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

> ***"The severity of one's disability does not determine their level of potential. The greatest barrier that people with disabilities have to face is not ramps or curbs, it's expectations."***
>
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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.

Introduction

Family Advocacy is a state and federally funded disability advocacy organisation that works across New South Wales (NSW) and was founded 29 years ago by families who were concerned with the rights and interests of people with developmental disability[1] (hereinafter "disability") over the span of their whole life. This includes Australian First Nations people and culturally and linguistically diverse people with disability.

We provide support in the following ways:

- Statewide Advocacy advice and advocacy information to individuals
- Advocacy development for family members of a person with disability - Advocacy is often undertaken by families and can be required over the lifetime of their family member.
- Systemic Advocacy - informing government regarding legislation, policy, funding, monitoring, and practice in areas that impact on the needs of people with disability.

Our goal is to advance and protect the rights and interests of people with disability so that meaningful lives can be enjoyed by experiencing the same opportunities and living conditions as the majority of Australians. This includes the right to live safely and with dignity, free from violence, abuse, neglect or exploitation. We recognise that the advocacy undertaken by families with or on behalf of their family member with disability can be the greatest safeguard in their family member's lives.

Family Advocacy is pleased to make this submission to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (hereinafter, the 'Disability Royal Commission' or 'DRC') in response to the Rights and Attitudes Issues Paper. We welcome the DRC's reference to the United Nations' *Convention on the Rights of Persons with Disabilities* (CPRD) and many of its principles in the Terms of Reference. As Australia has signed and ratified the CPRD, any strategy concerning people with disability must be based on its principles.

The answers and recommendations in this submission are premised on three decades of experience working with families who have promoted and defended their family members interests and rights, our widespread knowledge of national and international research in the field of inclusive education, customised employment, microbusinesses, independent living and supported decision making, as well as foundational work in utilizing the theory and practice of Social Role Valorization in the much of the work we undertake.

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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.

This notion of socially values roles and its impact is explained throughout our response which underpinned by the foundations of Social Role Valorisation (SRV)[2] theory. To this end, we draw attention to and endorse two submissions already provided to the Disability Royal Commission in response to the rights and attitudes issues paper which answer the Commission's questions by drawing on the theoretical and practice framework of SRV: by John Armstrong and by Jane Sherwin.

Family Advocacy welcomes the opportunity to provide evidence when there is a hearing date issued in relation to rights and attitudes as well as facilitate the process for families to give evidence, if required. Due to the population size and complexities of the NSW education system, the poor employment record of people with developmental disability, the continued pattern for congregated living arrangements, we strongly recommend that a hearing in NSW is an essential step for the Commission to gather evidence on the significant issues of abuse, neglect and exploitation of people with disability.

Q 1: Where and when in life do people learn about the rights of people with disability? How could this be reinforced and/or improved?

Q 2: What stops the rights of people with disability being respected, promoted or realised? How is this linked to violence, abuse, neglect and exploitation?

> *The continuing inequality we face will not be rectified by ramps, lifts and accessible communications, or by the outlawing of discriminatory behaviour, welcome as these may be. The wellspring of our oppression comprises deeply held social attitudes that reflect generations of prejudice, fear and discrimination towards disabled people in education, work and social life. The main reasons are negative attitudes and stereotypes, which are based on untrue ideas that have been around for thousands of years, and which are amazingly persistent.*
>
> Richard Rieser, disabled academic, advocate and educator

For rights to be respected, promoted or realised, someone has to give you the authority to exercise that right. For example, a person without disability needs to believe a person with disability's right exists and then allow the right to be exercised. And we need a pathway to get there, a practice framework that opens the doors to their rights. This is where Social Role Valorisation (SRV) comes into play, and this will be explained further below. Currently, we are not living by the standards set by the CRPD and CRC, because we need the support of the majority as well as the political will, which does not exist. The unfortunate fact is, the will is not there to recognise that everyone is equal. At the core of it, despite the

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[2] 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.

rhetoric, the majority do not believe in equality. Society is comfortable with the status quo. So the question is, why is this the case? SRV helps us answer this, to dig deeper into the human psyche, understand human behaviour and importantly, be helpful in the lives of people with disability, including in respect to their rights[3].

Unconscious bias

The term 'cognitive bias' was coined by Amos Tversky and Daniel Kahneman in 1972 which quite simply means "our tendency to filter information, process facts and arrive at judgments based on our past experiences, likes/dislikes and automatic influences." So we are instinctively categorising things/people without being aware of it. It is a flaw in our thinking which is guided by past experiences and preconditioned thinking. When we read this we no doubt think, Me? Biased? Nobody likes to admit it, and often we are unaware of it. And it is this unconsciousness that is the enemy of devalued people, a category which people with disability fall into[4].

Devaluation of people with disability is entrenched in history

Without going into a deep dive, to understand how people with a disability continue to be subject to violence, neglect, abuse, and exploitation in Australia, it is helpful to reflect that throughout history, societies and cultures around the world have discriminated against, segregated and even treated people with disability as sub-human due to the unconscious bias of them being "less" than people without disability[5]. Within Australia, there is a shameful history of the segregation and institutionalisation of people with disability. Often hidden away, the entrenched low expectations and social narrative of shame associated with disability has meant that equality for people with disability in society is limited and gate-kept by those without disability.

In more recent history, we have witnessed many paradigm shifts, deinstitutionalisation, a slow shift from the medical model towards the social model of disability, and the disability rights movement. Indeed, it is important to acknowledge the significant work of recent governments with the National Disability Strategy (NDS) to overhaul the disability sector. The human rights, social and economic imperatives of the NDS are now well embedded in Australian legislation, governance mechanisms and policy directives. The fundamental purpose of the strategy is to include Australians with disability as full and equal citizens in Australian society. The reform agenda dictates that people with disability participate in the mainstream of

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[3] Jane Sherwin, Submission in response to the rights and attitudes paper, Royal Commission into Violence, Abuse, Neglect, and the Exploitation of People with Disability, p1.

[4] John Armstrong, Submission to Royal Commission into Violence, Abuse, Neglect, and the Exploitation of People with Disability, p6 at XII.

[5] For a thorough explanation of disability history, we refer to the All Means All Submission to the Disability Royal Commission into Violence, Abuse, Neglect and Exploitation: Education and Learning, dated 17 March, 2020, p24-49.

society – in health, education, transport, housing and so on – and access specialist support and services only when required. The National Disability Insurance Scheme sets out to bring this to fruition.

Despite the progress, there is still a long way go to before the changes to which people with disability aspired to are achieved including safeguarding people with disability against low expectations, prejudice, discrimination, protection from violence, abuse, neglect and exploitation. To achieve inclusive and accessible communities requires a paradigm shift in community attitudes. Communities and institutional contexts can only become inclusive and accessible when they too take on board that people with disability are citizens first and foremost, and entitled to a respected place in society, due process and protection from harm.

The stories shared by our families in ***Submission No.1 - Inclusive Education*** show we currently have a culture of exclusion which prohibits many students with disability from enrolment in the regular classroom, highlighting the limitation of legislative and policy frameworks such as the Disability Discrimination Act 1992 and Disability Standards for Education 2005. Widespread research showed unequivocally that exclusion has a negative impact on students with disability. Devalued status invites and legitimises bad treatment[6]. Expectations are lower, principals/teachers justify rejecting enrolments, only allowing partial enrolments, issuing suspensions and expulsions even where adequate supports are not provided, and undertake restrictive practices.

Conversely, there is evidence that students with disabilities who are educated alongside their non-disabled peers are subject to higher expectations from teachers compared to students educated in separate settings[7]. Many families have also shared that a positive, welcoming attitude of those in charge of the school and classroom can make a lot of difference. When the attitude is altered due to the role of 'regular student', expectations are higher[8]. The researchers analysed the content of the Individualised Education Plans (IEP) associated with general education versus special education classes from the students who had made a transition from special to general education. The results showed a significant increase in the quality and expectations of the IEP objectives that were written for students with disabilities once they were placed in inclusive settings[9].

In addition, as previously defined, unconscious bias is in part the result of past experience. So students without disability are missing out on the opportunity to overcome unconscious bias by not having students with disability in their class. Presence and participation of students with disability in the regular class can

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[6] Armstrong, J. Getting the best and reducing the worst in how humans act. Community Resource Centre Conference, Brisbane, 2007.

[7] Hunt, P., & Farron-Davis, F. (1992). A preliminary investigation of IEP quality and content associated with placement in general education versus special education classes. *Journal of the Association for Persons with Severe Handicaps, 17*(4), 247–253.

[8] Hehir, et al. (2016). A Summary of the evidence on Inclusive Education. Instituto Alana in partnership with Abt Assoc., Harvard Graduate School of Education, p20.

[9] Ibid.

provide the opportunity for relationships to form so people can see the person beyond the disability, to develop empathy, as well as understanding a person's disability thereby taking out the fear of the unknown. And these relationships provide a natural safeguard from violence, neglect, abuse and exploitation as there is shared humanness. Therefore, continuing to segregate will continue to adversely impact safety outcomes for students with disability in the long run as they move into adulthood. Where are rights learnt? In everyday experiences and societal norms.

Another point to note is that unconscious bias is so entrenched in us as humans that even people with disability have what some scholars describe as a "hierarchy of disability"[10]. Certain groups such as those with intellectual and cognitive impairments, are ranked lower and experience prejudice from within the disability community[11]. This understanding must remain front and center when considerations are being given to the voice of people with disability as one voice.

Why are people with disabilities devalued?

As previously mentioned, we draw from SRV, a theoretical and practice framework that explains that people with disabilities experience heightened vulnerabilities to relation to their rights being disregarded and experiencing violence, abuse neglect, and exploitation due to their devalued status.

What is difficult to think about is the fact that we live in a society that devalues certain qualities and conditions. For example, ageing, physical impairment, intellectual impairment, being impoverished, being dependent. When people embody these qualities and conditions that society devalues, people becomes themselves devalued, seen as not quite as worthwhile as, not as deserving as other citizens. Rather than seeing a person with an identity, a personality, likes, dislikes, dreams, people become seen as their impairment and this then leads to a deficit orientation where people cannot see the potential. This type of thinking leads to othering of whole groups of people. So logically, they think you need to be in special places with special people with special materials so people end up being distanced, put apart and away, physically and/or socially. All of which leads to a significant increase in the likelihood of abuse, neglect, violence and exploitation.

It is difficult to imagine, but some of the negative roles and perceptions that get in the way of people with disability being afforded the opportunity of having access to things that most Australians enjoy and act as a barrier are some of the perceived devalued roles below:

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[10] Mark Deal "Disabled People's Attitudes Toward Other Impairment groups: A Hierarchy of Impairments" (2003) Disability and Society, 18:7, 897-910.

[11] All Means All Submission to the Disability Royal Commission into Violence, Abuse, Neglect and Exploitation: Education and Learning, dated 17 March, 2020, page 17, 2.4:32.

Not being fully human - We have many examples of comments from people to justify this. For example, being told the person with disability don't know the difference if they have a friend or not. People with intellectual disability do not experience grief, 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.

An object of pity - charity recipient, with approaches often derived from a place of pity not rights or valued status. 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 found in special schools/support units. 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 year. Often dramatically changing 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 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 pediatrician, GP, Service professionals, educators and broader society. All reinforcing this negative assumption with many people with disability only knowing this way of being treated with many learnt responsive 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 take a 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 medical specialist in relation to whose live 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.

These perceived devalued roles bring with them horrific consequences. 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. The more valued roles a person who is devalued has the more other non-disabled people can personally relate to them creating a safeguard against some of the negative assumptions which heighten the risk of abuse, neglect, violence and exploitation.

We now know from the Royal Commission into Institutional Responses to Child Sexual Abuse[12], segregated settings are harmful and are a factor that heightens risk of abuse of children with disabilities. A research project commissioned by that Royal Commission presented about the prevalence and prevention of sexual abuse of children with disabilities in institutional contexts, found that:

‘Segregation and exclusion in closed institutional contexts away from public scrutiny leaves children (and adults) with disability at heightened risk of violence and harm including sexual abuse. Further, when children with disability are stereotyped as dependent and passive and unable to ‘speak up’, they are at heightened vulnerability to being segregated, abused, overlooked and not heard. The Royal Commission into Institutional Responses to Child Sexual Abuse recognised early on the likely particular vulnerabilities of children with disability and the institutional contexts which they encounter.’[13]

The research also found:

“*The current approach in Australia tends to focus on children with disability as a special group. In our view, there are distinct dangers in doing so. The most obvious is that responsibility for special groups is thought to reside ‘outside’ the mainstream. The converse is that the mainstream is ‘relieved’ of their responsibilities for children with disability. This is contrary to Australia’s obligations under CRC and CRPD. Child safe organisations must be child safe for all children. This means that in child safe organisations due diligence must be paid to ensuring any particularities relevant to children with disability are understood and responded to using evidence-informed strategies, practices and behaviours.*”

When looking at the ‘factors that increase risk’ and ‘drivers for abuse’ (NDS, 2015), the research noted that ‘impairment does not of itself make a child or young person vulnerable’ (p 3). Robinson noted that ‘other features in young people’s environments, relationships and the cultures of their communities may have a greater part to play in how vulnerable (or otherwise) children with disability are to abuse and

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[12] Royal Commission into Institutional Responses to Child Sexual Abuse Final Report in 2017

[13] Prof Gwynyth Llewellyn, Disability and child sexual abuse in institutional contexts, The University of Sydney Faculty of Health Sciences, 2017.

neglect than does their impairment[14]. This is welcome and in line with international understandings of disability and the CRPD (UN, 2006).

When children are excluded from regular class, 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 things most Australians take for granted. Accordingly, the inherent existence of devaluation means that vulnerability is heightened and safety is compromised. This wounding experienced across all ages and settings in Australia will most likely continue. One way to mitigate the wounding is through intentionally creating socially valued roles that support fuller lives for people with disability and that strengthen the connection that this group has with other members of society. Remembering that many people with disability are currently seen in roles of client, special school student, support unit student, day service client, group home resident, riding for the disabled client, participant of tennis group for people with disability. This list goes on and on with many of these current roles once again reinforcing the stereotypes and assumptions held deeply by other society members. So when we talk about intentionally creating social valued roles we are not talking about the roles just discussed above as these roles are not valued, and this is explained in our response to Questions 5 and 6.

Q 5: How do attitudes contribute to violence, abuse, neglect and exploitation against people with disability?

Q 6: How do attitudes affect responses to violence, abuse, neglect and exploitation of people with disability?

> *“Unconsciousness is the enemy of devalued people.”*
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> John Armstrong

Family advocacy supports families to advocate with or on behalf of their child or adult family member to have the good things in life most of us would expect in Australia. What does a “good life” mean?

- **Home** - Living among people I know and who care about me, feeling and being safe there
- **Health** - enough to eat, drink, access to healthcare
- **Material comfort** - enough money to meet needs, some things of my own to enjoy, warmth, shelter
- **Sense of belonging** - being seen as having value

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[14] Robinson, S (2012) *Enabling and protecting: proactive approaches to addressing the abuse and neglect of children and young people with disability* Children with Disability Australia, Clayton, Victoria (p 7) p.12.

- **Opportunities** - interests, varied experiences, work, self-expression and personal development, study, chances to contribute
- **People who know and care about you** - family, friends, acquaintances

No matter our differences, we all want to belong, participate and contribute. They are universal needs. These needs come through being included at your local school with your neighborhood friends, having a job or owning a business, a place to call home, and a valued place in the community amongst friends and family. It is the same for a person with a disability, they just need some support (both paid and unpaid), to enable this to happen.

A byproduct of this “good life” are the socially valued roles that follow[15]. For example, being a student in the regular class at the school, an employee, a flatmate, a friend, a community club member. When we have these valued roles, freely given relationships follow and with that, comes a natural safeguarding from violence, abuse, neglect and exploitation. Generally speaking, people with these valued roles are safer by the simple fact they are physically “seen” in the community (not hidden away in institutions or segregated settings and programs), and metaphorically “seen” as “one of us”. People with disability that have valued roles are treated more favourably by individuals and groups.

Valued Roles

A socially valued role is the pathway to a full, meaningful and inclusive life and importantly it keeps people more protected against harm. It is defined as “a socially expected pattern. Of behaviors, responsibilities, expectations and privileges” (Carson). For example:

- Relationship roles: family member, friend, spouse, neighbour
- Work roles: colleague, classmate
- School: student, classmate, teacher
- Community roles: club member, sports team member
- Leisure roles: Gym member, golfer
- Cultural roles: elder, church member
- Household roles: tenant, home owner, gardener, cook, cleaner
- Citizen roles: committee/council member

The more roles a person has, and the more valued those roles, the more likely the person is to experience the “Good things of life. We are familiar with the term ‘person centered’ or individualised when

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[15] Family Advocacy’s initiative, Resourcing Inclusive Communities, has produced a booklet called *Life Long Learners* (2019) to illustrate these socially valued roles. https://www.ric.org.au/assets/Uploads/resources/1574141eb1/lifelong-learners-booklet.pdf

it comes to planning. The strength in using roles thinking is that you will come up with a truly personalized approach which will help:

Build identity - roles help shape what people think of themselves as well as what others think of them.

Increase participation – rather than mere presence in community

Roles can **open doors to relationships**

One role can open the door to life - Once someone is in a role, then there's a greater chance that the door to another role will open. This is because people start to expect more of someone, the person starts to expect more of him or herself, and they also start to learn things and develop skills.

This is very different from slotting a person into a pre-existing program like a day service program. 'Think roles, not programs' 'think being someone, not just being busy/occupied'.

Roles can be difficult for a person with disability. When considering valued roles as the pathway to achieving the vision for a good life, it helps to consider the following:

People - We ask the question, who is a person of the same age group spending time with in this role? If someone is in the role of fisherman then they spend time with other fishermen. If someone is in the role of student, then they spend time with their same-aged peers at their local school where their siblings, preschool and neighbourhood friends attend.

Places - Where do people in this role spend time? Where does a fisherman spend time? On the water, river, pier or beach. So for someone to be authentically in the role of fisherman, we would want to get at least those things right. If we think about the role 'classmate' then who would a classmate spend time with and where? – with the same aged peers not classified by disability usually at their desk in their regular classroom. Where? - in school, camp, incursions, excursions.

For example, if a student is not attending excursions/camp/incursions, is seated out the way in a corner of the room or they're out of the classroom more than in the classroom, it's a sign that the student is not really fulfilling the role of classmate. They will more likely be viewed as a visitor and then not automatically included in all class activities.

Past-times - We need to pay attention to how people spend their time. For someone in the role of student, we would expect there to be curriculum related, sporting, musical and playground activity happening. Unless a student is exposed to all of those things, then it's unlikely that they're authentically in the role of student.

When - ‘When’ is another aspect of roles we need to get right. A colleague has a picture of a bowling alley and he can tell what day of the week it is without actually being there. ‘It’s Tuesday because all of the vans are parked outside’.

The people are bowling at the regular bowling place - so they’ve got the place right, and maybe they have the activity right for the people who actually enjoy bowling, however they go at a time when no typical bowlers go. This works against the people being recognised in the role of ‘bowler’ and is more likely to convey the role of ‘client’ for those who participate. What would be a more appropriate time?

A similar analogy can be used for when the kids from the special unit/school come for a visit to join the rest of the students in the mainstream for music or art.

Appearance - Many family members are tuned into this aspect of roles very well. We know of family members who bend over backwards to make sure their son or daughter is really well presented. Trendy clothes, great hairdo’s, clean, neat appearance and the gadgets/belongings that are right for that age group. Additionally, the person needs to appear right for the role being undertaken. So the fisherman would have a rod, bucket, hat, waders, tacklebox etc.

The student would have the same uniform, backpack as their peers and a permanent desk to sit and work on and be working on the same topic as their peers even if it has been adjusted so they can access it and be assessed at the appropriate level. Also, the student would be taught by the same teacher as their peers rather than having a teacher's aid permanently “velcroed” to them. Should the student require extra assistance, the teacher’s aid would be there to support the entire class as well as the student with disability.

Language - Finally, we need to think about what language is being used to and about the person as well as that about the role the person is in. So, for example, if the person is a keen football player then they would talk about football in football terms, a scrum, the ball, the rules etc. All making the role authentic.

The points above are critically important as many supports, mainstream service and disability organisation provide what we call a ‘pseudo role’. A role that kind of looks like a bit of a real role that other people enjoy but it is actually an odd version of a role or a role that doesn’t make sense. This is a major oversite from many people currently involved in supporting people with disability and has dire consequences as discussed. A question that begs to be asked is why do we arrange supports and structures so adversely different for people with disability than for other societal members that continue to keep people at arm’s length from the rest of society and at heighten risk of abide, neglect, violence and exploitation. More importantly what do we intend to do about it was a society?

When considering the above components, we come up with what is referred to as a culturally valued analogue (CVA) which acts are a guide of sorts so that solutions afforded to people with disability are as normative as possible to the rest of the population. Minimising the risk of odd support responses to take its place.

Valued Citizen v Service recipient

In our service-oriented approach, we tend to focus on providing people with disability with activities to do, which are not purpose driven or capacity building. Whilst doing an activity, once a week is better than doing nothing at all, this is very different from having a valued social role. Human services are often run without considering the real needs of people, or how they are we 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. The flow on effect is model incoherency. For example, those running day programs think if people with disability turn up and are happy with some kind of choice, they are doing a good job. Such as sending a group off to bowling at 2pm on a Tuesday or Disco at 2pm on a Thursday. These are just activities that are 'time wasting' and far removed from normative expectations of what other people of a similar age do on a Tuesday or Thursday afternoon. Services often coming up with solutions on how people with disability can spend their time instead of supporting the same person to join in on what is expected of a person of a similar age. With many people and professionals still carrying the assumption that this is out of reach for a person with disability. Continuing to reinforce the parallel life for people with disability which continue to leave them at heightened risk.

Q 4: What advocacy or advocacy assistance is currently available to people with disability? What are your suggestions for reform or improvement to advocacy, to help prevent and improve responses to violence, abuse, neglect and exploitation of people with disability?

Because the needs of individuals are complex, there are many different 'forms' of advocacy required. No one kind of advocacy will provide 'the answer' nor will a 'one-stop' shop approach work towards reducing or removing the multitude of barriers experienced by people with disability.

Therefore, it is important to differentiate between the different forms and functions or mechanisms of advocacy.

Forms of Advocacy:

- **Individual Advocacy** - of which there are subsets:
  - self-advocacy: people with disability advocating for themselves
  - family advocacy: parents or relatives advocating on a person's behalf with the support of advocacy advice, advocacy development strategies, information and referral
  - citizen advocacy: an ordinary citizen taking up the advocacy issue on behalf of a person with disability
  - paid, formal advocacy: advocacy conducted by paid advocates
- **Systemic Advocacy** - of which group or representative advocacy are subsets.
- **Legal Advocacy** - upholds the rights and interests of individual people with disability by addressing the legal aspects of discrimination, abuse and neglect.

Each different form of advocacy uses different **advocacy mechanisms or strategies:**

Individual advocacy uses a combination of advocacy development (developing the person's advocacy skills), provides advocacy related advice and information provision, so that the person is knowledgeable about the issue at hand and referral when necessary.

It is important to note here that Family Advocacy would be very concerned if there was a move to increase 'professionalised advocacy', or advocacy that is conducted only by paid advocates, and to reduce funding from agencies committed to supporting unpaid, informal advocacy eg. Citizen Advocacy and advocacy agencies that provide advocacy advice and development for families. **We strongly recommend that is it necessary to increase and continue both forms of advocacy.**

When formal advocacy that focuses on *doing for*, is only utilised, it also creates an environment whereby the remedy and reliance are only on support to do for others, instead of providing support to equip others to do for themselves. Further to this and when considering families, it is almost guaranteed that issues requiring advocacy will continually emerge for their family members with disability. As families' competencies in advocating and understanding systems develop, we have noted a reduction in the contact with our organisation over time, hence minimising the reliance on formal advocacy supports. These same families may reconnect with our organisation when they come into contact with another system or barrier that they are unfamiliar with and the process starts again.

Family Advocacy has spent many years building the advocacy competencies of families and has many examples of how this advocacy leadership development has created safer and more optimum arrangements for many people with disability. This also extends to the impact that families have had in creating systems change across NSW and also across the country.

It has long been recognised within the advocacy arena that ‘paid’ advocacy has the potential to drive out unpaid or voluntary advocacy. This comes about for a number of reasons starting with the strongly held assumption within our culture that professional solutions are best. Instead of ‘doing for’, empowering people who are willing and well positioned tremendously bolsters the advocacy efforts and most importantly adds a vital layer of protection for people with disability.

The ‘quick fix’ mentality which is also rampant in our culture, can also mean that the easy, ‘solvable’ issues get attention by paid staff so that ‘outcomes’ can be produced whereas the more difficult, long-term issues that can have life-changing outcomes for a person, may be relegated to the ‘too hard basket’ and not be given the attention they rightly deserve.

Again, an advocacy sector that supports both formal and informal advocacy models is essential in ensuring that the vital layers of protection are in place and for the long term to prevent violence, abuse, neglect and exploitation of people with disability.

Systemic advocacy uses a combination of strategies such as: lobbying, running campaigns, holding public meetings, responding to Inquiries, State and Federal Submissions, meeting with and writing to those in positions of power to take up issues pertaining to law, policy and procedures, resource allocation and other decisions made by Government and other agencies, attendance at roundtable discussions, reference groups, consultations and a wide variety of stakeholder meetings.

Previously in NSW, there was a push to limit systemic advocacy to issues that “emerge from individual advocacy”. This is a very narrow and constraining view of the function of systems advocacy and places systems advocacy in a position of ***reactive*** advocacy only and does not allow for ***proactive*** advocacy.

It is common for agencies carrying out systemic advocacy to be aware of emerging issues that have the potential to impact profoundly on people with disability in the future, and which people with disability themselves may not be aware of. To be hobbled by a system that limits advocacy action only to those issues raised by individuals, completely undermines the function, intent and efficacy of systems advocacy and will significantly narrow the breadth of issues that could be taken up and importantly limits the progression.

One example of this was the extensive work undertaken by NSW advocacy organisations in relation to progressing the closure of large institutions in NSW. This issue was not necessarily identified through individual advocacy responses received across the state but was seen as a critical step that Government needed to take from a social justice perspective and a human rights framework. This is also an example of systems advocacy work that can be undertaken that may be at odds with some groups and in this case, some families.

Australia, like many countries, often tends to think in isolation to what is occurring around the world and in many cases is behind many jurisdictions concerning the progression of the rights and living conditions of people with disability. It is the job of systemic advocacy organisations to keep track of this, and to gather learnings from these countries concerning these progressions, make contacts with relevant agencies abroad and to then translate that to ‘our environment’ for possible development.

Systems advocacy should also operate as an “early warning system” so that actions are taken preventatively. This monitoring role requires an extensive network of contacts and information sources. Advocates focused on individual issues are unlikely to have the time, expertise or networks to facilitate this. Once a problem has arisen and is already impacting on people, it can be much harder to undo than if it had been prevented in the first place. Proactive systems advocacy is an essential element of any advocacy system; it must not be stymied by a narrow approach and should be guided through a human rights framework such as the United Nations Convention on the Rights of Persons with Disability (UNCRPD).

Also, having a ‘systems view’ to identify and attempt to alleviate the multitude of issues experienced by people with disability is key to the systemic work undertaken. It is not uncommon for many mainstream and service systems to have within them many points of tension that significantly impact on the rights and interests of person with disability. It is a requirement of the systemic advocate therefore to pinpoint the ‘most appropriate’ point that will work towards alleviating the tensions more broadly, instead of attempting to address all the tensions that exist. As the latter approach would not lead to the necessary adjustments and most potent systems reform needed. This work can therefore occur over the longer term and in some cases many years.

Interplay between individual advocacy and systemic advocacy

In its 2001 paper, Advocacy for NSW A Critique of Government process and a way forward, the Disability Safeguards Coalition stated:

Many people with disability, particularly people with developmental disability, have no support and cannot access services designed to support them on an individual basis. Many do not understand the purpose of individual advocacy and how they could personally benefit. They have no-one to argue for them and are too vulnerable to advocate for themselves.

Individual advocacy provides many people with the much needed support to prevent abuse, discrimination or negligent treatment and/or enable them to lead meaningful lives as contributing *members of the community. Individual advocacy provides an avenue for people to access their rights. It can provide people with support and means to redress injustice on an individual basis, and is often personally empowering for the person who is seeking redress.*

However, individual advocacy cannot change the structures and systems which determine the way that laws are written, government policy is determined and implemented, and the way that services are provided to groups of people.

Individual advocacy is most effective when located within a framework that recognises the need to continually critically evaluate our structures and systems and improve the way they serve the needs of individuals. Systemic advocacy serves to ensure that such a framework is in place.

Systems advocacy by its very nature is in conflict with government as advocates highlight the ways in which current arrangements lead to abuse, discrimination, negligent treatment, inhibit the achievement of rights or place barriers in the path of full inclusion of people with disability.[16]

For example, with knowledge that particular policies and practices of the Department of Education and Training prevent children and young people being fully included in the regular class of their local neighbourhood school, it would be ineffective to simply support the parent in negotiations at the level of the local school. It is far more sensible to seek to change the practice at the state level thereby obviating the need for advocacy support for many other local parents.[17]

Advocacy Development

Within Individual advocacy, there must be recognition of advocacy conducted by families and the importance of an advocacy development framework to support this.

"Advocacy development is those actions and processes that enlist the energy and commitment of individuals and groups in our community so that they choose to take a considered action called advocacy on behalf of and alongside people with disability".[18]

Family Advocacy strongly encourages the formal recognition of Advocacy Development and points to the inclusion of Advocacy Development into the NSW Disability Advocacy and Information System funded through the Department of Aging, Disability and Home Care (ADHC). However, for Advocacy Development to be undertaken effectively, there needs to be a clear and shared understanding of what

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[16] Advocacy for NSW A critique of Government process and a way forward. The Disability Safeguards Coalition, May 2001, p. 26

[17] Advocacy for NSW A critique of Government process and a way forward. The Disability Safeguards Coalition, May 2001, p.17

[18] Queensland Advocacy Development Project, *A Working Framework for Advocacy Development in Queensland,* March, 1996, p. 14.

Advocacy Development is and whose interests are to be taken up by those undergoing "advocacy development" training.

Family Advocacy contends that it is people with disability whose interests should be paramount here, and that any advocacy development must be focused on outcomes that improve the lives of people with disability. Otherwise, there will be great confusion in terms of whose interests receive primacy within any resulting advocacy action.

"Advocacy development is very much a journey during which the person or group becomes firmly grounded in advocacy principles, an understanding of the real-life issues and vulnerability of people with disabilities and their families, and the vision of valued, inclusive lives for people with disabilities in their community."[19]

Some principles which could be used to guide Advocacy Development could include but not be limited to:

"Advocacy development:

- *is guided by a heightened sense of the vulnerabilities and needs of people with disability*
- *seeks out, supports and develops people who are (potential) advocates and who stand with/for people with disability*
- *encourages (potential) advocates to stand with people with disability who are vulnerable, against all that stops or denies people a life free from violence, abuse, neglect, exploitation, destruction, segregation and isolation*
- *encourages (potential) advocates to strive for the inclusion of people with disability in all spheres of life and society*
- *encourages and strives for better understanding within the advocacy community of advocacy principles, including the need for advocate and program independence, concern with fundamental needs, loyalty, minimised conflict of interest and vigour."*[20]

Advocacy development will be required by people with disability, families and carers, citizen or volunteer advocates and for paid advocates themselves. A funding enhancement to cover the cost of advocacy development activities is fundamental, otherwise current agencies will have to reduce the amount of formal, paid advocacy undertaken to free up funding for this development.

Advocacy development is a specialised area of advocacy, which requires a high level of expertise in processes that:

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[19] Advocacy Plan Working Group, *The Development and Funding of Advocacy in Queensland*, August, 1994, p. 10

[20] Queensland Advocacy Development Project, *A Working Framework for Advocacy Development in Queensland,* March, 1996, p. 18.

- draw people in
- teach the theory and principles of social advocacy
- identify and support advocacy leadership
- harness people's energy and passions
- develop a commitment to and shared vision about advocacy
- identify conflicts of interest
- critically examine the lives of people with disability.

Family Advocacy would open to having further discussions with the DRC in this regard.

Alignment with the CRPD

The CRPD clearly outlines the obligations, and the directions required, to ensure that people with disability realise their rights and interests as full citizens. We recommend it is vital to align any advocacy framework and efforts with the principles and objectives of the CRPD. This would enable a more consistent and potent approach across the country and avoid misaligned work to be undertaken - which currently stagnates and at times pushes backwards - the realisation of full citizenship. By utilising the CRPD, it would also assist Government in consistently working towards their obligations as a signatory to the Convention.

Independent advocacy as a major safeguard

In order to be effective and coherent, there must be a clear division between agencies that undertake advocacy and service providers that provide direct service to people with disability, in order to minimize conflicts of interest.

Much has been written on the subject of conflict of interest, in relation to advocacy. Generally, it is also linked to the notion of ‘independent’ advocacy.

"Independent advocacy is a major safeguard and often the only safeguard for people with disability who are vulnerable. Independent advocacy promotes, protects and defends the welfare and rights of people with disability to ensure:

- *their human rights and citizenship*
- *their equality of opportunity to pursue options and choices similar to that of all citizens*
- *their access to goods, services and facilities essential to ordinary life in the community*
- *their participation in decisions and in social and political life*

- *the fair and equitable distribution of power and resources".*[21]

The very word 'independent' begs the question - independent of what? There are a number of points along the process where these two related issues take on significant meaning.

Independence is a cornerstone of advocacy. In order to ensure that independence is not undermined, a number of elements must be considered:

- the sources of funding for advocacy programs
- the recipients of advocacy funding
- the management of advocacy organisations
- the way in which advocacy agencies recruit staff and/or advocates.

The important role of relationship for reporting

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 such as the Ageing and Disability Commission. 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, we strongly recommend that Family Advocacy's model will provide a safeguard to continue the essential work of collaboration so as to ensure the essential multi-layered supports exist for people with disability.

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[21] Queensland Advocacy Development Project, *A Working Framework for Advocacy Development in Queensland,* March, 1996, p.14

Advocacy must be free and accessible to all

Advocacy must never become a ‘fee for service’ support. All people with disability in Australia, regardless of whether they receive funding support or not, must be able to access advocacy if and when they need it, and across their lifespan. The instability that this approach would create would have significant ramifications for people with disability and for the stability of the advocacy sector more broadly.

NSW disability funding is not guaranteed

We bring to the DRC’s attention, and like to emphasise that, the DRC is being conducted at a time when there is no guarantee of funding for NSW advocacy services post December 2020. Before any steps are taken to reshape the current arrangements, it is critical that the NSW government commit to an extension of the current funding agreements to June 2022. This will enable any recommendations from the DRC to be considered and where applicable, adopted. This process should not be rushed and should be well thought through to ensure we are left with a stronger and more responsive advocacy sector for people with disability.

An international example - Provide support and training to parents seeking inclusive education for their children

Parents often need support in seeking to exercise inclusive education for their children and in maximizing their child’s development. This can be a difficult role. In the United States, parent-training centers have been funded by the federal government to provide this type of support. The Massachusetts Federation for Children and the Colorado Peak Center have been particularly effective in teaching parents about the importance of inclusion and how to obtain and support effective inclusive placements for their children.[22]

Q 7: How do poor rights awareness and negative attitudes contribute to laws, policies and practices that discriminate against people with disability, ignore the experiences of people with disability, or lead to unintended consequences for people with disability? Please provide specific examples in your response.

One area where we see this type of discrimination is in the education sector. Many parents and the NSW Department of Education argue against inclusive education and for segregated settings on the basis of the parent choice argument, the basis that parents should have a choice to send their child with disability to whatever setting they see fit.

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[22] Ibid 6, p26.

We remind the DRC that the right of the child overrides the right of the parent in accordance with the UN Convention on the Rights of the Child (CRC). In any other area, our government puts what is in the best interests of the child based on evidence, except in the education sector. The Government passed laws to enforce the wearing of seatbelts and immunisations and parents are forced to comply. Yet when it comes to schools, the evidence is ignored and parents are given “choice” over what is best for their child. The socially valued role of parent trumps the devalued role of disabled child.

On this note, we assert that parent choice is a furphy. There is no real “parent choice”, rather ‘parent concession”, a direct result of the failings of the system which ultimately funnels children to segregated settings[23]. Whilst parallel systems of education exist, families are often pushed toward the exclusionary setting through an informal process of gatekeeping by school principals or staff, whether consciously or unconsciously. Parent demand for special schools and units, including:

- experience in early intervention has led to the belief their child can only learn in one to one situations with a skilled adult, and needs special education with special teachers in special places
- a lack of choice. Often parents are not provided with information about the rights of the child and the possibility of a regular class enrolment for their child. Only the segregated options are offered
- parents who have ‘battled’ teachers and schools that are unwelcoming of their child
- low expectations of children with disability, including the deficit model of disability and the notion that a person must be ‘ready’ to participate with their peers. A more enabling model is one where the system is expected to guarantee participation in the regular class and all those involved ask ‘what will it take’ to enable the child’s full participation.
- Many families have also experienced the current education system let their child down or come to harm due to the unwillingness, lack of skill and funds to instead support them well.

All these reasons clearly point to an inadequate system that continues to fail students with disability leaving many families choosing the ‘least worst option’ based on lack of rights awareness, and negative attitudes or valuing the right of the parent over that of the child.

Demand for segregated settings also comes from teachers and schools that have invested their time plus bricks and mortar/ infrastructure in the segregated sector. Where a support class or special school exists, students will be found to fill it. Regular class teachers then feel able to indicate that there is a ‘better’ place for students with different learning needs. The inclusion of students with disability threatens the status quo due to fear of the unknown.

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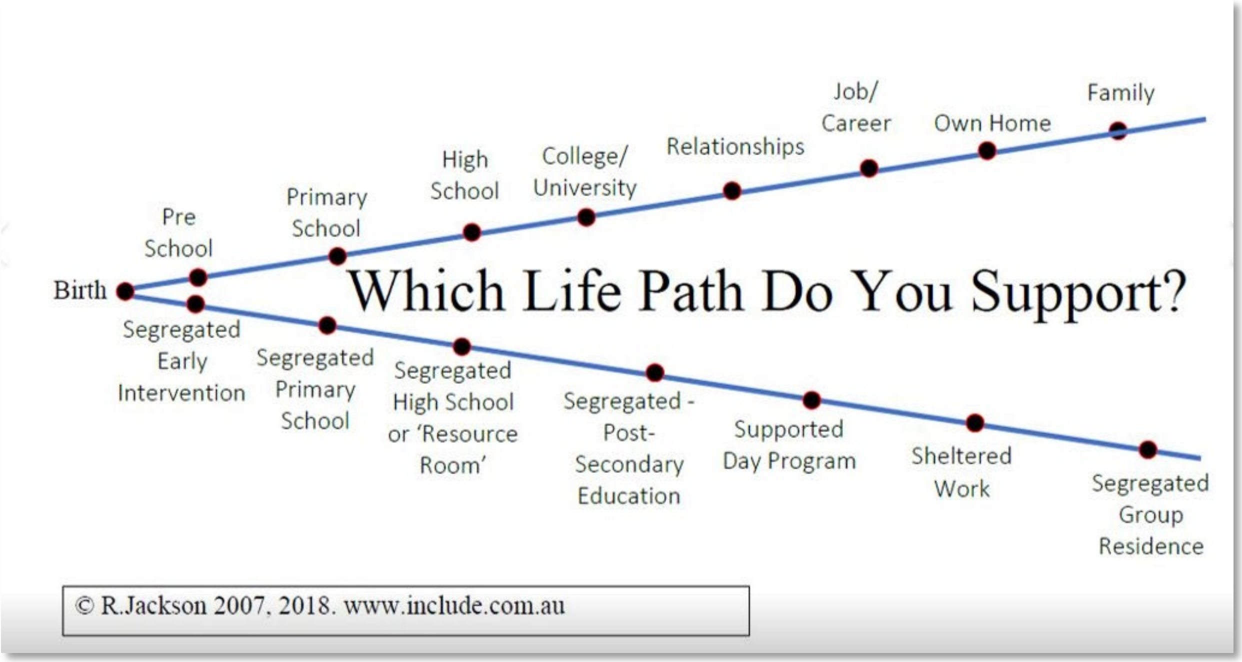
[23] Ibid. 8, p94-101, 5.4.14.

Other recognised influential factors can be the opinion of the families GP, obstetrician, paediatrician, allied health professional, Early Childhood professional, Tertiary leaders, other parents, or society as a whole. Thus, it is essential that unconscious bias awareness be address in all these areas.

Parents are making these "choices" unwittingly, not really understanding the long-term consequences. Here, we refer to Dr Bob Jackson's Life pathways diagram previously provided in Submission 1-Inclusive Education.



The diagram above 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 the "good 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". This supports the research that inclusion provides better outcomes and is a safeguard, whilst segregation is harmful and costly.

On this basis, we recommend our governments at State, Territory and National level, formulate a plan to ensure SRV is known and understood by those involved more closely with people with disability and the community at large. There are various touch points such the family directly, the medical profession, allied health professionals, educators, bureaucrats and parents at school environment. In this way, over time we can close gap in societies understanding and acknowledgement of unconscious bias that exists, and the necessity that valued roles play in providing safety for a person to be protected from violence, neglect, abuse, neglect and exploitation.

Q 8: What can be done to improve attitudes towards people with disability? Please consider policy, laws and other approaches. What good practice examples should we know about?

Examples of good practices

Family Advocacy believes in the very real possibilities that people with disability can and should have in our society. Now, more than ever, there are emerging opportunities that families can embrace and shape to bring about a good life alongside their sons and daughters, a life full of potential and learnings. Story telling through film is one way of showing families and the general public what is possible and challenging stereotypes. Below are examples of films we have produced with our families over many years. Family Advocacy encourages families to exercise intentionality to redress the negative assumptions held around these people from an imagery and competency perspective. We go to great lengths to consciously ensure the nuances in positive imagery and competency are relayed in the films.

For ease of reference, we have listed which stage of life each film relates to (education, employment housing, community participation), the title, the length, a link to the film, a brief explanation about the film and some quotes from people featured in the films so you can get a flavour of the variety of voices included such as parent, teacher, principal, student, friend, and support worker.

Inclusive Primary Education - Joscelyn's Journey - (23.45 minutes)

This film is about Joscelyn's inclusive education at primary school from Kindergarten to Year 6.

Principal, Lee Oliver - "We really are a reflection of society and that's what schools are. So if we can provide for Joscelyn or any child, the ability and skills and knowledge to go out on to high school or the wider community, Joscelyn will make a significant contribution to Lake Albert Public School, to high school and the workforce down the track. So it's been a team effort and a positive one."

Inclusive High School Education - Al's story - (15.51 minutes)

This film is about Al Graham and his inclusive education journey through the lens of his last week at Turramurra High School in NSW. Thank you to the Graham family and Turramurra High School.

Al's school mate - "The opportunity it's given me and others has been really significant to our lives and had a really huge impact on us".

Al's teacher - "All those soft skills go out into the workforce and out into the community, and that's where you start to get the inclusiveness that you want in our communities, and the acceptance, the promotion of diversity".

Inclusive High School Education - Jacob's story (18.59 minutes)

School is one stage in life where we learn to become an adult, form our viewpoints, determine our social peer groups and be an individual. Families often express how valuable it is to hear from other families about their experiences, what are others doing out there in the real world?

We decided to make this film in order to provide families with this experience of one student's journey through primary to high school and showcase how Jacob's school is adjusting and providing for him to have the same opportunities and school life as every student in the regular class.

Employment/ Microbusiness - Josh's story - (6.07 minutes)

Josh attended his local school in the regular class and completed his work experience with two businesses whilst at school; he is now volunteering at both businesses as well as running his own mail pick up service. This story highlights how far reaching the beneficial impacts of an inclusive education can be and how instrumental it is for families to have a strong vision of the possibilities of the future.

Independent living - Jac's Place - (9.46 minutes)

Jacob Hughes has made the move to live independently. This film is about his life, the plan to give him the opportunity to have his own place and the team of people who worked together to make it happen.

Jac's support worker - "Since Jac has moved in to his own place, it had had a really good impact on Jac's independence and Jacob not being a 26-year-old guy who lives with his mum but now being an independent young man who lives in his own place.

Circle of Support member, Melanie - "Jacob has really taken to living on his own and being in charge per se, because you can see he is up for a social gathering that he has initiated with support and he is doing a lot more on the weekends and you can see how engaged he looks on his face. I feel like it's made a difference to the people around him because we know it's what Jacob wants".

Community Participation/ Self-managed supports - Rachel's story - (7.57 minutes)

Rachael is discovering her passions and challenging herself with a close team of assistants. Rachael uses a power chair but it hasn't stopped her from exploring her strength as a pole dancer.

Visit our Resourcing Inclusive Communities website for ideas, stories, resources and event information to support people with disability to lead a meaningful life as valued members of the community.