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

> “The complaints system we have relies on people with disability making complaints rather than being proactive... the power differential is so great
>
> *Eleanor Gibbs, People with Disability Australia*[1]

Cecile Sullivan Elder
Executive Officer, Family Advocacy
cecile@family-advocacy.com

Leanne Varga
Systemic Advocate
leanne@family-advocacy.com

Family Advocacy
(02) 9869 0866
Suite 704, 88-90 George Street,
Hornsby, NSW 2077, Australia

Acknowledgement:

Family Advocacy would like to acknowledge the traditional custodians of the lands on which this report has been written, reviewed and produced, whose cultures and customs have nurtured and continue to nurture this land since the Dreamtime. We pay our respects to their Elders past, present and future. This is, was and always will be Aboriginal land.

---

[1] Whilst giving evidence at the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, Public Hearing 5: COVID-19, Sydney, 19 August 2020

Table of Contents

Introduction

Family Advocacy is an independent disability advocacy organisation that works across NSW to promote and defend the rights and interests of people who have developmental disability2 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 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 they can live full and empowered lives.

We acknowledge the advocacy undertaken by families can be the greatest safeguard in their family member's lives. One of our initiatives, Resourcing Inclusive Communities, aims to assist families to develop skills and confidence so that they make informed decisions around supports that facilitate individualised lifestyles for their family member with disability, such as attending mainstream schooling, gaining employment or individualised housing arrangements.

Putting the person with disability at the centre of the decision making with regard to arrangements and supports is a critical component of this. And it is with this in mind, we are strong promoter of self-managing within the NDIS scheme. We believe this to be one of the most beneficial gateways to achieving self-determination, authentic social and economic inclusion, individualised living and generally as a means to participate and contribute within the wider community.

Family Advocacy appreciate the opportunity to provide a response to the Australian Government's NDIS Quality and Safeguarding Framework (Framework) Issues Paper as part of a review of the NDIS Quality and Safeguards Commission (the Commission). We applaud the Australian Government acknowledging the Framework requires a reset in order to drive more effective quality and safeguarding arrangements with a commitment "to ensure it is fit for purpose and reflects the lived experiences of the disability sector".

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, and the multiple submissions we have written for the NSW and Australian governments and the current Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (Disability Royal Commission).

We recommend the Commission take heed of our main points below:

- Broaden the scope and audience of the Framework
- Promote a positive culture of quality supports that lead to the good things of life
    - Changing community attitudes
- Put more resources into the developmental safeguards
    - Invest in the advocacy leadership development of families
    - Provide training around devaluation and how to mitigate this with socially valued roles
    - Build capacity for Supported decision making and Circles of Support
    - Strengthen capacity building for supported decision making
    - The Framework must support the call for an end to segregation

---

[2] 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.

- Provide clarity and consistency
- Ensure the Framework strikes the right balance to promote self- management and the use of unregistered providers with the need for safeguarding
- Place a greater focus on the reduction and elimination of Restrictive Practices rather than the authorisation process
- Ensure greater transparency and a more robust process of any investigations that ensures families, informal supports and the person are involved not just the service provider.
- The need for advocacy to support a person with disability

Broaden the scope and audience of the Framework

In a previous submission to the Joint Standing Committee into the NDIS[3], Family Advocacy expressed concern that some elements of the QASC are weaker than others and the establishment of the NDIS Commission will not provide comprehensive protection against violence, abuse and neglect for all people with disability across a broad range of service systems and situations.

We noted that our support for an independent, national statutory mechanism and the recommendation from the Senate Community Affairs References Committee was not confined to the NDIS. We highlighted the NDIS Commission will only provide protection to the 10% of people with disability who directly access NDIS supports. It will not have a mandate to address individual or systemic issues outside of the NDIS. This means that the majority of people with disability, as well as NDIS participants when interacting with other mainstream systems, will only have protection through existing regulatory and policy frameworks that have to a large extent been shown to provide inadequate protection.

Indeed, it is the failure of these regulatory systems which led to the establishment of a Royal Commission into the Violence, Abuse, Neglect and Exploitation of People with Disability. Therefore, we need urgent changes to improve the way the current safeguarding is overseen and implemented and broaden its remit to include all services.

Education provides a good example of where students with disability are subject to neglect and harm and why this broadening is necessary. The Parliamentary Inquiry in New South Wales on Education for Students with Special Needs (2017) heard that advocacy groups ‘are getting increasing reports of restraint and seclusion’ (Legislative Council Portfolio Committee No 3 — Education, above n 14, 24; and 106) and reported serious concerns about ‘harm caused to students when practices like restraint and seclusion are used’.

Further, the data from a 2017 Australia-wide survey of 745 families (parents, carers, and students with disability) showed over 70% report experiencing one or more examples of gatekeeping used to minimise the enrolment into mainstream, and/or restrictive practice (Poed et al. 2017).

This demonstrates that only having guidelines as is the case with the Disability Standards for Education 2005, are not enough to motivate all schools to reduce and ultimately eliminate restrictive practice. We note the Department of Education has in Term 1, 2023 released a Restrictive Practices Framework. The implementation of the National Disability Insurance Scheme (NDIS), and the Framework are only limited to the regulation of NDIS-funded supports and providers. A student with disability, being subject to repeated unauthorised restrictive practices at school ought to have an

---

[3] Submission to the NDIS Joint Standing Committee into the NDIS

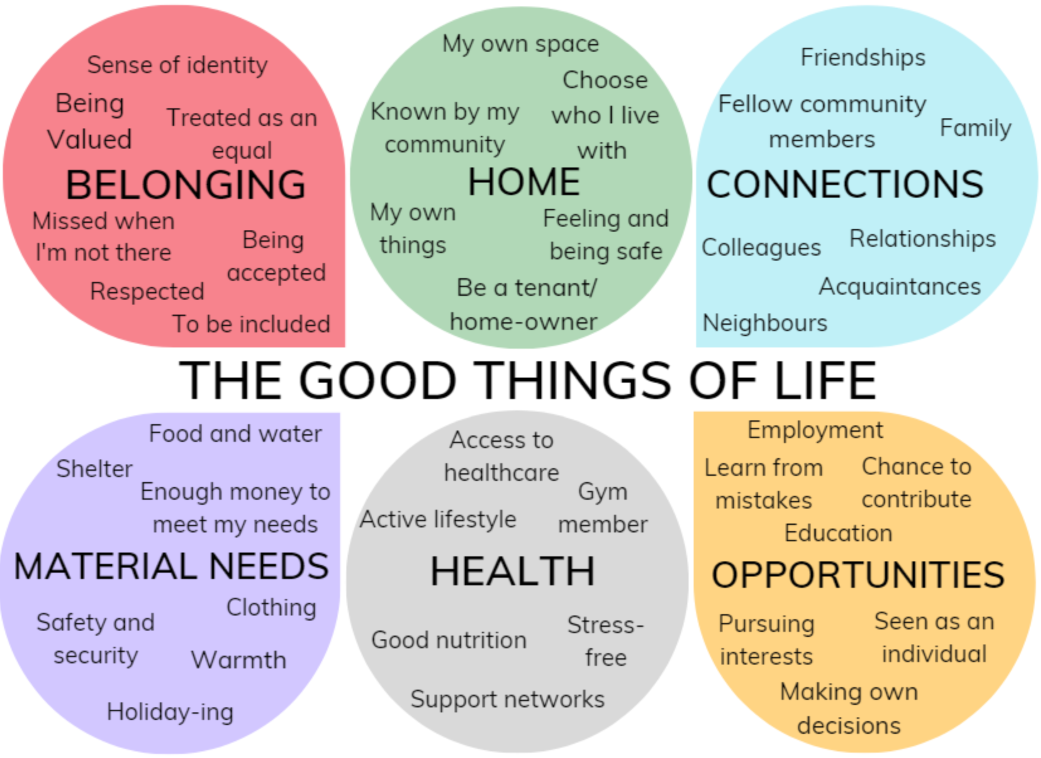
avenue for complaint via the NDIS QASC and as such, the Framework needs to broaden its remit to provide protection and an independent body for complaints.

Promote a positive culture of quality supports that lead to the good things of life

Quality supports lead to people with disability accessing the good things of life

We strongly submit, the NDIS Commission as a regulator should lead strategies to promote a positive culture of quality, even if it outsourced/performed by different organisations. It makes sense because there will be a consistency for all of the stakeholders (individuals and their formal/informal supporters) plus the Commission will be at the coalface hearing complaints to know how and where the culture needs to improve.

It is our strong submission that **quality supports are those that lead people with disability to accessing the good things of life.** We wish to clarify we are not talking about living "the good life" that advertisers try to sell in the modern sense of being simply about pleasure and being on vacation in an exotic location. 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 overleaf.



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

The theoretical and practical framework of Social Role Valorisation (SRV) created by Wolf Wolfensberger[4] 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.

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.

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.

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 happen to people with disability as well.\

The process of these inequalities comes from perceptions 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, Australian Disability Enterprises, and group homes.

Thus, the key to procuring normative and even valued conditions of life for people 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; 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.

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 SRV, why people with disability are devalued and how to mitigate the devaluation. We would recommend the Commission invest in SRV training of providers/workers and family members as well as the person with disability to understand how to provide quality support to the person with disability. Both enhancing competency and imagery encourage and enhance improved mindsets and the necessary cultural changes required around people with disability in society.

In contrast to the above examples of valued roles, 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 in segregated settings, doing

---

[4] 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.

different activities and interactions best served by formal supports instead of everyday community members. There are many models of support that lead services away from this outdated option and we recommend that the Commission invest in this knowledge and then lead the service sector to a new frame of delivering quality supports that lead to better lives for the people they serve.

Changing community attitudes

At a foundational level, it is culture and community perception of a person with disability that needs to change in order to reduce and prevent violence, abuse and neglect against people with disability. Family Advocacy recommends the Commission invest more broadly, as part of education and outreach in promoting safety, educate its staff, service providers/workers, individuals and families on a level that goes deeper than learning about the mechanics of the job and properly addresses the unconscious bias which lead to prejudice, low expectations, and devaluing a person with disability. For there to be any chance of this becoming a reality, attitudes towards disability need to change, people with disability need to have socially valued roles, be included in the same ways as non-disabled people, and have effective mechanisms to support and enable the human rights of all people with disability to be upheld.

Put more resources into developmental safeguards

As stated in the Issues paper, there has been insufficient focus on developmental safeguards to support individuals in the NDIS, including participant capacity building, the provision of information, the development of natural safeguards (such as family, supporters and community), and initiatives focused on supported decision making and advocacy. And similarly, there has been insufficient focus on developmental strategies to improve the quality and performance of providers and workers. Where there has been any work in these areas, there is a lack of refection, oversight or monitoring to ensure the practise on the ground is both robust and relevant. This will be our main focus throughout this submission.

Invest in the advocacy leadership development of families

At first instance, it is absolutely vital to acknowledge, that advocacy undertaken by families is the greatest safeguard. It is the most significant and plentiful form of advocacy that exists, as families are advocating for their family member, in some form or another, sometimes from birth. As pointed out by the Issues Paper (Page 17), 60% of adults in the NDIS have conditions that could affect their decision-making capacity and 42% are less than 15 years old. This means many people in the NDIS may need support to adequately self-advocate and make informed decisions.

> *“We are her voice when she has no voice.”*
>
> – Parents of a child with disability

As a general rule, parents and family members of people with disability:

- know their family member most fully and for the longest period of time,
- are the constant in people’s lives,
- are the setter of expectations,
- are the repository of knowledge,

- tend to care the most, and provide the most care,
- have a greater responsibility over their family member’s wellbeing,
- have a stake in their life outcomes,
- hold a degree of independence which allows them to call into question the credibility of other parties,
- demonstrate deep care,
- take greater responsibility over their family member’s wellbeing,
- are often best positioned to see the big picture, to see how everything in its entirety, builds into a person’s life, and therefore, can often see the incongruences of different interventions in early childhood, in education and employment.

For this reason, informal advocacy undertaken by families of people with disability provides the greatest potential for advocacy to be done potently with high expectations and support for a life of inclusion and the natural by-product is safeguarding the person from violence, abuse, neglect, exploitation. In many cases, family advocacy is undertaken when their family member with disability experiences limitations in cognitive understanding, has limited decision making competencies and may not be able to express their own interests, needs or rights in a multitude of situations. It is usually the family that first identify a significant issue in their family member’s life that needs urgent attention. It’s also usually the families that ‘push back’ in the first instance when systems designed to support this group, fail their purpose. Family advocacy also acts as a quality measure against poorly delivered services or lack of access to more community focused services whereby, if not invested in, leaves many people with disability at the mercy of poor services and support.

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.

Case study – Parent and Al's Circle of Support help Al to live independently in home of his choosing

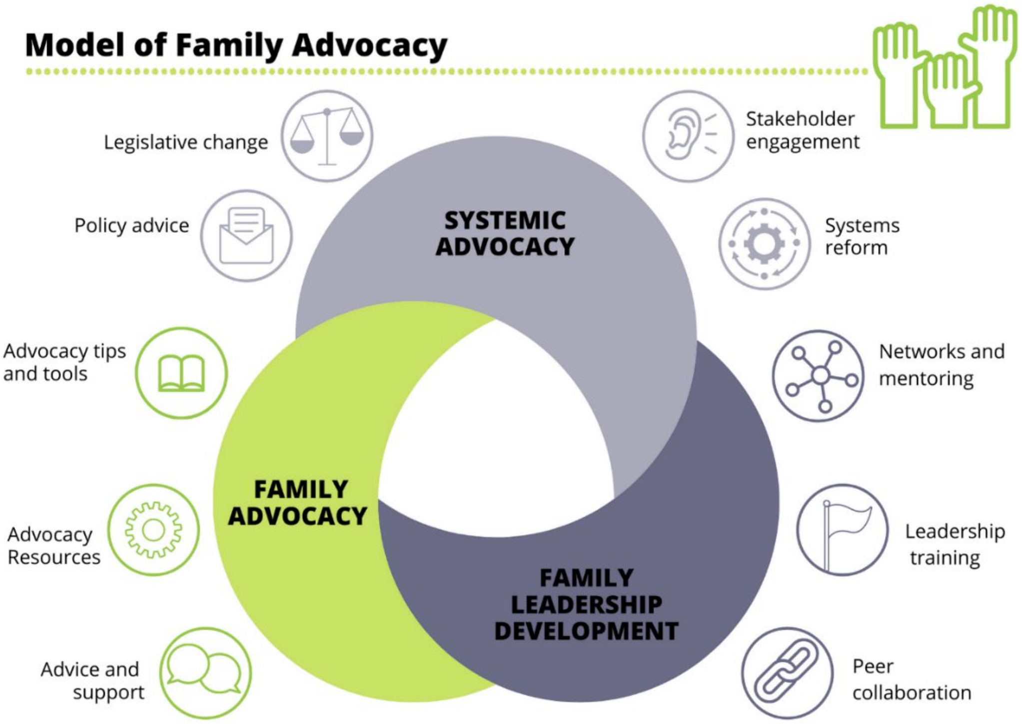
After finishing his Inclusive Education journey, Al communicated to his family (Circle of Support) his desire to live independently. His mum, Penny, advocated at many points alongside Al to enable this to happen, from advocating around ensuring her son to the right information and level of supports, and navigating the barriers of the NDIS.

Recently, all their efforts paid off, and Al moved into his own home where he lives independently with supports in place. 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.

"Part of the joy of living in your own place"

Al Graham hosting his first Christmas brunch with family in his own home

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 Commission recommends the investment in the advocacy leadership development of families and we refer to the Family Advocacy Model of advocacy upon which we are founded.



The infographic illustrates the Model of Family Advocacy, and is discussed in much more detail in UNSW, Social Policy Research Centre's (SPRC) report, [Family Advocacy Model Research.]()

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. However, they don't tend to build the person's capacity to tackle future advocacy issues making the person reliant on the formal process which is 'doing for' and perpetuating vulnerability. This model of 'doing for' forms a major part of the Australian disability advocacy landscape.

Our model, however, works 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 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.

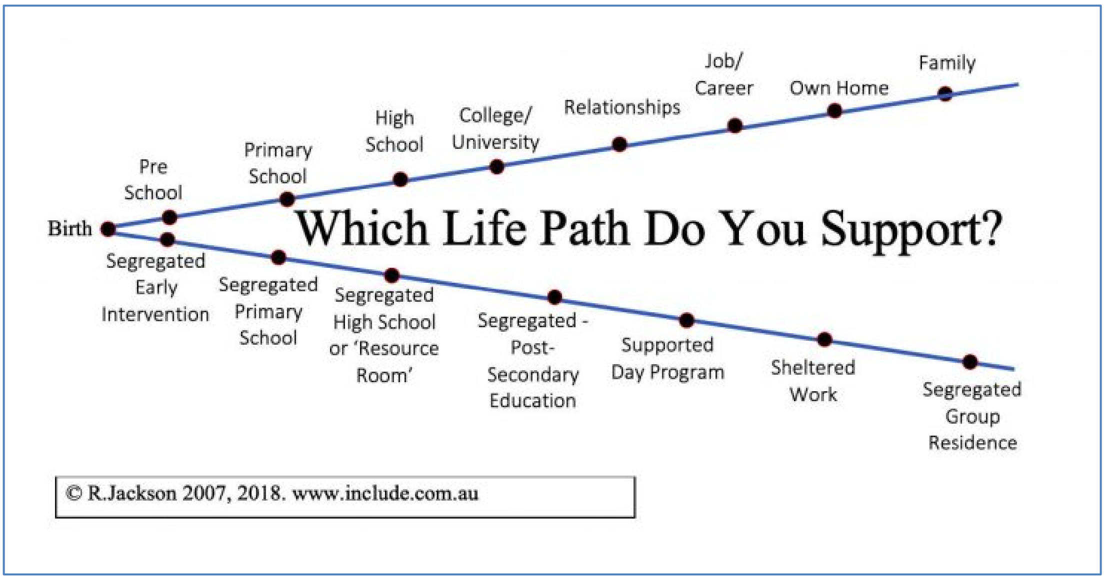
Provide training around devaluation and how to mitigate this with socially valued roles

Whilst we acknowledge the role of the Commission, it is not the panacea but merely a part of the mix of safeguarding measures of people with disability. 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. It is not human services that keep 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 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. Below is a depiction of the parallel life we refer to as illustrated by Dr. Robert Jackson:



It is not the NDIS that will keep people with disability safe. The NDIS is simply a funding scheme to provide services. 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. It is not legislation such as Wills/Trusts that keep people with disability safe. Whilst these legal instruments 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.

To reiterate, it is people who care and love the person with a disability, so freely given relationships, that keep people safe. Therefore, it is people who care about a person with disability in a freely given relationship that are the best safeguard. 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 a byproduct of the person with disability having socially valued roles that are age appropriate. Unfortunately, these valued roles are not being found in many of the traditional disability services across Australia.

The 2015 Senate inquiry said 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. 47 per cent of adults with disability have experienced violence, compared with 36 per cent of non-disabled people (AIHW, 2022). On this basis, to bolster its safeguarding capacity, it is necessary for the Commission to promote the importance of socially valued roles to service providers and support workers through the Framework.

Build capacity for Supported Decision Making and Circles of support

As stated in the Issues Paper, people with disability "have different levels of readiness to take control of their supports and manage risk, and should be supported to exercise choice and take reasonable risks. However, this has not happened enough under the Framework."

It can be dangerous to move to self-determination and citizenship of the person with disability overnight 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 self-determination. However, 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 for many of the people we are concerned about there has been limited occasion 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[5] 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 Framework 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.

The Framework must support the call to end segregation

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]

---

[5] https://www.ric.org.au/circles-of-support

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

Segregating leads to segregation. This is best depicted in Dr Bob Jackson's diagram illustrated above, "Provide training around devaluation and how to mitigate this with socially valued roles" which shows the natural pathways of childhood and the impact of an ordinary pathway versus a segregated pathway. 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.

> *"The further you travel down the segregated path, the harder it is to come back to being part of the community".*
>
> – Parent Advocate

We cannot underestimate the damage that can be done due to subconscious devaluation and segregation. For example, 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. In short, they are seen as different and often are not afforded many of the good things of life.

We need to gradually phase out all segregated settings towards full inclusion. For example, in education, ALL children, even those with severe and profound disabilities, are included in the regular classroom of their local school. 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.

For this reason, we recommend the Framework broadens its oversight mechanism to include all providers of services to people with disability including education, employment, housing, and transport. And doing what it takes to phase out segregation in these systems ought to form part of the measures targeted at individuals, the workforce and providers within developmental, preventative and corrective domains (as discussed in the Issues Paper). We have already discussed building the capacity of the family as the gateway to inclusion, to accessing quality supports and ultimately, providing a greater safequard from harm.

Provide clarity and consistency

The issues paper mentions the "expectations of intermediaries such as plan managers, support coordinators and local area coordinators (LAC) in quality and safeguarding are not always clear, despite significant interactions with participants". We agree the Framework must address this issue and provide clarity around the role of intermediaries. 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[7], 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.*

---

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

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 successful 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 Framework provides clarity on the LAC role, as well as the other service navigator roles already mentioned. All of these roles require 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.

Further, the Framework states its consistency with the NDIS Act 2013, but it must also be updated to include linkages and consistency with other policy settings such as Australia's Disability Strategy 2021-2031 and the Disability Discrimination Act 1992. It must also be updated to reflect changes in policy such as such as the NDIS supported decision making policy and best practice (currently referred to as "informed decision making" in the Framework).

Furthermore, we agree with the points within the Issues Paper that outline the lack of long-term, whole-of scheme approaches to NDIS quality and safeguarding arrangements. For example, the restrictive practice authorisation process has varying arrangements in states and territories, as is the NDIS worker screening arrangements. Accordingly, any reset of the objectives of the Framework must connect with these legislative and policy settings as a way of driving clearer and more consistent principles nationally and, as a result, more consistent shared understandings of the Framework's purpose.

In addition, this consistency must be communicated in an accessible way. We note we have been unable to access the current Framework in an Easy Read format, and this must be remedied when the updated version is ratified.

Ensure the Framework strikes the right balance to promote self- management and the use of unregistered providers with the need for safeguarding

We provide case studies below showing how self-management and the use of unregistered providers has achieved inclusive outcomes and increase independence and why therefore, the Framework must strike the right balance in the tension between safeguarding and providing too much red tape which could prevent innovative solutions that have led to inclusive outcomes, as shared below. These case studies show that overall, self-management and using an unregistered provider brought about the flexibility and control to choose how the person with disability reached her goals in an innovative way (without having to go through a review process again).

Case studies showing how self-management and using unregistered providers have achieved inclusive and more independent outcomes

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 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.**

Pole dancing supporting mobility/strength/stamina

The idea of pole dancing came from an international dress-up day at Girl Guides. Rachael wore a Polish dance costume and I took a photo of her holding on to a structural pole in the hall with the other Guides. And when sharing the photos with a friend, we were having a bit of a joke about Rachel being a “pole dancer” and then it clicked. Rachael LOVED to dance, but she does require something/someone to hold on to And I didn't want her to be at the back of any other dance group because that is quite isolating. But we realised that everyone has a pole to hold onto in pole dancing – so it's more typical!

This is something that Rachael has been doing for a quite a few years now, and she loves going. She has a really lovely friendship group there (e.g recently had pool party outside of the lessons, attend birthdays etc), and her of course, her strength and stamina has built up.

Holding this role has also meant her communication has improved, because the OT has linked some of her exercises to pole, that actually support her use of the communication device. AND it actually gives her more to talk about, so therefore more motivated to communicate. We feel like the roles of “Pianist” and “Pole Dancer” are important for Rachael because they have given her a sense of identity and that self-determination over her own life. And we've really seen her become more empowered and confident in her day to day life, which as a parent, that's what we like to see.

Considering and weighing up supports

Choosing a local barber led to employment

A family identified that a man in his mid-20s needed support to shave every day. He grew facial hair fairly quickly, and in order for his appearance to be maintained and to be seen as valued in his work role, this man needed help to shave/groom. They thought through the “who”

- Who is skilled to do this/in the community = local barber
- What are the formal options = support worker
- Or who can do it from within the household = family member or housemate

When they weighed up the pros and the considerations they saw that

BARBER =

Pros: Professional handling and care, being pampered. See each other most days, person with disability and barber get to know each other well; possible friendship grows. Extra business for the barber - known in community.

Considerations: Getting to and from the barber

SUPPORT PERSON =

Pros: Support worker can come to the house. Support worker can provide other supports as well, not just shave

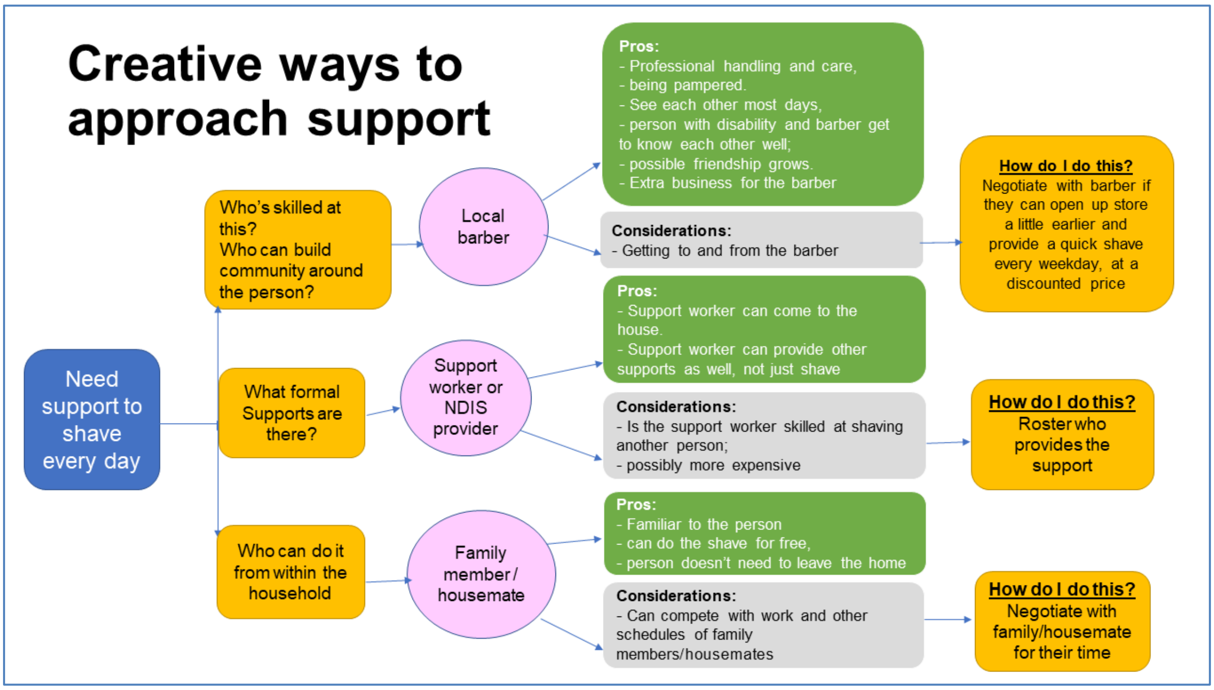
Considerations: Is the support worker skilled at shaving another person; possibly more expensive

FAMILY MEMBER/HOUSEMATE =

Pros: Familiar to the person, can do the shave for free, person doesn't need to leave the home

Considerations: Can compete with work and other schedules of family members/housemates

Then they thought about the ways they could actually go about it.



Now, after weighing all this up this family decided in the end to go with the barber.

Their particular circumstances were that the person wasn't really needing support with other things. The person also lived with a housemate, however their schedule wouldn't really fit well for it, and they preferred the housemate to not cross over into the role of personal care support. They were drawn to the barber because there was one nearby (only a short walk away from the person's house), and they liked the idea of being in community. This decision has proven fruitful as the person with disability now has a job in the barber shop, which shows how being known and having relationships in community led to employment.

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!" So 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.

The case studies provided above are some of the reasons why Family Advocacy strongly promote the NDIS Self-management model and unregistered providers as they provide more flexibility, better opportunities for typical age-appropriate roles and therefore, better safeguarding. From our experience, the mark of quality of a service rests with the character and tone of the interaction between a participant and a support worker, that is, having the right relationship. 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. Therefore, we recommend the Commission needs to support safeguarding more innovative models such as the families we know who self-manage, in a way that supports these models to flourish, rather than force those with contemporary solutions to fit into the Commission procedures.

Place a greater focus on the reduction and elimination of restrictive practices rather than the authorisation process

Restrictive practices, by their very nature, completely undermine a person's choices and preferences, or their opportunity to a self-determined life. There is also a strong relationship between the use of restrictive practice and other forms of violence, neglect and abuse against people with disability which undermines the ability of people with disability and support workers to recognise violence and respond to it as a crime (a very slippery slope.

We are concerned about the rise of reported unauthorised use of restrictive practices (URP) in the NDIS QASC Activity Report. For Jan-Mar 2023, 439,322 URPs were reported, up by 33% from the same reporting period the year before[8]. It is not enough for the Commission only be process oriented and simply monitor compliance of practices whereby states and territories continue to authorise these practices under each jurisdiction's legislation and policy. This makes it inconsistent. This highlights one example where gaps and inconsistencies can be present when different jurisdictions' regulatory

---

[8] NDIS Activity Report: 1 January to 31 March 2023

bodies or government departments fall outside the remit of the Commission.

> *"There is a significant imbalance of power experienced in all settings for person with disability receiving services and supports. Of course, I would like my son to have a say in his behaviour support plan that includes using restrictive practice but he has an acquired brain injury and cannot verbally communicate. So to the best of my ability and with my son's best interests at heart, I advocate for him. My son has a very particular passion for newspapers. If Derek carries a newspaper under his arm, it makes him feel stable and confident in the world.*
>
> *If he does not do this, the need would arise for restrictive practice, as his anxiety would rise and behaviours of concern would follow. Often, if given the chance, the person with disability themselves knows the solution as to what stabilises them. Rather than having a theoretical, broad brushed approach, really knowing the person and tapping into an individual's true desire, however unusual it may seem, is the key to reducing the need for restrictive practices."*
>
> \- Alan, father of Derek

All avenues available must have been explored in the behaviour support plan prior to applying a restrictive practice. It must genuinely be a "last resort" rather than a convenience, or the staus quo. It is vital that the person with disability and their parent/guardian give informed consent.

> *I was not informed of any behaviour support plan in place at school, nor that a restrictive practice took place. I found out because my son was distressed and he told me that two teachers pinned him to the ground face-down and he didn't understand why. This approach is simply not acceptable.*
>
> \- Dana, mother of James

Our experience has taught us that service providers cannot be relied on to make the necessary changes to structures, environments and supports unless they are forced to through legislation, and that this legislation has strong enforcement powers. History has shown us that service providers, whatever their perceived good intentions might be, are motivated by profit or self-preservation using the path of least resistance, most convenience, and will only take positive action when they are forced to. Of course, for service providers there is also the very real conflict of supporting their staff which is often the reasoning behind the use of restrictive practices. The Framework needs to address these conflicts through a more robust process.

An example to this point: While positive behaviour supports have been demonstrated to reduce the incidence of restraint and seclusion practices, and are strongly supported at a national level, they have not been adopted universally. In 2017, only approximately half of all schools in New South Wales had adopted a positive behaviour support approach to behaviour management (NSW Ombudsman 2017). As such, while positive behaviour support programs are important, it remains critical that the Framework be strengthened with legislation to provide clear guidance on the acceptable use of restraint and seclusion in schools with strong enforcement powers.

Given the scarcity of consistent data in NSW, we recommend that the Framework or provisions in legislation require the collection and reporting of comprehensive data on the use of restrictive practices in NSW, including established targets to reduce restrictive practices. Further to this, that agencies involved in restrictive practices should be required to supply relevant data. The point should also be made that any regulatory function must be designed and implemented in a way that does not duplicate nor encroach on processes such as those which already provide an established regulatory function.

On this basis, we recommend the Commission should have the strongest powers possible with regard to the elimination of restrictive practices. The enforcement powers ought to be able to have sanctions or compulsory orders aimed at deterring the use of unauthorised or unnecessary restrictive practice.

Alternatives to restrictive practices might include making changes to the person’s environment such as support arrangements or home arrangements that better reflect the person’s choices and preferences. The focus should be more about improving the quality of a person’s life rather than the reduction of the behaviour of concern (Carr et al. 2002). Again, our experience has shown time and again how 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.

For example, research into inclusive education, where the person with disability is seen as “student or one of the kids” rather than “special” has shown improved behavioural development, with less “challenging” or “disruptive” behaviour. Another reason why the Framework must support the end of segregation in the education system and promote an inclusive education system.

Ensure greater transparency and a more robust process of any investigations that ensures families, informal supports and the person are involved not just the service provider.

A further point to make is in relation to the need for the Framework to ensure more transparency and a more robust process of any investigations. We have received reports from our families who support a person with disability that when a complaint is made, the Commission just calls the provider and believes what they say without proper, thorough, balanced investigation. We hear reports where the person is not even interviewed at first instance or asked to respond to the response of a service provider. The person with disability is then devastated and loses all confidence in the complaints process. It places the burden on them once again to do all the heavy lifting, the system should be proactive in stamping out poor practices. The person with disability and their family members say they have given up trying to fight for their rights as they feel powerless. The power imbalance is immense. There are also reports once a complaint is made, the person making the complaint is informed about the process of investigation, or timelines around the process. For this reason, greater transparency of any investigations, and a more thorough process is required to ensure families and the person are involved, not just the service provider.

The need for advocacy to support a person with disability

It is our experience that in many cases, a vulnerable person with disability would tend to be hesitant or fearful to take a significant issue directly to an authority or independent body. For many people experiencing abuse, neglect and exploitation their first port of call would be their community-based connections through the advocacy sector. Vulnerable adults generally will only disclose abuse and neglect to people they are familiar with and/or trust.

In the first instance, we would provide advice and support concerning serious issues and, where deemed appropriate, support and direct them to the relevant authorities. We echo the view expressed in the NSW Ombudsman's report into the ‘Abuse and neglect of vulnerable adults in NSW - the need for action', 2 November 2018 that: "There is a vital continuing role for community advocates who work with and support people with disability and other individuals who require decision-making and advocacy assistance, and who advocate for broader, systemic issues across a range of life domains."

With this in mind, Family Advocacy's model provides a safeguard to continue the essential work of collaboration so as to ensure the essential multi-layered supports exist for people with disability. We submit that the Commission could access and collaborate with advocacy organisations as another support and oversight mechanism.

Further, we are concerned with the power imbalance whereby the onus for making complaints lies with people with disability, their families and carers (as the quote on the title page asserts). The Commission remit is limited in that it can only respond to complaints. From these observations, it appears the Commission is fairly passive as a regulatory body focused on service quality. We recommend the Commission be more proactive systemically in monitoring human rights breaches, outreach to people with disability where a provider may be subject to an investigation, exercising its "teeth" when it comes to unlawful practice and challenging systemic enablers that allow abuse and neglect to continue.

Conclusion

Despite the progress in recognising the rights of people with disability, and irrespective of the rhetoric, the Disability Royal Commission has illustrated our ongoing inability as a society to consider people with disabilities as equal members of the community, with equal human and civil rights, equal claims to citizenship, and equal moral agency. This fundamental inability has potentially catastrophic consequences. The need for advocacy has never been greater. As is the need to build the capacity of the individual and those who informally support the person with disability.

The Framework will need to enable the Commission to combat devaluation and harm by broadening its remit, influencing community attitudes, building the capacity of the individual, their supporters and all stakeholders to better support people with disability, provide more proactive education and outreach, support flexible individualised options of support for people with disabilities that choose to self-manage and use unregistered providers.

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.

Acknowledgement of references

Carr et al. 2002, 'Positive Behaviour Supports: Evolution of Applied Science', *Journal of Positive Behaviour Interventions*, Volume 4, Number 1, Winter 2002, pages 4-16, 20.

Cologon, K (2013). *Inclusion in education, towards equality for children with disability*. Children with Disability Australia

Convention on the Rights of Persons with Disabilities, opened for signature 30 March 2007, A/RES/61/106 (entered into force 24 January 2007) ('CRPD')

Convention on the Rights of the Child, opened for signature 20 November 1989, GA/RES/44/25 (entered into force 2 September 1990) ('CRC')

Children and Young People with Disability Australia, CYDA Education Survey 2017

De Graaf, G, van Hove, G, and Haveman, M. (2013). More academics in regular ECECs? The effect of regular versus special ECEC placement on academic skills in Dutch primary ECEC children with Down syndrome. Journal of Intellectual Disability Research, 57(1), 21-38.

Deloitte 2017, *Review of Education for Students with Disability* in Queensland State Schools

Dessemontet, RS, & Bless, G. (2103). The impact of including children with intellectual disability in general education classrooms on the academic achievement of their low-, average-, and high-achieving peers. *Journal of Intellectual and Developmental Disability*, 38(1), 23-30. He

Disability Standards for Education 2005

Hehir, et al. (2016). *A Summary of the evidence on Inclusive Education*. Instituto Alana in partnership with Abt Assoc., Harvard Graduate ECEC of Education.

JFA Purple Orange 2017, 'An Overview of Restrictive Practices, and the Key Issues for Consideration in Relation to the Establishment of an Office of the Senior Practitioner: A Public Discussion Paper Prepared for the ACT Government to Assist Public Consultation'

Kendrik, M. 1996, 'The Natural Authority of Families', https://www.family-advocacy.com/our-resources/the-natural-authority-of-families/

Legislative Council Portfolio Committee No 3 — Education, Parliament of New South Wales, Education of Students with a Disability or Special Needs in New South Wales Report No 37 (2017).

McCarthy, T. 2018, 'Regulating restraint and seclusion in Australian Government Schools, A Comparative Human Rights Analysis', *QUT Law Review*, vol. 18, no. 2, pp. 194–228

National Framework for Reducing and Eliminating the Use of Restrictive Practices in the Disability Service Sector 2014

National Safe Schools Framework 2010

National Disability Insurance Scheme (NDIS)

National Disability Insurance Scheme Quality and Safeguarding Framework

New South Wales Ombudsman 2017, Inquiry into Behaviour Management in Schools: A Special Report to Parliament Under s 31 of the Ombudsman Act 1974

Poed, S., Cologon, K. and Jackson, R. 2017, 'Gatekeeping and Restrictive Practices with Students with Disability: Results of an Australian Survey', paper presented at *The Inclusive Education Summit*, Adelaide, October 2017

Weissbrodt D. et al 2012, 'Applying International Human Rights Standards to the Restraint and Seclusion of Students with Disabilities' *Law and Inequality: A Journal of Theory and Practice,* no. 30, pp. 287, 288

Whitfield, S (2019), Inclusion is more than a word. Independent Education Today. Professional development lead at The International Leadership Academy, The British ECEC in the Netherlands, 12 November, 2019.