as devaluation and heightened vulnerability) have been limited opportunity to explore opportunities, develop preferences and to seek opportunities provided outside the service offerings they have experienced. Choice, in this regard is based on experience and as we have often only provided life limiting opportunities within the service sector, to genuinely explore this there will be many people left with choosing much of the same and even if it risks their personal safety. Informed choice needs opportunity and capacity and we have discussed this in detail in our **Submission to the NDIA on the Consultation Paper: Supporting you to make your own decisions**.

Circles of support which can be informal or formal such as Microboards[2] can also assist with building the individual's capacity to make informed choices whilst weighing up the dignity of risk. Everyone needs a support network to function well in their daily lives. For people with disability this needs to be more structured so that individuals can achieve their goals and have people looking out for their well-being. Intentional support networks are key to keeping people safe and supported into the future, especially after parents may no longer be able to. It is vital the NDIS Review team directs the capacity building of informal and formal supports to understand risk, how to cultivate supported decision making, and how to provide Circles of Support for the person with disability.

Safeguarding by Creating Socially Values Roles

Unconscious Negative Assumptions and the heightened risk of vulnerability

We appreciate the nuance in the Proposals Paper where it stated "Having disability is not inherently risky…In many cases, risk arises due to the attitudes and behaviour of other people, and the failure of others to provide suitable supports and environments for people with disability to be safe". People with disability face a heightened vulnerability not due to their disability per se but rather due to social devaluation[3]. Australian statistics show 47 per cent of adults with disability have experienced violence, compared with 36 per cent of non-disabled people (AIHW, 2022).

Social devaluation is largely unconscious. Devalued people suffer much damage from other people's unconsciousness. It is worthwhile briefly discussing the negative assumptions/ unconscious bias society generally has of people with disability and the impact this can have for the rest of their life. Confronting as it may be, some of the negative roles and perceptions that act as a barrier for people with disability being afforded the opportunity of having access to the good things of life that most Australians enjoy are listed below:

Not being fully human - We have many examples of comments from people to justify this, which are shocking. For example, being told the person with disability don't know the difference if they have a friend or not, do not experience grief, or do not need a medical procedure that most people would need. There are many examples were people with disability are not given the same access to rights, choices or the right supports to achieve this, things we would automatically afford as essential to a person that was not devalued.

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[2] For more information, see Resourcing Inclusive Communities website, https://www.ric.org.au/circles-of-support

[3] A Senate Community Affairs References Committee Inquiry 2015 found that "a root cause of violence, abuse and neglect of people with disability begins with the de-valuing of people with disability." How people with disability are treated at work, at home, at school and in the community matters.

An object of pity - charity recipient, with approaches often derived from a place of pity not rights or valued, often leaving the person more vulnerable.

Burden - people see the person with disability as a burden to the family or society more broadly. Unable to contribute back to society and to constantly take and not give.

Menace - crafted as a menace by being caged like an animal such as those reported in some schools. Being seen generally as being menacing such as violent, sexual deviate with this stereotype filtering across many people with a particular disability diagnoses and often carrying this unworthy reputation with them for years. Often, this dramatically affects how they are seen and what treatment they receive and, in many cases, putting them at substantial risk due to this.

Loss of authentic identity - not called by name but as “clients” or “participants” being equated with their impairment, for example, the downs girl or the autism kids. People see the label first or the role of client rather than the human behind it.

Eternal Child – people with intellectual impairment are often seen as children who will never grow up. Families who embrace this idea find it hard to break out from this. And of course, it is then reinforced by many specialist roles such as pediatricians, GP, service professionals, educators and broader society. All those reinforcing this negative assumption cause many people with disability only knowing this way of being treated and results in many learnt responses being experienced with this. ‘An adult man of 55 years who has a mental age of 6 years’ is a very common negative assumption and keeps many people trapped in childhood role forever.

Better off dead - people may not be aware they are thinking this way, however, we only have to look at the statistics around people with disability of all ages to identify that quality of life measurement that is afforded to most Australians, aren't often afforded to people with disability. Mortality rates are grossly avoidable, with many lives cut short due to a call from a medical specialist who decides whose life is worth living and what conditions makes a person’s life not worth living. This is a modern-day reality with medical safeguarding being seen as essential for both formal and informal advocacy.

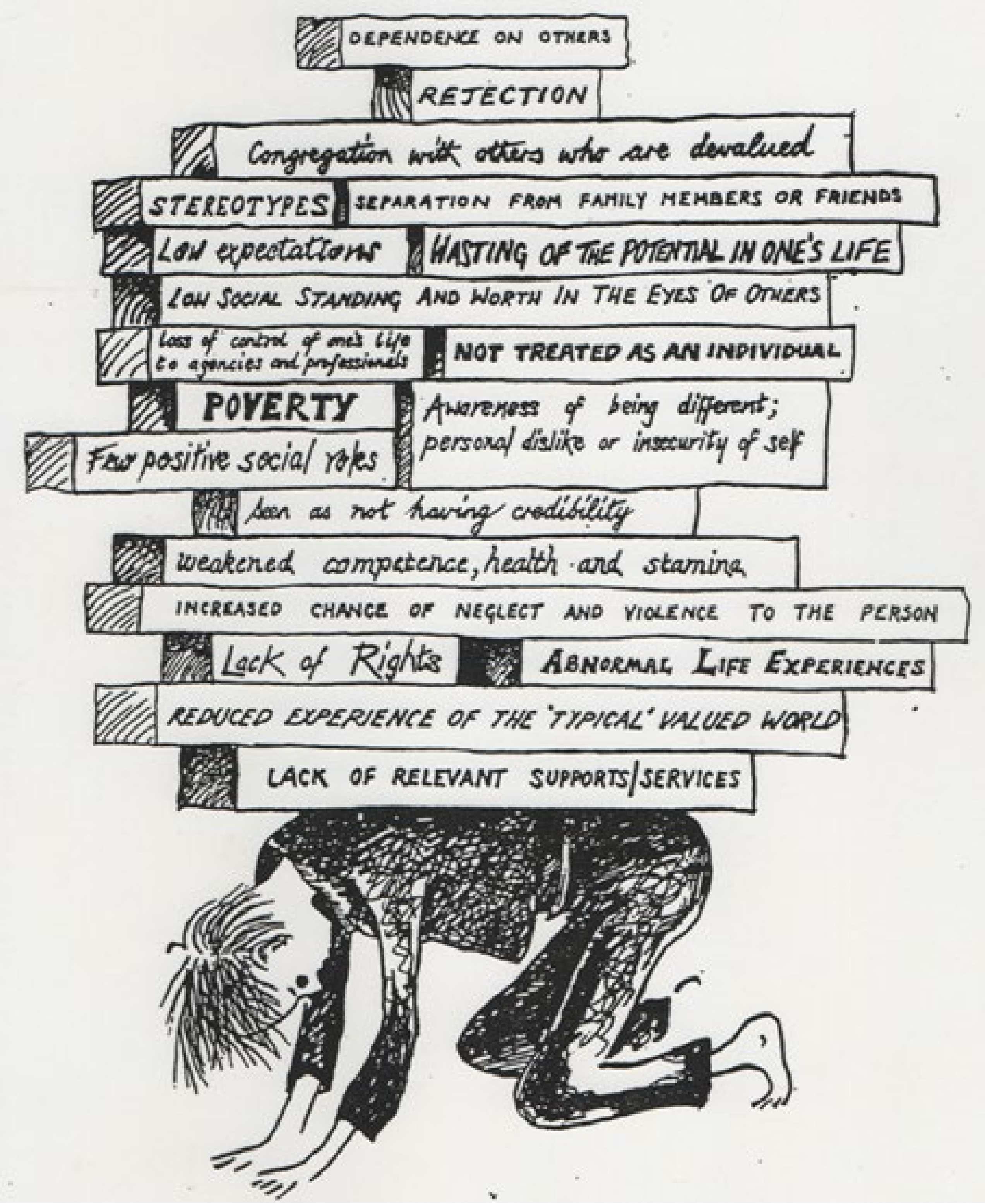
Understanding the impacts of devaluation

These perceived devalued roles bring with them horrific consequences. Rather than a person being seen with an identity, a personality, likes, dislikes, dreams, people are perceived as their impairment, a deficit orientation where one does not see the potential in a person with disability. For example, being spoken about as the Downs girl or the Autism boy rather than Jacqui or John. This type of thinking leads to the “othering” of whole groups of people, whereby it is assumed a person with disability needs to be in a special place with special people with special materials, such as is the case with special schools or support units. People with disability end up being distanced, pulled apart and away, physically and/or socially. It is this othering that can dangerously lead to the likelihood of abuse, neglect, violence and exploitation, of which we have heard many reports in the current Disability Royal Commission in all settings.

The image on the front cover and again below (The Impact of Devaluation) is very powerful as it illustrates the impacts of negative attitudes towards people with disability can often start to accumulate – wounds, discrimination, devaluation, needs not being met, loss of opportunity, rejection, segregation, lack of choice, sometimes poverty and risk of abuse. These happen through social processes of restriction, control, scapegoating, de-skilling and negative imaging.

The response of an individual or group to this devaluation may reinforce the negative social perception of them in a highly negative and damaging feedback loop. We can see some of the outcomes of being cast into a negative social role.

The Impact of Devaluation[4]



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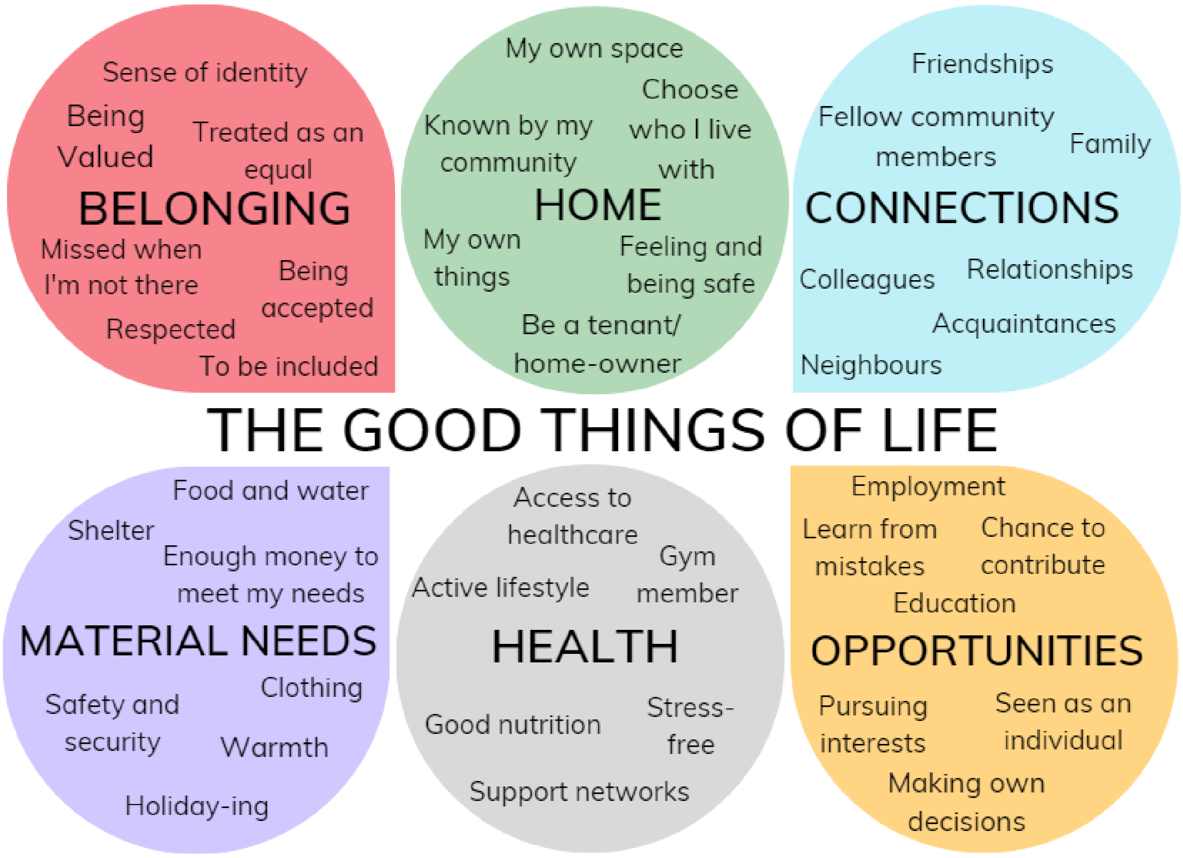
[4] This material belongs to the Training Institute, Syracuse University, NY.

Reducing the negative impacts of devaluation by creating Socially Valued Roles

The theoretical and practical framework of Social Role Valorisation (SRV) created by Wolf Wolfensberger[5] provides us with a strong foundation and pathway to ensure a person with disability lives a life of value and belonging in the heart of their community. According to SRV, how people are perceived and treated by others, and whether they are accorded the good or the bad things of life, depends largely on the social roles they are seen to fill.

Roles give a person a “place” in society. People who hold positively valued social roles are highly likely to be positively valued by others, and to receive from society those good things in life that are available, are more likely to enjoy normative settings, activities, and routines, to be respected by others, to have positive relationships with others.

We distinguish the good things of life from “a good time”. To ensure there is no confusion, we believe it is worthwhile briefly exploring what we mean by the good things of life, as depicted in the diagram below.



For all of us, as individuals, these are really important aspects because they provide richness, variety, choice, safety, purpose, happiness and fulfilment. And so, access to the good things in life is equally as important people with disability to achieve as well. Having said that, we know it’s not always as

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[5] Wolfensberger, W. A brief introduction to Social Role Valorization. A high-order concept for addressing the plight of societally devalued people, and for structuring human services. (4th edition.) Plantagenet, Valor Press, 2013.

easy for a person with disability to access, however, the good news is many families share with us stories that, it's the pursuit and **holding a strong vision, along with intentional planning to create socially valued roles, that can help to achieve the good things of life.**

People who occupy social roles that are negatively valued are themselves likely to be devalued and more likely to get settings, activities, and so forth that valued people in society would not want, to be kept apart rather than welcomed into societal participation, to be subjected to non-normalizing conditions altogether. In fact, harmful and hurtful things are common occurrences, even to the extent of jeopardizing their lives, though often those who inflict this harm are unaware of doing so.

Apart from the accessing and enjoying the good things of life, once a person with disability has socially valued roles, then the likely benefits in all probability, are:

- Image enhancement and defence
- Opening of opportunities – access to valued places, positive association, competency development, all sorts of good things of life
- Have defenders and protectors
- Defence against being valued, being cast in devalued roles (employed by sheltered workshops for $2 per hour), being stuck with wounds, and any wounds becoming overpowering and life defining.
- Of special importance to people with cognitive impairment – that people will be seen as more intelligent

Very importantly, Family Advocacy has heard of instances where applying the SRV framework which focuses on placing the person in socially valued roles and accessing the good things of life very often leads to a significant reduction in any behaviour related concerns and hence the response of restrictive practices. By making changes to the person's environment such as support or home arrangements that better reflect the person's choices and preferences, the focus becomes more about improving the quality of a person's life rather than the reduction of the behaviour of concern (Carr et al. 2002). The natural flow on effect is though is that the behaviour of concern generally dissipates thereby reducing restrictive practices.

Throughout history, there has always been groups that have been devalued by societies all around the world. We as human beings often seem to put distance between "us" and "them." We see this time and time again, for example, the mistreatment of the Jewish people in the second world war to the many indigenous cultures around the world who often face a devalued status. It remains true in our own society today, and unfortunately, continues to happen to people with disability as well.

The process of these inequalities comes from <u>perceptions</u> of people, with the follow-on effect of this being that people and sometimes whole groups are placed into negative social role/s, for example, congregated settings such as special schools, Day programs, and group homes.

Thus, the key to living a typical normative life and even valued conditions of life for people with disability is to try to procure for them valued social roles, and to help them to carry out such roles. The two main avenues for achieving and maintaining positively valued social roles are **personal competency enhancement**, because many valued roles require certain competencies (for example, literacy as a student; skills in employment); **and positive social image**, because imagery both shapes and reflects a person's social roles, and conveys to observers what social roles a perceived party holds (for example. school uniform, work uniform).

Socially Valued Roles lead to Freely Given Relationships, the greatest safeguard

When asking the question, “what keeps a person with disability safe?” it is helpful to realise what doesn’t. The current approach in our society appears to believe the answer is a cocktail of human services, the NDIS, the government, and legal instruments.

Human services have limitations at keeping people with disability safe.

As much as we would like to think otherwise, human services are often run without considering the real needs of people, or how they are going to be of benefit to this person. They use the correct terminology such as ‘Person centredness’ but this is only at a superficial level, with the driving force being what suits the requirements of the business or what has historically occurred in the service sector. The relationship has become transactional, the person with disability has moved into the “customer” role, the focus has moved to costs, the visions of control over one’s life has been reduced to choosing from a business menu of product options.

In our society’s service-oriented approach, we tend to focus on providing people with disability with activities to do, which are not purpose driven or capacity building. And at worst, people with disability are left dormant with little or no avenue for development. Services are often coming up with solutions on how people with disability can spend their time. Whilst doing an activity, once a week is better than doing nothing at all, this is very different from supporting the same person to have a valued social role such as student or employee and belong in community, and to join in on what is expected of a person of a similar age. Many people and professionals in disability services still carry the assumption that this is out of reach for a person with disability which continues to reinforce the parallel life for people with disability and leaves them at heightened risk.

Unfortunately, valued roles are not being found in many of the traditional disability services across Australia. Many services currently providing supports to people within the NDIS, act in counter cultural ways to seeking valued social roles. Instead, they perpetuate negative roles such as ‘forever client’, often leading to many years spent in programs that do not lead to any of the normative pathways mentioned earlier. In many ways, providers are perpetuating the sense that people with disability are best placed segregated in different settings, doing different activities and interactions best served by formal supports instead of everyday community members. We alert the NDIS Review team to a recent news story “NDIS provider urged to ‘do better’ after vulnerable client found in squalor”. Aside from the negative aspects of the story regarding the neglect and exploitation of the service provider, we can see the main safeguard for this individual was the people at the local Pub who employed him. Without the socially valued role of “employee”, he would have easily slipped through the cracks and continued to be exploited by the service provider.

Funding has limitations to keep people with disability safe.

The NDIS is simply a funding scheme to provide services. Whilst the NDIS can certainly assist in providing services to meet a person’s needs, there is no guarantee of safety. The government will not keep people with disability safe. The need to call for the Aged Care Royal Commission and the Disability Royal Commission are proof of this.

Legislation has limitations to keep people with disability safe.

Whilst legislation (such as the Disability Discrimination Act) or legal instruments (such as providing Wills or Trusts) have the intent of protection and can be a tool to put the vision for a good life in place, they are not an end in themselves and are inherently limited. Whilst we acknowledge the role of the various safeguarding bodies such as the NDIS Quality and Safeguards Commission, it is not the panacea but merely a part of the mix of safeguarding measures of people with disability.

Freely given relationships are the best safeguard.

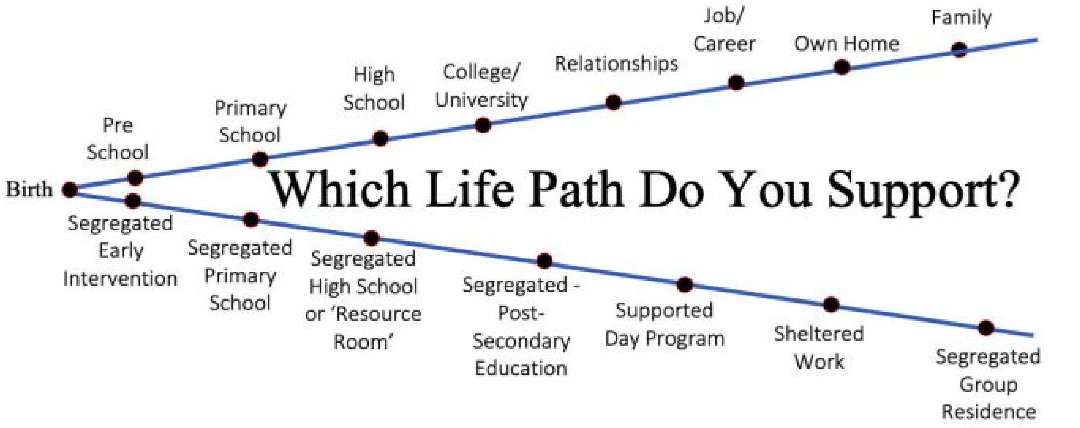
People who care for and love the person with a disability, keep people safe. Where a person with disability is in a freely given relationship and is part of community, these are the best safeguards. This is usually a family member, a work colleague, a flat-mate, a friend, a member of the community in which a common interest may be shared. These relationships are most often a byproduct of the person with disability having socially valued roles that are age appropriate.

On this basis, to bolster the safeguarding of a person with disability, it is necessary for the NDIS Review team to promote the importance of socially valued roles to all stakeholders including the person with disability and their family, service providers, the disability workforce and community. There is much more to discuss around SRV and we are happy to share more should there be an interest to learn more. However, for the purposes of this submission, our main point is that all supports, both informal and formal, need to understand why people with disability are devalued and how to mitigate the devaluation through people with disability having socially valued roles. We would recommend the NDIS Review team invest in SRV training for the person with disability/providers/workers and family members to understand how to mitigate against the negative impacts of devaluation.

Reducing the negative impacts of devaluation by promoting inclusion and phasing out segregation

Many families have found that being aware and conscious of negative labels, stereotypes and their impacts – allows for that greater protection and planning to avoid people with a disability falling deeper into this harmful loop. Fostering inclusion through socially valued roles from childhood has the potential to break the cycle of stigma associated with disability. Conversely, another major safeguard for people with disability is to gradually phase out segregation.

Segregating leads to segregation. This is best depicted in Dr Bob Jackson's diagram below which shows the natural pathways of childhood and the impact of an ordinary pathway versus a segregated pathway. For many people with developmental disability, due to the historical practice of being placed on a segregated path, valued roles have become out of reach. Every step taken down the segregated pathway is a step away from being part of regular society/community and being able to access the good things of life. As one family member noted, "the further you travel down the segregated path, the harder it is to come back to being part of the community".



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We cannot underestimate the damage that can be done due to subconscious devaluation and segregation. For example, socially devalued roles such as when children are excluded from a regular classroom, or young people are funnelled into a Day program or sheltered workshop, we set them up on a path of being “othered” and “done to” in all areas of their life. As discussed, they are seen as different and often are not afforded many of the good things of life.

Historically, due to social devaluation, society has believed the best place for people with disability is with “their own kind” and away from the rest of society. Sadly, we have come to learn that it is these very acts of congregation and segregation that perpetuate the social devaluation and leave people with disability more open to the risk of harm.

The findings from Royal Commission into Institutional Responses to Child Sexual Abuse Final Report (2017, Page 17) and interim findings of the Disability Royal Commission have made it abundantly clear, the dangers of segregation being a gateway to Violence, Abuse, Neglect and Exploitation. This finding prompted Family Advocacy to join with 42 organisations to call for an end to segregated environments. [6]

To provide a greater safeguard from harm, we need to gradually phase out all segregated settings towards typical everyday opportunities that align with the expectations that most Australians are afforded. For example, ALL children, even those with severe and profound disabilities, should be included in the regular class at their local school and special schools should be gradually phased out over time. We refer to the Australian Coalition for Inclusive Education’s paper - ‘Driving change: A roadmap for achieving inclusive education in Australia’ which provides a 10-year plan underpinned by six pillars to help realise inclusive education in Australia in schools. These pillars are drawn from the evidence base and embed the rights of children as set out in the United Nations CRPD.

Safeguarding by Monitoring for Service Quality via Service Model Coherency

We recommend that the NDIS Review team invest in learning about a relatively recent concept of Model Coherency, The Key to Human Service Quality[7], and Service Design and Evaluation (2021) and lead the service sector to a new frame of delivering quality supports that lead to better lives for the people they serve. We will not go into too much detail in this submission but provide a brief explanation and would be very happy to connect the NDIS Review team with the experts in this area.

Improved quality of a provider is paramount to safeguarding. Human service is a complicated endeavour, in which a number of component parts must fit together and work in harmony in order to benefit the recipients. Model coherency is about putting the component parts of a service together properly – coherently. **Model coherency answers the question, Are the right people being served by the right people, in the right setting, using the right tools and methods?**

We recommend the NDIS Review investigate the recently published book about Model Coherency, plus Service Evaluation and Service Design. This offers advanced insights into the fundamental importance of assumptions, service recipient needs, service content, the culturally valued analogue, the interconnection between model coherency and SRV, the construct of need and the distinction between service content and service process.

Model coherency involves constructs of relevance, potency and no avoidable harm, explained briefly below.

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[6] https://dpoa.org.au/endsegregation/

[7] W. Wolfensberger, Model Coherency, The Key to Human Service Quality, Volume 1 – An Explanation of Service Models, and Service Model Coherency; Volume 2 Designing a Human Service to be Model Coherent in Accord with SRV; Volume 3 – Evaluating a Human Service by Means of the Model Coherency Rating Tool (Valor Press 2021)

Relevance is precise matching of service content to a recipient's needs or problems. Major problems and needs are correctly identified and addressed with more basic/urgent needs and problems first (Hierarchy of needs). For example, body nourishment is more important than the need for say higher cognitive needs such as expressing one's creativity.

The questions to be asked are:

Who are the people to be served? What do they need? How should what they need be delivered? Using what methodologies, in what settings, in what kind of grouping, by what servers, and how should all of this be talked about?

And underpinned by what assumptions about each of the above?

Assumptions are really important. "A key thesis of the model coherency construct is that coherent models correctly derived from valid assumptions will tend to yield high quality service – indeed they constitute the essence of service quality." For example, the assumption that people should be segregated is the cause for segregated settings such as special schools, group homes, sheltered workshops and day programs. Another assumption is Devalued people are all the same and hence the grouping of devalued people of different ages, conditions, and degrees of need together.

Potency refers to the strength of the process for change, growth or learning likely to bring about a result. The question to be asked is:

What are the most powerful ways of delivering the content addressing the need? For example, dance therapy has much potency to build bodily strength but is not potent to deliver on a need for literacy.

One must also ensure **no avoidable** harm is inflicted that enlarges the problems or needs or the person.

Benefits of Model Coherency

- A model coherent service is more likely to be rooted in SRV and the valued culture
- Enhances awareness of the person with disability's real and most pressing need
- Provides a structural framework for pursuing SRV
- Is more likely to be both effective and image enhancing
- Is a powerful safeguard against deterioration for service quality
- Model coherency and service quality are highly correlated.

One of the ways a service provider can be measured is via the Service Model Coherency with a Rating Tool to evaluate a Human Service. We recommend the Model Coherency Rating Tool be adopted as a way of monitoring the quality of a service provider (in the NDIS and beyond). While we cannot thoroughly explore all of the areas, we do encourage the NDIS Review team to further study the writings about them in the recently published book from 2021[8].

Other recommended safeguarding measures

Community Visitors Scheme

Community Visitors are essential to monitoring the quality of a service. NSW has an Official Visitors Scheme administered through the office of the Ageing and Disability Commissioner. Family Advocacy note there are many versions across Australia. We recommend a nationally consistent Community

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[8] *Ibid. 5*

Visitors Scheme across Australia. It is vital the Community Visitors scheme is recognised and properly funded as an essential monitoring, outreach and visitation strategy to an expanded range of visitable services.

To keep their integrity, Community Visitors must be independent from government agencies and service providers. They should also have the ability to receive referrals, enter services without provider permission, visit all disability services (including in the case of referrals schools, hospitals etc.), make confidential reports, transfer information to other safeguarding agencies where relevant,be appropriately trained and paid.

In the NSW Official Community Visitors Annual Report 2021-22, we note, of the 2,030 visitable supported accommodation services for adults with disability, only 919 or 49% were allocated for regular visiting. We understand this is due to lack of funding. It is our recommendation that sufficient Community Visitors must be employed to enable them to make regular announced and unannounced visits to services and to make return visits as necessary.

Right Relationships between Service Providers and the Person with Disability (& their Family)

We provide case studies below showing how having the right relationships between family and services that really work, have a strong vision to promote age appropriate typical experiences have led to inclusive outcomes and natural safeguards. From our experience, the mark of quality of a service rests with the character and tone of the interaction between a person with disability and a support worker, that is, having the “right relationships”[9].

Regulations and quality audits do not sufficiently examine that interaction nor its supports. Audits are too preoccupied with items that relate to administration, policy compliance and reporting requirements that reveal little association to factors that influence the actual quality of service. Services that have met audit requirements have been found abusing and neglecting people.

And yet, many families we know who self-manage, tend to have great support staff in ordinary people as they have real choice and control over whom they employ and this tends to lead to less staff turnover, more consistency in staff leads to really getting to know the person with disability and their needs/interests and this ultimately leads to more trust and safety.

Case Studies

RACHAEL

Piano supporting Communication

Self-Management has allowed us to be creative in how we support Rachael to enjoy the journey working towards her goals. Generally, clinical supports are no fun they are dull, boring without any motivating factor (especially as kids become young adults) so we look for more exciting ways to build capacity. For example, Rachael was watching a movie with Miley Cyrus playing the piano. And she turned to me and communicated that she wanted to play the piano. I asked would she like to have piano lessons and I got a big Yes. And that’s what we did.

Piano lessons are building and maintaining Rachael’s dexterity and assisting her accessing her communication device. It also can allow for other opportunities to snowball into the next. Soon she did not need the key guard on her device, (which supported her access to the set screen template). So when that was removed, that opened up the opportunity to learn how to connect her mobile phone to the communication device to make phone calls, send texts, go on Facebook and messenger. Rachael

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[9] See 12 minute video on Right Relationships by Michal Kendrick or 32 minute video Right Relationships: Is it possible to create a partnership between families and services that really work? By Margret Ward.

is very social and really enjoys keeping in touch with her friends. Which led to connecting with her friends and also building her communication and literacy skills. And **her device has now gone from a 12 button per page template to now 60 button per page, so she is better able to communicate which is an important safeguard as she much more able to self-advocate and get her needs met.**

Gardener helps after a bicycle fall

Another example is about a family whose daughter, Janet, needed assistance with mowing the lawn. The family was weighing it up, and whilst the father could have done this, they chose to hire a gardener because it brought another person in that then knew the person in the community (people keep people safe) and because it was typical. Many months later, Janet fell off her bicycle whilst riding home from work. The gardener, who happened to be driving home from work, recognised Janet on the side of the road and so stopped and was able to help her. If Janet's parents had mowed her lawn, the opportunity for that relationship where she was known in her community would not have come about. And he was also able to communicate to the parents "she's okay but she might need a new basket!" For this family, they also felt more reassured that there are familiar people in the local community to lend a hand if needed, a natural safeguarding.

Reinstate the original intent of the Local Area Coordinator

For many years now, Family Advocacy has advocated the LACs role must be reviewed by the NDIA and it is time to go back to the essence and original intent of the LAC role. Bartnik and Broad[10], who were on the team that first implemented the concept in Western Australia, define the notion of local area coordination as:

about people and the communities in which they live. It's about understanding, celebrating and nurturing the strengths, aspirations, valued contribution, choices and rights of all people in our communities and the power, connections and possibilities of the communities in which they live.

As the NDIS has evolved, there has been a disconnect between this definition of the role and the realities of how the role of the LAC now works in the scheme. The success implementation of LACs worldwide has thrived on partnerships with local government, which is contrary to how in Australia LACs are contracted out to a few large service providers. It is imperative the original intent of the LAC role be reinstated, even if it is renamed. This role requires an understanding around SRV, devaluation, valued roles, and the good things of life as previously discussed, none of which to the larger extent have been provided to the current workforce of LACs.

Conclusion

We urge the NDIS Review team to adopt our recommendations and be interwoven into the three ideas being proposed, where relevant. If our recommendations were adopted, we are confident there will be much better outcomes for people with disability with more inclusion in community, accessing the good things of life which ultimately provide natural safeguards.

Family Advocacy welcomes the opportunity to answer any questions or discuss our ideas further.

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[10] E Bartnik, R Broad, Power and Connection: The International Development of Local Area Coordination, August 2021

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