Submission to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability

Submission No.6: Response to Promoting Inclusion Issues Paper

> **"Children that learn together, learn to live together"**
>
> *Jody Carr, Former Minister for Education, New Brunswick, Canada,*
> *speaking at*
> *Family Advocacy's National Symposium on Inclusive Education 2017*

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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.

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Recommendation 5

That the Royal Commission recommend the following changes to education policy regarding students with disability:

- Accountability - Review the Disability Discrimination Act 1992 to align with the UNCRPD
- Cease funding new fully segregated schools
- Create an inclusive education system
- Reform teacher standards
- Funding attached to the child not the setting
- Provide support and training to parents seeking inclusive education for their children.

Recommendation 6

That the Royal Commission recommend the adoption and implementation of the Australian Coalition for Inclusive Education's, *Driving change: A Roadmap for achieving inclusive education in Australia.* Importantly, this includes the phasing out of segregated education settings by 2030.

Recommendation 7

That the Royal Commission mandate that each the Australian Government, and each State/ Territory Government adopt an inclusive education system in accordance with the definition of inclusion under General Comment No. 4 of Article 24 (Right to an Inclusive Education) of the UNCRPD.

Recommendation 8

That the Royal Commission declare segregated settings are discriminatory and recommend no more new special schools be built and that those that currently exist be phased out in a considered but time bound manner.

Recommendation 9

We recommend a national disability employment strategy that incorporates the recommendations from the *Willing to Work* report and contains targeted general measures for increasing workforce participation, including addressing structural workplace barriers. This includes setting a quota for public service employment of people with disabilities, including specific quotas for people with developmental disabilities, that reflect the natural proportions in society.

Recommendation 10

That the Royal Commission recommend the Australian and State/Territory Government's put the interests of people with disability over the vested interests of services such as Australian Disability Enterprises, Day Services and Disability Employment Services. This means a plan be put in place to end segregated settings such as ADEs, to significantly overhaul Day Services and support the transition of workers to regular employment settings and this includes equal remuneration - real jobs for real pay.

Recommendation 11

That the Royal Commission recommend the overhaul of the Disability Employment Services for more innovative and effective pathways that have appropriate supports, information, on-the-job training and skill development to ensure people with developmental disability receive a fair days work for a fair days pay. Some examples of these models are customised employment, and micro-enterprises.

Recommendation 12

That the Royal Commission recommend the Australian and State/Territory governments develop a national plan to promote independent living and address the many housing issues faced by people with disability so they can maximise their level of independence and freedom; and allow people with disability to control the resources they require to live with dignity in the community, ensuring that people with disability are able to choose where and with whom they live.

Recommendation 13

That the Royal Commission recommend a commitment be made at national, state and local levels for funding projects and initiatives focused on changing community attitudes towards disability, and that these initiatives be co-designed and implemented by people with the lived experience of disability and their families and supporting organisations.

Recommendation 14

That a commitment be made at national, state and local levels for funding projects and initiatives focused on promoting employment and improved community attitudes towards disability, such as the National Alliance of Capacity Building Organisations (NACBO). Such an investment must be across the life of the National Disability Strategy and needs to recognise this goal will require an ongoing and sustained effort.

Recommendation 15

As tools to influence changing attitudes, that the Royal Commission recommend our governments at State, Territory and National level, do the following:

- formulate a plan to ensure comprehensive theories such as Social Role Valorisation are known and understood by those involved more closely with people with disability and the community at large
- investigate the influence of media as a tool to challenge stereotypes, and
- fund independent advocacy.

Recommendation 16

That the Royal Commission recommend to support the capacity building of the family to have the skills, knowledge and confidence in order that they can support or advocate for, with or on behalf of the person with a disability in their life.

Recommendation 17

That the Royal Commission call for reform to streamline existing services and supports between various levels of government to make them easier to use and more person-centred. For example, improve linkages between key systems/agencies to reduce duplication.

Recommendation 18

That the Royal Commission recommend greater accountability of the National Disability Strategy with the need for:

- establish cross-agency collaboration within and between federal and state/territory government
- establish a central administering body to facilitate both the government and non-government sectors to take carriage of consistent and long term data collection, measurement, monitoring and reporting requirements to hold the National Disability Strategy accountable to its intent to achieve an inclusive society.
- proper consultation where people with disability, their families and supporting organisations are involved in co-design the implementation, measurement, monitoring and reporting of the National Disability Strategy.

Recommendation 19

That the Royal Commission recommend the Australian and State/Territory governments commit to both annual and longitudinal reports across the life of the National Disability Strategy and that such reports be tabled within parliament.

Recommendation 20

That the Royal Commission recommend robust data gathering is required to maximise public accountability. Investment in a national system, with built-in accountability is required.

Introduction

Family Advocacy is a state and federally funded disability advocacy organisation that works across New South Wales (NSW) and was founded 30 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.

Family Advocacy has a vision of a future where inclusive thinking is the norm. 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 their greatest safeguard as well as their greatest conduit for promoting inclusion.

Family Advocacy is pleased to make this submission to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (hereinafter, the 'Royal Commission') in response to the Promoting Issues Paper. We welcome the Royal Commission'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.

However, it would be a huge oversight for us not to mention a more powerful driver for inclusive policy would be for Australia to actually enact the laws required of signatory parties to UN Conventions. Unfortunately, Australia has failed to legislate to protect the rights of its citizens. As a result, even scrutiny and criticism from the United Nations does not ensure that the Australian government has to meet the responsibilities of the CRPD. Without a legal system that ensures human rights are protected, Australia has been able to contravene the CRPD without retribution. Commonwealth law overrides state/territory law, so state government can enact a charter of rights without needing to deliver on them.

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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.

For this reason, we strongly recommend Australia adopt a statutory Bill of Rights[2] to strengthen the potency of the National Disability Strategy.

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 experience in the promotion of inclusive education, employment, 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.

Family Advocacy welcomes the opportunity to provide evidence if there is a hearing date issued in relation to promoting inclusion as well as facilitate the process for families to give evidence, if required. Due to the population size of NSW, and 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 Royal Commission.

Recommendation 1

That the Royal Commission recommend the Australian Government adopt a Statutory Bill of Rights to ensure that ensures human rights are protected and strengthen the potency of the National Disability Strategy.

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[2] https://www.humanrights.unsw.edu.au/news/five-reasons-why-australia-should-adopt-statutory-national-bill-rights

What does inclusion mean to you?

We share some quotes from a recent survey asking our database of families what inclusion meant to them:

People with a disability being wholeheartedly included in all aspects of society - socially, in education, in work, in family life.
Where a person with a disability can join and participate like any other person with minimal focus on their disability and a full acceptance of them as a person that feels wanted and safe in that particular group.
Inclusion to me is everyone having the same opportunities and sense of belonging as their peers.
Ability to access any services like everyone in the planet. Valuing someone for their individual strengths and not measuring them against a 'norm'.
Where everyone is included and not separated on the basis of their disability or their differences.
Inclusion is to be embedded within the community in a meaningful way. This should be based on the person's passions and interests among peers, friends and family of their choice.
Inclusion does not have an othering rule- good for some but not others.
Belonging, having the same choices and opportunities as people without a disability, to participate in what life has to offer eg school, recreation, employment, along with everyone else, not in a segregated setting.
Inclusion is being accepted to be myself and accepting others for who they are.
Inclusion is about equity and access, planning and building systems and processes so that people with disability are not disadvantaged. Inclusion is the way we think, openly and genuinely about our desire to make life accessible

Inclusion and developmental disability

> *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

People with developmental disability have faced discrimination, segregation and stigmatisation, and negative attitudes for millennia. History paints a very clear picture that segregation has come off the back of discrimination. We impress on the Commission the absolute necessity to declare that segregation is a form of discrimination. Family Advocacy is one of the 42 disability rights and advocacy organisations that supported the Disabled People's Organisations Australia (DPOA) Position Paper, which calls for an end to segregation of people with disability in Australian education, housing and workplaces.

The DPOA's Position Paper asserts that "people with disability are separated from the rest of the community by law, policy and practice frameworks that enable 'special' segregated arrangements." And "this is particularly the case for people with intellectual, cognitive or psychosocial disability, neurodivergent peoples, people with multiple impairments and others who are warehoused in segregated settings and environments due to a lack of adequate supports and services". The Position Paper calls for six actions to end segregation, and we recommend they be implemented.

Recommendation 2

Support the implementation of the six recommendations to end segregation as proposed in Disabled People's Organisations Australia (DPOA) Position Paper.

A life course approach

Inclusion and early childhood

Inclusion should start early, essentially with a child's first formal education experience in pre-school at age three or four. As the Issues Paper states "a person's experience of inclusion during the early years may have lifelong positive effects throughout their life whereas early experience of exclusion may have lifelong negative effects". It makes sense to build connections with community from the same age other children do, so that children with disability move naturally with their peers into inclusive education settings. In this way, fostering inclusion in childhood has the potential to break the cycle of stigma associated with disability.

Early intervention and educational learning support of a child with disability should take place within the settings the child would naturally be part of – family life, local community daycare, community pre-school and community school[3]. Supports should be brought to the child to facilitate his/her participation in natural settings, rather than removing the child from his/her natural setting to access disability or early intervention support.

An education policy which supports education of students with disability with targeted support and early intervention from the earliest stages of formal learning in pre-school environments clearly requires engagement with early childhood policies and practices. Some of the key intersects in this space are: the federal government's National Quality Framework for Early Childhood Education and Care; the Early Years Learning Framework; My Time Our Place – Framework for School Age Care in Australia;

In addition, in 2020, Reimagine Australia designed and delivered the first National Blueprint for Early Childhood Intervention to 2030, on behalf of the Commonwealth Government, called 'Reimagine Early Childhood: A National Action Plan to 2030: Supporting outcomes for children with disability or developmental delay and their families'. The 10 year plan provides a clear road map to support the development of children, optimise social and economic outcomes for children from birth to six years with developmental delay or disability and support their families in a broad range of evidence-informed and innovative approaches. Family Advocacy endorses this Action Plan.

Recommendation 3

That the Royal Commission recommend the adoption and implementation of the 10 year Action Plan 'Reimagine Early Childhood: A National Action Plan to 2030: Supporting outcomes for children with disability or developmental delay and their families.

Inclusion is not just about being present in a mainstream setting, it means being actively engaged, and creating environments for all children to be able to develop relationships. For the child's participation to be meaningful, the child's role and contribution must be valued by all those involved in the activity, including the child themselves. For inclusion to be successful, **below are 12 principles** we recommend in the early childhood learning space. These principles also apply to all education settings from primary, secondary to tertiary levels.

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[3] Following the natural paths of childhood, Bob Jackson (This paper is a development of a paper "Should Schools include children with a disability?" Robert Jackson, Ron Chalmers and Daryl Wills, Interaction 2004)

12 Principles of Inclusion	
Leadership	Children with disability flourish when leadership in the early learning environment ensures children with a disability are valued and disability is viewed as adding diversity to the class.
Natural Proportions	Children with disability should be spread out in natural proportions rather than being grouped together by the category of their disability.
Supports	Support needs to come direct from the teacher rather than aides (school learning support). We need to move away from 1:1 support.
Time for Planning	teachers should have sufficient co-planning time to ensure children with disability have adequate and appropriate support and reasonable adjustments made.
Mobile services	rather than taking a child out of the regular classroom, services should be delivered in the context of the regular classroom. Learning skills in a natural environment is more effective than practicing a new skill in an isolated setting once or twice a week.
Specialist Teachers	should be supporting the teacher in the regular classroom
High expectations	assume every child can learn without requiring evidence of their capacity. Inclusive education needs no prerequisite skills.
Collaboration	develop partnerships based on mutual commitment, trust and respect between the early learning centre and the student and their family/ guardian.
Peer Learning	To foster friendships and avoid micro exclusion in classrooms, instigate peer learning opportunities.
Changed mindsets	are required for inclusive education where traditional views of education are transformed.
Continuous reflection	required on practices, policy, values and beliefs and how they impact the inclusion of children with disability.
Student and parent voice	acknowledge the lived experience of the child with a disability and their parent, their experiences, their needs and their solutions.

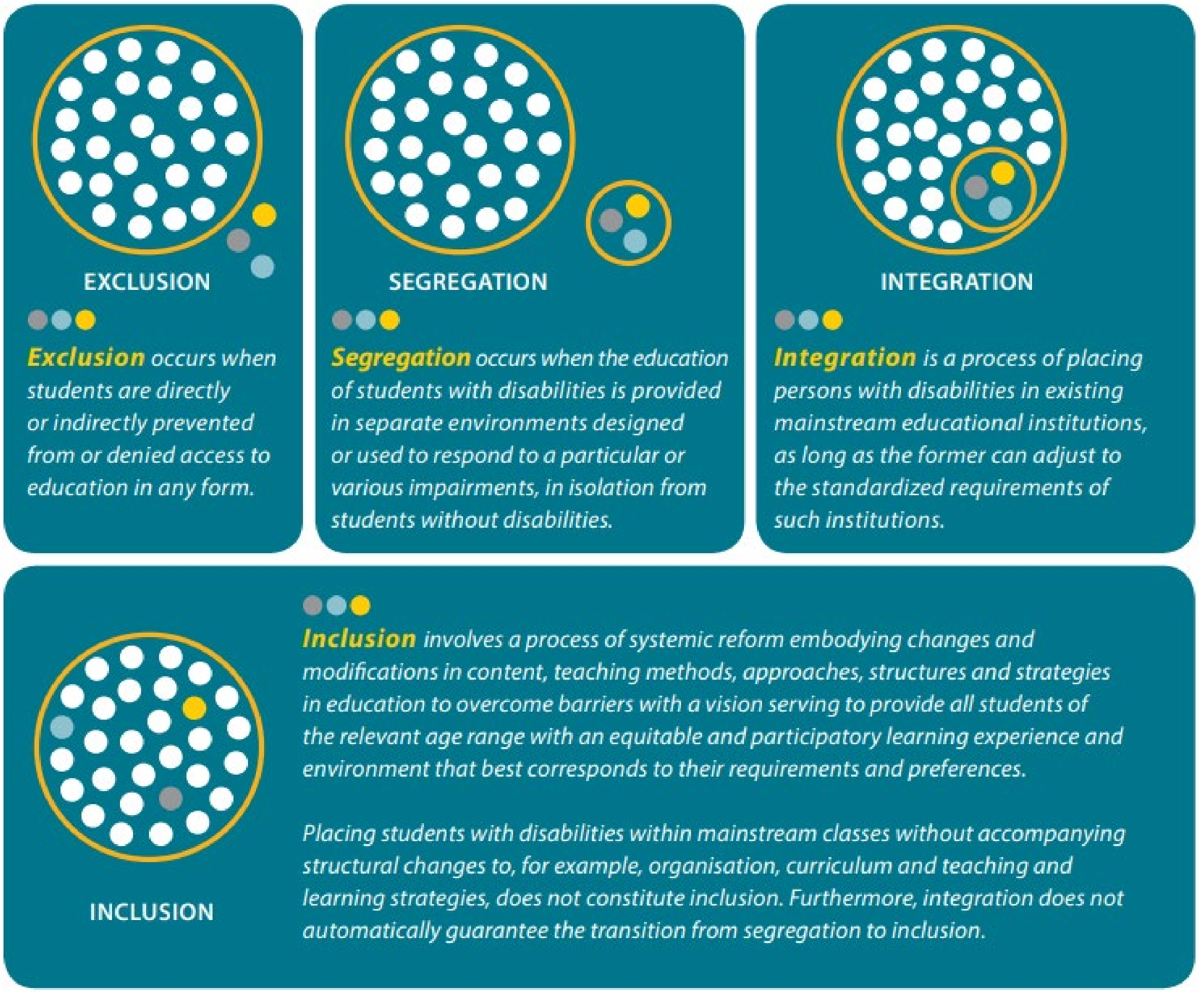
Recommendation 4

That the Commission recommend the 12 principles of inclusion be adopted and implemented in all education settings – early learning centres, schools and tertiary settings: Leadership, Natural Proportions, Supports, Time for Planning, Mobile Services, Specialist Teachers, High expectations, Collaboration, Peer Learning, Changed Mindsets, Continuous Reflection, Student and Parent voice.

Inclusion and Education

Inclusion is a concept in school and tertiary education most often associated with minority groups and people who experience disability, but in fact, inclusion is about everyone. Inclusion is a human right (Declaration on the Rights of Disabled Persons 1975 and the UNCRPD), a legal entitlement to all (Commonwealth Disability Discrimination Act 1992) and a core pillar of educational policy (Disability Standards for Education 2005).

The definition of inclusion is clearly defined in General Comment No. 4 (GC4) under Article 24 (Right to an Inclusive Education) of the UNCRPD – depicted by the diagram below. The need to distinguish inclusion from exclusion, segregation, and integration is critical.



Exclusion *occurs when students are directly or indirectly prevented from or denied access to education in any form.*

Segregation *occurs when the education of students with disabilities is provided in separate environments designed or used to respond to a particular or various impairments, in isolation from students without disabilities.*

Integration *is a process of placing persons with disabilities in existing mainstream educational institutions, as long as the former can adjust to the standardized requirements of such institutions.*

Inclusion *involves a process of systemic reform embodying changes and modifications in content, teaching methods, approaches, structures and strategies in education to overcome barriers with a vision serving to provide all students of the relevant age range with an equitable and participatory learning experience and environment that best corresponds to their requirements and preferences.*

Placing students with disabilities within mainstream classes without accompanying structural changes to, for example, organisation, curriculum and teaching and learning strategies, does not constitute inclusion. Furthermore, integration does not automatically guarantee the transition from segregation to inclusion.

Source: United Nations Committee on the Rights of Persons with Disabilities General Comment No. 4 (http://www.ohchr.org/Documents/HRBodies/CRPD/GC/RighttoEducation/CRPD-C-GC-4.doc)

Given there has been significant ambiguity as to what is meant by “inclusive education” and that ambiguity has complicated efforts to implement inclusive education systems, the purpose of GC4 is to provide Governments with guidance on the scope of their obligation to provide quality inclusive education for people with disability. GC4 came about after a two year process involving the review of a draft General Comment and submissions for State Parties (including Australia) interested NGO’s (including Children and Young People Australia) academics and disability advocates.

The Royal Commission has noted it will examine inclusion through a human rights approach, acknowledging Australia’s obligation as outlined by the eight principles of the UNCRPD. On this basis, it follows that the Royal Commission adopt the definition of inclusion in accordance with the UNCRPD as per the diagram above. It also follows that the definition of segregation, exclusions and integration be adopted. On this basis, we recommend the Royal Commission declare segregation is a violation of a child’s human right and phase out special schools in a considerate but timely manner.

For an in-depth discussion of the transformation required in legislation, policy and the mechanisms for funding, design, delivery and monitoring, we refer the Royal Commission to our previous submissions, see No. 1: Inclusive Education, No.2: Response to Education and Learning Issues Paper and Family Advocacy’s, Witness Statement of Cecile Elder, who gave evidence at Public Hearing No. 7 on 12th October, 2020.

The traditional model requires bringing the child to the special education services. Outcomes from established special education programs indicate that they just haven’t worked. The Royal Commission heard the evidence of Ms Catherine McAlpine, (CEO of Inclusion Australia in Public Hearing 9) where she spoke about the “polished pathway” as a means of describing the relative ease of transition from special or segregated education into supported or segregated employment and congregated housing. She also gave evidence that people have to be “pretty determined” to reach the goal of open employment when their education has been in a special or segregated setting. 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”.

The diagram below shows the natural pathways of childhood and the impact of an ordinary pathway versus a segregated pathway[4].. Every step taken down the segregated pathway is a step away from the “good life” being in community where natural safeguards occur.

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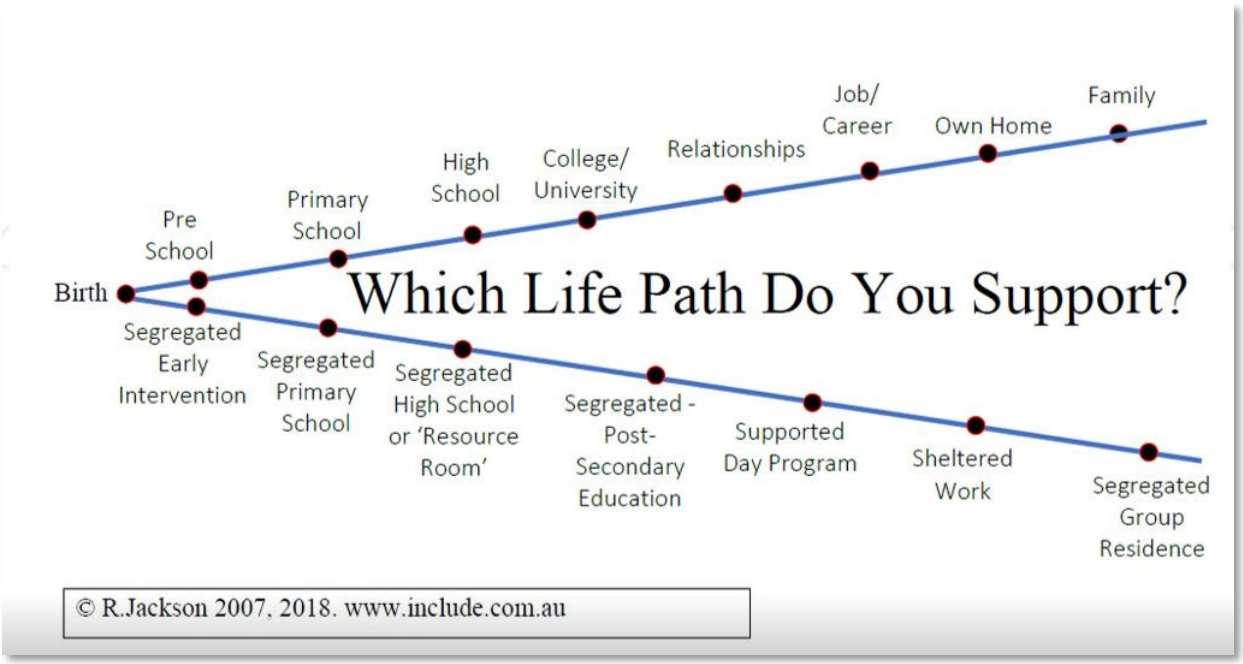
[4] Jackson, R (2008). Inclusion or segregation for children with an intellectual impairment: What does the research say? Queensland Parents for People with a Disability.



The inclusion model requires bringing the special education services to the child. Inclusion cannot be viewed as a way of eliminating special education costs. Special education delivery must be reconceptualised. There requires a merger of governance of special and regular education and their funding streams. Full inclusion would encourage that special education services generally be delivered in the form of training and technical assistance to “regular” classroom teachers. Effective inclusion is characterised by virtual invisibility. Children with disabilities are not clustered into groups of persons with similar disabilities but dispersed proportionately in whatever classrooms they would otherwise attend.

Mac’s story – a case study of inclusion in education

Mac, the son of a family member connected with Family Advocacy, was selected as an exemplar of practice in 2015 by the Australian Government, see https://www.dese.gov.au/swd/resources/exemplars-practice.

Mac attends a mainstream primary school in rural NSW. Through successful inclusion in his school, Mac engages in the standard school curriculum and enjoys participation in school activities with an extensive friendship group. His positive experience of school life is a result of his parent's advocacy, the school's philosophy of inclusion, and the use of communication technology.

Mac's cerebral palsy means he has no independent movement, has significant vision impairment, and needs assistance with every aspect of his day. Mac uses a device with his feet, pressing through and selecting options to undertake tasks and demonstrate his learning. A communication partner holds the device against his feet.

The school where Mac goes had not previously supported a child with Mac's extensive support needs, and although they were apprehensive about their ability to accommodate Mac, the school welcomed him and his family, acknowledging it was the beginning of a steep learning curve.

Through detailed discussions, an independent learning plan was developed for Mac and is reviewed each year and as appropriate. The initial plan included the basic, but essential goals: get to know Mac and understand his learning capability. His parents had been told that Mac must have a massive cognitive deficit. In a 'light blowing moment' however, it became clear he was learning at the same rate as his peers.

Ultimately it was the NAPLAN testing that allowed Mac to reveal his cognitive capability. In the year five NAPLAN test, Mac's communication partner used earphones and sat, turned away to prevent hearing or seeing the question, which was read to Mac by another adult. In this way there was confidence that no unconscious assistance was provided by the communication partner, and all options were selected by Mac himself. The outcomes determined he was learning at his year level and this means his outcome goals have now been set in line with the other children.

A key message from Mac's experience is to move beyond the planning of physical and care needs, to a deeper understanding of what access to the curriculum and inclusion in social life actually means.

This has developed from the need to find the balance between the school's perspective about how to perform their duty of care around the supervision of Mac, and his parent's vision for Mac to enjoy an 'ordinary life: tonnes of friends and fun, tonnes of natural support, employment — same as any child'. It is this vision that has set the framework for many decisions over time: whether an activity, a type of support, a teaching approach, or interaction, aligned with the vision. If not, then re-thinking may be required to align with the vision for Mac.

An example of re-thinking the school’s care of Mac in line with the vision framework, occurred when it became apparent the aide (school learning support officer) took Mac with her if she left the classroom, but this took him away from his peers and the class activity underway. Mac also let his mother know he was lonely at lunchtime, because he was with the teacher on duty, again away from his peers. The school worked to change this by implementing a variety of creative solutions including helping the students to identify games that Mac could participate in, for example time trials of an obstacle course that Mac could complete with his friends.

Reasonable Adjustments

The adjustments made have included:

- changes to tasks and their associated outputs — such as the time given to complete a task, the amount of work required and how Mac demonstrates his learning — which are all based on the Disability Standards for Education (2005) and the NSW Primary School Syllabus guidance for students with special needs
- ensuring the teacher is working with Mac, like they would with any other child, rather than having the aide pass on the teacher's instructions
- the school supporting teachers to get past their nervousness that they will do the 'wrong thing'.
- In addition to specific adaptations, creative means are used to promote participation, for example:
- when studying and creating shelters in class, Mac acted as a council inspector to assess the physical accessibility of his peers' shelters
- in science, children designed and developed a simple device for Mac's chair for handball games
- in a peer-led initiative, Mac's classmates developed a presentation about Mac's capabilities for the school assembly, providing insight about his classroom work, humour and contribution
- acknowledging the school's concern for Mac's safety by developing a 'wheelchair attendant licence' for children before they could push Mac's chair
- developing a competency within the curriculum that allows Mac's peers to develop their skills against this to take on the role of communication partner.

Cost

Mac's parents have opted to provide Mac's communication technology, and the school has provided a laptop for the aide to load up teaching material for Mac's reader.

The aide is funded by the NSW Department of Education's Disability Support Program, which covers all but a half-hour of the school day. The assistance the aide provides gives Mac's teacher support to prepare his learning materials, attend to care needs, and to support Mac's participation in games and playground activities.

Outcomes

Mac's mother identifies the biggest success as the level of autonomy Mac has with his peer group, who have become confident and skilled in supporting his physical engagement. Examples of this autonomy include sleeping in a room with five mates at camp, and the development in science class of a device for Mac's chair for handball games.

The benefits to the other children and the broader school community have also been overwhelmingly positive. Creative solutions — like the wheelchair attendant licence — also addressed the perception that only people in paid roles could touch Mac or his chair. It also promoted peer responsibility for their classmate, and their friend.

Parents and the school measure success in the normalised way Mac receives consequences for occasional misbehaviour, and his routine of going home to a friend's house every Tuesday. The principal hears back from other parents about the respectful way their own children talk about Mac at home, providing another indicator that the school's investment in inclusion is rippling out to benefit the wider school community.

Mac's mother notes that inclusion isn't innate: people take time to learn, and don't always get it right. Not always knowing the answer is also part of the learning.

“We had an expectation he'd go to school with kids from his neighbourhood to learn at his level and to start out and remain an engaged and valued member of his community”. Mac’s mother

Skills and behaviours

Everyone knowing what they are working towards for Mac has kept the effort on track and by committing to keep working alongside each other, not pulling back when it gets hard, and keeping the focus on Mac, inclusion has been a reality for him.

Mac's parents sometimes take time to consider an idea, and they have found going to the formal planning meetings together is an effective way to make the smaller decisions on the run. Additionally, plans are documented and commitments are followed-up and checked off, which all contributes to building and cementing the trust in the parent-school partnership.

Mac's mother has also invested time in parent advocacy courses and found this helpful in articulating and pursuing their vision for Mac: 'a good, ordinary, inclusive life’.

The principal describes their experience of Mac being in the school in this way: “It's broken down my barriers around disability. Made me think very differently about how kids should be accessing school. He's taken it to the next level. I didn't know how to be natural around him — [I] had to learn. When our teachers move on they will be able to contribute more deeply in their next school”.

“We had tonnes of meetings in the first couple of years — we were just so slow to move past our own limited understanding. Mac's Mum supported us in so many things and has given so much guidance, and waited for us to catch up. [The] only limitation we had, was ourselves”. Principal

We invite the Royal Commission to watch the following videos promoting inclusion at school.

- Communication partners for Mac – interviews with Mac's peers about school life with Mac
- Fun and Friends – a photo montage of Mac involved in all of the school's extra-curricular activities
- Mac – a 'how to' video – produced by Mac's peers to help his new teachers aide settle in
- Handball buggy – Mac's peers created modifications to his buggy so he could join them to play handball

Below are the comments provided from parents from a recent survey sharing their views on how inclusive education has benefited their child, the difference an inclusive attitude and environment makes in learning and the elements that led to successful transitions.

The positive benefits (short and long term) when the child is included in the regular class
Our daughter was in a mainstream school and was able to travel to an agricultural field day with her class and that lead to her career.
Friendships, and positives for how things can be inclusive. Being able to participate in a swim carnival regular race using a canoe when your disability has prevented you from being able to swim or walk.
My child has felt like he's one of the kids. Adults (teachers) including him has helped develop compassion and empathy in some of his classmates who've been more patient and understanding of my son than would have otherwise.
My child, J, went on many inclusive excursions. Ironically, the deputy principal of his primary school was not helpful but J had many natural friendships and the staff that attended were very aware of our family's definition of inclusion. It was very successful. Many successful excursions occurred eg. theme parks, camps, snow skiing, adventure parks flying on flying foxes, parliament house, universities; all were overnight excursions. He also attended short term excursions to the beach, rainforests, lookouts and nature reserves. He always travelled with his peers, sitting with his peers, laughing with his peers and getting in to trouble with his peers. He had a support worker close by but not in his face. I ensured the support worker was on the 'same page' as us.
Being part of the whole year excursion - having mainstream peers greet her with familiarity and genuineness. Long term - confidence and an increased sense of belonging. Perhaps for the mainstream peers a greater acceptance.

Incredible and numerous benefits, which I believe will be lifelong! He was happy, had fun, experienced friendship, learned so much by being part of a regular class, had to live up to high standards of appearance, punctuality etc (all good skills for future employment), got to play handball at lunchtimes with the other kids (who adapted the rules to include him, without any adult/teacher intervention), was a part of important school rituals such as formals, graduation dinner, athletics and swimming carnivals, school concerts and camps along with his peers. The long term benefit of being a student at the local primary school has been instrumental in him becoming a valued volunteer at the school for more than 7 years which continues to be a wonderful way to become known in the community. At high school he was able to experience a variety of sports including being introduced to spin cycle classes and a mainstream gym, which led to attendance at our local gym where he is well known, and is a regular in the spin cycle classes with the assistance of a personal trainer, another great way to be part of the community, not to mention the health benefits and increased physical ability. There have been immeasurable benefits, both short and long term, some of which we did not foresee at the time.

J has never been in a segregated class. At 3 years old he began his education at an inclusive preschool. However, he has experienced many segregated experiences. School cricket, soccer, athletic carnival were all initially off the school's agenda as he 'wasn't' physically able to contribute. He, his friends, his sisters, us and staff that 'got it' and recognised the segregation were quick to provide solutions. J didn't need to kick the soccer ball he could catch and throw it. His mates took it in turns to push him around the cross country course. As a result of this default expectation of true inclusion, J is now 21 years old, lives 300km away from the family home, with 2 flat mates in a house that is being modified. He drives his own modified vehicle independently, attends university, takes himself off to gym twice a week with a trained gym support worker and he goes to parties/pubs where sometimes accessibility is poor but he weighs up the risks and his friends do the muscle work.

An inclusive attitude or environment made a difference to the child's learning

Being included in camps led to her feeling included and this created a great learning environment as she was able to use drawings and pictures to do her presentations visually.

She had many outside interests ballet, sunbeams church swimming. She was just one of the group. She commuted with her sisters and then on her own to school. She enjoyed supported holidays on her own meeting new people, what joy. It all gave her a sense of independence, for me it was so important for her future.

Reading the same novel as the rest of the class when the expectations and workload were adapted for each individual. More than anything this taught me that teaching differentiated teaching can be a remarkably positive approach. In first grade her teacher placed the kids desks about one metre apart so my daughter could move between them. She took her first independent steps in this class and the whole class cheered for her.

J, his 2 sisters and his growing network of friends always assumed inclusion. They all knew what it looked like and how to achieve it. He didn't miss out on anything. He was included in all activities and it was his sisters and friends that came up with solutions of how he could contribute. Therefore his learning in general was so much more productive as he had a huge network of natural relationships. This attitude flowed on to his sister's friends and community as they witnessed and learned by example of what inclusion looks like. J was included in school carnivals and swam with his peers, he was just a lot slower. The entire school community was astounded at his ability and so, so supportive. This in turn gave him confidence to tackle anything.
Year 4 teacher - casual, very young and inexperienced - but willing to TRY different strategies and chat with me to try to work out how she could help. She devised a plan for teaching money skills which worked fantastically well. At the end of the year she told me how nervous she'd been, and said that if her first idea didn't work, she'd try something else. What a great attitude. Proves that you don't need an "expert", just someone willing to try, and try again. Surely a great attribute for any teacher. It was the teacher's willingness to make adjustments that resulted in great learning outcomes. With the assistance of a great teacher's aide who "got" inclusion, the whole class benefited. No fancy or expensive resources required, just a positive attitude.

Transition – Elements for success
Not re-inventing the wheel each year, sharing good examples of testing ideas, file with helpful information and good opportunities for partnerships with school and easy communication channels
Understanding of his disabilities. Regular communication.
Creating a connection to her community and utilising her interests instead of placing her where they think people with a disability should work. Having flexibility
Not pulling out of the class and help other students understand everyone is included and need help.
Lots of parent teacher communication to build up trust and respect Visits to new class/ school beforehand. Set up of physical environment and equipment so it is ready. Staff training. Social stories and visuals.
Respect or her rights - listened to family goals and values - considered whole child - no issues with funding

Getting away from a school that has a support unit on site - there is a strong community perception that if you have a disability then you belong in the support unit. Local school - great seeing familiar faces at other places in the local community eg shops, pool. Attitude of staff, families, students Teacher's aide who "got" inclusion. Strong support from family, and involvement with school, support for fundraising, working bees, canteen etc
The attitude of teachers and principal was an important factor for successful transition.
The most important element was for us to be prepared and sure/educated in what we wanted his experience to look like. In our instance this was to approach the school 2 years before enrolment. We found many barriers put up by the executive staff of his primary school as to why it wouldn't work. This was due to lack of understanding, education and experience. It was a huge benefit to have started this early. Our family were sure to have a positive approach. Year 6 to high school was less emotionally draining but more challenging in regards to structure of the school. However, the executive staff were much more willing to listen to our family, welcomed the challenge and our suggestions of how this would work. They were open-minded and educated themselves within the dept as well as taking advice from our family. It was a 3 story school of 900 students and built on a hill. However this was where his 2 sister's went and the majority of his friends were going and, most importantly, where he wanted to go. It happened and was extremely successful.

Recommendations for education policy regarding students with disability

The following policy recommendations are:

- Evidence based
- Consistent with the obligations to the United Nations
- Are in line with best practice in education
- Have the capacity to bring a group into society that has been isolated for millennia
- Result in considerable economic savings and engage a large number of people in productive activity, with independent lives and reduced but appropriate support.

The recommendations draw on numerous government report such as the recent Deloitte report in Queensland[5] and other State reports as well as evidence from hundreds of families looking to achieve an ordinary life for their children as well as adults with disability who have experienced both segregated and inclusive education.

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[5] http://alana.org.br/wp-content/uploads/2016/12/A_Summary_of_the_evidence_on_inclusive_education.pdf

Accountability - Review the Disability Discrimination Act 1992 to align with the UNCRPD

To provide some accountability, it is time to review the Disability Discrimination Act 1992 to align with the UNCRPD. The UNCRPD includes several critical considerations applying to students with disability[6]. General Comment Number 4[7] makes several points around students with disability were clarified after extensive consultation with the over 150 nations involved. These clarifications in General Comment 4 include:

- Inclusive education is a *fundamental human right* of all children.
- Not being allowed to attend a regular school is *exclusion.*
- Separate educational facilities for students with disability are *segregation.*
- Separate classes or units on a mainstream campus are *segregation.*
- Placing students with disability in existing mainstream educational institutions with the understanding that they can adjust to the standardized requirements of such institutions is *integration* NOT inclusion.
- Placement within a mainstream classroom separate from other students (with or without an aide) is *segregation* NOT inclusion.
- *Inclusion* is presence, and full and valued participation, in the mainstream class and all activities with mainstream peers. For example, being engaged in the same lesson, with all adaptations as needed.
- Adequate education for all teachers and other staff to support inclusive education is required, including *at least one* dedicated unit on inclusive education in each teacher education course and appropriate professional development.
- Full inclusion is a requirement for all people with disability at every level of education from early childhood onwards.
- All forms of exclusion of students with disability from the general education system should be prohibited.

In addition to these clarifications, Australia also agreed to the goal of having a fully inclusive education system by 2030, just 9 years away.

Cease funding new fully segregated schools

Work with the States and Territories to ensure they cease funding new fully segregated educational establishments such as ‘Special Schools’, ‘Autism schools’ or similar.

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[6] https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-24-education.html

[7] www.ohchr.org/Documents/HRBodies/CRPD/GC/.../CRPD-C-GC-4.doc

In sharp contrast to this objective, the reality is that the rate of segregation of students with disability is increasing[8]. It has also been found that when families do try to access a mainstream education for their son or daughter with disability, over 70% experience gatekeeping to deter them from enrolling, pressure to go to segregated options if they do enrol, and/or restrictive practices to force the student out of the mainstream school.[9] This is despite over 40 years of uncontested research showing that students with disability who are included in the mainstream lesson do better academically and socially than if they are segregated[10].

When included, students with disability are also more likely to have the opportunity to make friends where they are placed with more people, a chance to find common ground with others through all the opportunities that schooling brings. When included, students with disability tend to have a lower probability of difficulties at school, including bullying, and have a much higher likelihood of going on to independent living and participation in the general workforce than students who are segregated[11]. That is, not only is the practice of segregating students with disability directly against the research evidence and our international commitments, it is continuing to isolate a significant group of our community, leading to a life apart and resulting in the spending of millions of additional dollars over a lifetime due to the required residential and daily activity support.

Many families who have a child attending a segregated facility (segregated school or segregated unit within a mainstream school) are unhappy with this situation. However, we also are aware that many of the families who have a child attending a segregated facility are happy with this form of education. Many of these families have experienced gatekeeping and restrictive practices when they tried to access a mainstream education for their children (e.g. at the school of their siblings). These families face very frequent recommendations by education and other professional staff that segregation is a 'better' alternative. But because it is not couched that way it is far more problematic. They don't say 'segregation' they say 'small class size means more learning' or 'more teacher support' but this doesn't prove to be the case.

In addition, their child may have experienced exclusion within a mainstream setting, including bullying and rejection, isolation with an aide doing different work to other students, and isolation in the playground. In comparison these families are commonly welcomed into the segregated education system. For some families, this has resulted in the conclusion that they do not, in fact, have a choice and that segregation is the only option actually available. For these families it is often not until the end of school that the

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[8] Australian Institute of Health and Welfare, 2017. *Disability in Australia: changes over time in inclusion and participation in education*. https://www.aihw.gov.au/getmedia/34f09557-0acf-4adf-837d-eada7b74d466/Education-20905.pdf.aspx

[9] Shiralee Poed, Kathy Cologon and Robert Jackson (2017). *Gatekeeping and restrictive practices with students with disability: results of an Australian survey*. Paper delivered at the Inclusive Education Summit. Adelaide, October.

[10] Jackson, R (2008). Inclusion or segregation for children with an intellectual impairment: What does the research say? Queensland Parents for People with a Disability. Kathy Cologon (2013). Inclusion in education: towards equality for students with disability. Children and Young People with Disability Australia. http://www.cyda.org.au/inclusion-in-education

[11] http://alana.org.br/wp-content/uploads/2016/12/A_Summary_of_the_evidence_on_inclusive_education.pdf

consequences of segregation become apparent - a lifetime of segregation during schooling leads to a segregated life after school.

It is clear, from the experiences of families, that to have any genuine choice in the education of their children, real change to the mainstream system is required whereby all schools are welcoming of all students and all students are genuinely supported to have a full and inclusive education. Hence, our recommendations are that the initial focus should be on developing the skills of mainstream schools to include all students. It has been found internationally and in Australia that parents will choose mainstream schooling if their child is welcomed, included and adaptations are made to enable to experience the full range of educational experiences along with their peers.

We urge the Royal Commission to read these three articles about parent choice, and watch the two films produced by Family Advocacy below about their child's journey from a special to regular class:

- Glennys Mann, From here to there and back again: the story of a mother, her son, disability, and school choice
- Glennys Mann, An investigation of parents' decisions to transfer children from regular to special schools
- Catherine McDonald, "Choice does not equal informed choice around inclusive education" (see Appendix 1)
- Yolande's story: A child's journey from support unit to regular classroom (5.27 minutes)
- One of the boys, Luke's parents talk about their decision to move Luke from a special school to the regular class (5.02 minutes);

On the subject of choice, it is important to remember that child's rights trump parent choice[12] (in the United Nations Convention on the Rights of the Child). In any other area, our government puts what is in the best interests of the child based on the evidence, such as seat belt laws and immunisations. Yet when it comes to schools, the evidence that inclusion is in the child's best interests across their life course is ignored and parents are given "choice" over what they believe is best for their child.

Although we think it is best to work through this together with families that currently support segregation, we must most certainly do this with the realisation that the rights of the child are currently being usurped by parent choice, which, as discussed, is often not an informed choice. As a society, we can do much better than to provide the "least worst" option to a child and their parent. It is our assertion that parent choice is being used by our governments as an excuse for their inaction to plan and invest in inclusive education.

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[12] Catia Malaquias, Choosing segregated education – "Parental choice" or "parental concession"? http://www.startingwithjulius.org.au/parental-choice-segregation/

However, it is critical that any future funding decisions do not lead to situations that will increase the difficulty of achieving the UN goals that we have agreed to. For example, establishing new fully segregated education facilities on their own campus would be like building new institutions when we had a policy of de-institutionalisation. It would perpetuate the segregation of significant numbers of students far past the time when society had accepted that such facilities were inappropriate. On the other hand, alternative uses of facilities on the mainstream campus allows for easier transitions over time as skills and attitudes change.

Create an inclusive education system

The Royal Commission has already heard evidence regarding the poor employment outcomes for people with disability in Australia. We invite the Royal Commission to recognise there is a strong nexus between segregated education settings and poor employment outcomes. A 2018 comprehensive review of research by the European Agency for Special Needs and Inclusive Education, concluded that attending a special school setting is correlated with poor academic and vocational qualifications, employment in sheltered workshops, financial dependence, fewer opportunities to live independently, and poor social networks after graduation.[13]

Australia’s poor inclusive education record, by continuing to support segregated education, severely limits the possibilities for students with disability, threatens Australia’s human capital development and undercuts future economic development. If we are to achieve an inclusive society, the Australian government and the State/Territory governments must get serious about ensuring inclusive education becomes a reality in Australia and phase out segregated education settings. We must remember that today’s student peers are tomorrow’s employers.

To this end, the Australian Coalition for Inclusive Education has already developed a 10 year plan and we strongly **recommend the adoption and implementation of, *Driving change: A Roadmap for achieving inclusive education in Australia*** to help realise equitable education outcomes for students with disability and prevent violence, abuse, neglect and exploitation of students with disability. The 10 year plan is underpinned by six pillars that are drawn from the evidence base and embed the rights of students as outlined in the UNCRPD:

1. Ensure inclusive education
2. Phase out segregated schools
3. Improve educational outcomes
4. Stop gatekeeping and other discrimination
5. Eliminate restrictive practice
6. Prevent suspensions and expulsions.

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[13] European Agency for Special Needs and Inclusive Education, *Evidence of the Link Between Inclusive Education and Social Inclusion: Literature Review,* 2018, p 14.

The Roadmap has two key sections: the outcomes that need to occur, stepped out over the next 10 years, and the key levers for change needed to realise these outcomes.

We also refer the Royal Commission to Family Advocacy's Access Symposium, a platform dedicated to supporting the inclusive education community in all of its facets so we can collectively scale the conversation and drive momentum. By providing multiple perspectives in one place and fostering knowledge exchange within the sector, Access:Symposium is focused on closing the gap between policy and practice.

Inspired by the first National Symposium on Inclusive Education in 2017, created and facilitated by Family Advocacy, which shared multiple voices, perspectives and experiences **Access: Symposium** is an ever-growing online platform committed to challenge thinking, share examples and stimulate the necessary conversations to bring on change.

We strongly encourage the Royal Commission to watch all of the videos, which are a holding site for a grounding of information in education about what is inclusion, why include, how to include, changing mindsets, teacher impact, Australian examples.

Reform Teacher Standards

Significant steps have been taken in recent years towards a consistent national approach to education. The resulting National Curriculum, Graduate Teacher Standards, and the National Quality Framework (and Standards) provide a strong basis from which to continue to build a national approach to inclusive education. However, presently the Teacher Standards (at all levels) can be achieved in whichever way that tertiary institutions see fit. To adequately support the development of inclusive teachers (and to meet the requirements of the United Nations), it is essential that all teacher graduates have passed required *at least one* dedicated course on inclusive education, teaching to diversity and Universal Design for Learning. Currently many teacher education courses only provide electives, partial focus on inclusive education (within units focusing on other aspects of education), or focus on 'special education', not inclusion.

Funding attached to the child not the setting

All Commonwealth funding for students with disability should support the needs of the child no matter which setting they attend (mainstream class, support unit or special school). The funding should be attached to the child, not the setting. Without it, parents are left little choice but to go to a segregated setting, where they are informed they will receive so much more support through specialised teachers irrespective of the need for greater peer and community thinking.

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 maximising 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.[14]

Recommendation 5

That the Royal Commission recommend the following changes to education policy regarding students with disability:

- Accountability - Review the Disability Discrimination Act 1992 to align with the UNCRPD
- Cease funding new fully segregated schools
- Create an inclusive education system
- Reform teacher standards
- Funding attached to the child not the setting
- Provide support and training to parents seeking inclusive education for their children

Recommendation 6

That the Royal Commission recommend the adoption and implementation of the Australian Coalition for Inclusive Education's, ***Driving change: A Roadmap for achieving inclusive education in Australia***. Importantly, this includes the phasing out of segregated education settings by 2030.

Recommendation 7

The Royal Commission mandate that each the Australian Government, and each State/ Territory Government adopt an inclusive education system in accordance with the definition of inclusion under General Comment No. 4 of Article 24 (Right to an Inclusive Education) of the UNCRPD.

Recommendation 8

That the Royal Commission declare segregated education settings are discriminatory and recommend no more new special schools be built and that those that currently exist be phased out in a considered but time bound manner.

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[14] Ibid 6, p26.

Inclusion and Employment

Promote Work Experience

When it comes to work placements whilst in school, some families report to us that their child has been requested to stay at home instead of participating in work experience like other students, with many families having to fight hard and negotiate with the school around such arrangements. The example below illustrates one of our parent's experience of advocating for a flexible arrangement for her son's school work experience, which eventually resulted in paid work.

> *There is generally a lack of supported and flexible work experience and this impacts their knowledge of career planning and employment prospects. For my son, I had to advocate rigorously to get the school to give permission for my child to have a flexible work experience as it was not practical for him to do it every day for 2 weeks. Instead, the school gave us permission to go once a week for 2 hours for a few months.*
>
> *As it was well thought through and the right supports were put in place; this has led to future employment for my son. He now runs his own business as a mail courier. At the same time, I received a letter from the NDIA assuming the only option for my son was for a day program for work experience. If I did not have a clear vision for my son to have an inclusive life, and the support of Family Advocacy, his life would be on a very different path. I feel lucky to be educated and have English as my first language. What about those families that are not and do not know any better and do not have the support?*
>
> Carole

A great example of successful work experience done with the right supports, good collaboration between the employer and family member, and community based thinking is the video recently created by our initiative, Resourcing Inclusive Communities, *Rhiannon's work experience*[15] (6.26 minutes), a story about Rhiannon's successful work experience at her local Bakery.

Rhiannon's mother, Di, thought carefully about the tasks her daughter would be performing and prepared the employer and Rhiannon as much as possible prior to the work experience actually happening. Rhiannon was prepared for success as her mother collaborated with the employer and the employer was receptive to her input. We strongly recommend this video be adopted as an exemplar of good practice towards changing community attitudes, upskilling the capacity of parents, and lifting employer engagement.

Even though this was work experience and not employment per se, it does prove the point that the

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[15] *Rhiannon's Work Experience* can be viewed at https://www.youtube.com/watch?v=8UH-p7NrnxM

family's advocacy (informal supports) drove this to happen, through having good community relationships (not a service or a professional.)

And to show how real employment can come through the normative path of work experience, we strongly encourage the Royal Commission to watch 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.

Quotes from Josh's story

When our students leave Kelso High (a public school), part of the transition process is preparation for life after school, and we have that process for all our students. And in Josh's case, that meant some assisted work experience with a couple of local businesses. - ***Michael Sloan, Principal of Josh's School***

We're a customer-orientated business, and with Josh's autism, we weren't quite sure how that was going to impact our business. He's been a great fit, and he still does volunteer work for us at the moment. -
Brett Cranston, Kelso Truck Tyres & Mechanical

School to Work Project

At this point, it is relevant for the Royal Commission to be aware, Family Advocacy, through its initiative 'Resourcing Inclusive Communities', was recently successful in obtaining an Information Linkages and Capacity building (ILC) grant called the School to Work project, which will go towards lifting expectations of families in relation to post school transitions whilst utilising normative school pathways to achieve real employment outcomes in the workforce.

The School to Work Project aims to inspire and equip students with disability, through the support of families, to seek meaningful, paid employment in the community. The project is currently running webinars across three year groups, Years 7-8, 9-10 and 11-12, as well as workshops in various NSW locations. In the future, it will also roll out conferences and newly developed resources. Resourcing Inclusive Communities is working with Imagine More in the ACT and Community Resources Unit in Queensland to deliver the project.

Importantly, all students in all settings will be targeted in this project, as each young person has the ability to contribute to the Australian economy. We will also be working with families concerning the flexibility of arrangements, such as shorter work experience placement sessions over a longer term than the usual two-week time frame, that may be helpful for students with disability obtaining work experience. The aim is to heighten the expectation that employment is an option which in many cases goes against what traditional professionals have recommended which is clearly part of the problem.

We aim to be lifting expectations of families, educators and businesses alike in relation the employment outcomes that people with disability obtain and the many innovative models of support to enable this to occur. This is a three year grant and the intention is to target many students, families, educators and businesses across NSW.

Delivering this grant will also equip Family Advocacy with more knowledge of the extent of the system barriers that are currently occurring within the NSW education system.

Real jobs for Real Pay - Phase out Australian Disability Enterprises (ADE's) and significantly overhaul Day Services

The benefits of employment for people with a developmental disability are the same as the benefits for all humans - improved life satisfaction, a valued role in society, increased independence, reduced isolation, and protection against poverty. However, currently, Australia (and NSW) has a poor record for employing people with a developmental disability. For example, data from NDIS in 2018 showed only 33% of adults (25+) with an intellectual disability who were participants of the NDIS were employed, nearly 75% of which involved employment in segregated settings (Australian Disability Enterprise or ADEs), and only 3% were employed with open employment and paid full wages.

The recommendations from the 2016 *Willing to Work* report have not been implemented.[16] The Inquiry made recommendations with respect to Commonwealth laws and actions that could be taken to address employment discrimination. We recommend a national disability employment strategy that incorporates the recommendations from the *Willing to Work* report and contains targeted general measures for increasing workforce participation, including addressing structural workplace barriers.

The current employment pathways for students with disability at school and transition beyond school do not align with the objectives of the UNCRPD. The current situation with work experience and other programs deemed to be helpful in transition are not always on offer for a lot of students with disability or the programs on offer are segregated and ineffectual. Assumptions are being made that people with a disability are incapable of employment. We have heard from a family whose child was in a regular class at their local school that they received a letter from the NDIA regarding post school options which only included details for Day Services or ADEs and nothing about entering regular employment pathways. This is despite current policies that state otherwise.

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[16] Department of Social Services (DSS) National Disability Strategy, Second Implementation Plan: Driving Action 2015–2018.

ADE'S do not provide meaningful employment with opportunities for career progression or appropriate wages (with less than 1% having opportunities to move into mainstream employment). Students with disability are funnelled into ADEs as part of a work experience placement. People with disability working in ADE's are paid less than the minimum wage in this system, sometimes earning as little as $1 per hour[17].

We note the Royal Commission has been encouraged by Senior Counsel assisting to further investigate ADE's. Further, these settings reinforce to society at large that the segregation of people with disability is acceptable and that this group should be placed elsewhere and from the Royal Commission's position this should be seen as extremely problematic.

We recommend the Royal Commission recommend the creation of a roadmap to transition out of segregated employment models in a considered but timely manner, such as over the next 10 years, with short term, medium term and long term goals. It is imperative that any outcomes being measured must distinguish between different types of employment, looking at the percentage of people in real employment versus ADE's. Australia continues to run the significant risk of being left behind the shift in this regard in other jurisdictions and countries.

There are clearly both moral and social impacts to this pathway for many people with disability and the status quo of this pathway needs to be challenged. Like all students, leaving school is such a critical point where a young person with disability makes the transition successfully to tertiary study, part-time or full-time employment or they "fall through the cracks".

When a young person is only given the option of a Day Service (which many families report is the case), the message being received is low expectations for their future, that they are not capable of working ("unemployable") and there is no genuine pathway that leads to a real job for real pay. For an example of these low expectations, see the Sunnyfield Guildford Hub Weekly Timetable. The week is filled with activities such as arts and crafts, bowling, a disco during the day, aqua golf, gym and fitness, card making, movies, and gardening.

Whilst we all enjoy these activities as part of our recreation and leisure, they are not culturally appropriate activities for a young adult preparing for future employment but rather "time wasting" and filling the hours for a life without purpose, employment, income or inclusion. Whilst it may appear on the surface to be a good place for a person with developmental disability to attend, a Day Service is a segregated setting which reinforces a life lived parallel to the rest of community, thereby increasing the young person's risk of harm.

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[17] https://pwd.org.au/our-work/elections/election-archive/federal-election-2019/employment/

We see a similar comparison to assumptions of low expectations being fed to families by our government up until the 1970s when parents were being told that their children with disability were "ineducable". These assumptions must be challenged. NDIA processes must reflect the intent of the National Disability Strategy where a person with disability can have a real job for real pay, and Day services need to be significantly overhauled to be genuinely person centred.

Overhaul Disability Employment Services and adopt innovative, contemporary models

The review of the National Employment Framework was narrowly reduced to only focus on the Disability Employment Services (DES) program and has failed to deliver the comprehensive reform required. *Disability Employment Services* (DES)[18] continue to deliver poor employment outcomes for people with disability.[19] Evidence to this effect was given to the Commission to the point that it was expressly stipulated by Counsel Assisting the Commission, that the DES ought to be further investigated due to its ineffectiveness.

We refer the Royal Commission to some innovative, contemporary models, Customised Employment and Microenterprises, explained below:

Customised Employment

Success in employment for people with disability is usually driven via families with a determined vision[20] of meaningful employment. For example, we have heard about families taking unique approaches to supporting their family member with disability, using innovative and contemporary models of employment, such as customised employment, and microenterprises that support this cohort. Customised Employment is a process that matches a person with disability to the needs of an employer, creating a match in a customised job.[21]

In this regard, we strongly encourage the Royal Commission recommend to adopt the strategy of customised employment in the public sector and private sector. We refer the Royal Commission to the website of Marc Gold & Associates – The People who try another way[22] in the U.S, who are disability professionals specialising in the area of employment and community participation for persons with significant disabilities. Below is their explanation of customised employment from their website:

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[18] Australian Government, Disability Employment Services. Department of Social Services.
[19] Disabled People's Organisations Australia (DPOA) Factsheet: Employment of Persons with Disability. DPOA, Sydney.
[20] See Family Advocacy's website on Developing a Vision.
[21] June Alexander, 'Customised Employment', Presentation, Let's Get to Work Virtual Conference 2020, July 2020.
[22] http://www.marcgold.com/services

What is Customized Employment?

Customized Employment (CE) is a universal employment strategy that is especially useful for employment seekers with significant life complexities and barriers to employment, such as a severe disability. CE strategies result in competitive, integrated employment that is ***based on a determination of the strengths, needs, and interests of the employment seeker.*** *The specific abilities of the individual are matched to the business needs of an employer. CE is a* ***relationship*** *between an employer and an employee that is negotiated to meet the needs of both parties.*

CE is included as a strategy to support individuals with disabilities to obtain employment in the Workforce Opportunity and Innovation Act of 2014. What Does the Process Look Like?

STEP 1

Discovery: Discovery is a form of qualitative research that seeks to understand who the employment seeker is in as many aspects of life as necessary to inform an effective Customized Plan for Employment (CPE); it is used as an alternative strategy to a comparative assessment or other comparative procedure.

STEP 2

Profile: The Profile is a comprehensive descriptive document that is developed to capture the information gathered during Discovery about the employment seeker. The Profile becomes the written document that informs the Customized Job Development process.

STEP 3

Customized Plan for Employment (CPE): The CPE is a blueprint for employment for the employment seeker. The CPE is developed during a Customized Employment Planning meeting, a meeting that takes place after Discovery is complete and adheres to the values associated with person-directed and person-centered services. The employment seeker along with family, friends, colleagues and agency representatives attend the meeting and the Profile documents are shared, to support the planning process. Interest areas, tasks, specific employers, locations and other considerations that will increase the likelihood of employment success, are included in the CPE.

STEP 4

Visual Resume: A Visual Resume is developed for each employment seeker during the Customized Employment process. The Visual Resume is used to present an employment seeker to a potential employer, in a manner that highlights the best of who they are: their relevant interests, education, *employment and volunteer experience, potential contributions to the business, and a specific list of tasks the job seeker has to offer.*

STEP 5

Customized Job Development (CJD): The CPE becomes the basis for all CJD activities undertaken for the employment seeker. Job developers use the CPE "blueprint" to identify, engage, negotiate and customize a job, and any conditions for success needed by the employment seeker, with employers.

An Australian success story

We have a successful example of customised employment in Australia. We strongly urge the Royal Commission to read the transcript from a presentation made by Peter Symonds, General Manager for Operations at Possability in Tasmania called Customised Employment. Instead of competing for advertised jobs in the open labour market, customised employment strategies are used to support people to create opportunities in businesses and organisations that suit their unique skill set and support needs.

> *Measuring how successful an employer program is relatively easy. It's based on how many people get jobs, how long they keep them, what they are paid and do the hours of work match what the person is seeking."*
>
> \- Peter Symonds, General manager for Operations at Possability, Tasmania

The statistics presented by Mr Symonds speak for themselves:

> **What are the outcomes?**
>
> ***Tasmanian Customised Employment experience Jan 2014 – Dec 2015***
>
> ***75%** gained employment and of this group **91%** of these people remained in employment after 26 weeks*
>
> ***Disability Employment Service (DES) comparison***
>
> ***24.6%** gained employment and of this group **29%** remained in employment after 26 weeks*

Microenterprises

A microenterprise is a very small business, owned and run by an individual. It's simple to start, and needs minimal capital. It can have a vital purpose in improving people's quality of life and sense of contribution to society. It can give a person a valued role in their local community providing a service or goods, and be based around the person's passions, interests and skills. It is highly individual – able to happen at whatever level best suits a person. Microenterprises create independence and empower people to make a contribution while using skills and talents.[23]

We provide an example in the form of a film and recommend you watch *Josh's story*[24] (6 minutes) which illustrates that employment can be the norm following an inclusive education (rather than a Day Service and/or ADE). Josh now runs his own mail delivery business and is a valued and respected member of his community. We know of other examples of micro businesses such as a coffee cart business, a paper shredding business, a greeting card business where the artwork of the person with disability is used to decorate the cards, a biscuit making where the biscuits are sold in the local cafés and markets.

On the basis of the above, the Employment Strategy must employ measures to ensure that people with disability can access employment services that meet their individualised needs, and which are focused on long-term outcomes.

Recommendation 9

We recommend a national disability employment strategy that incorporates the recommendations from the *Willing to Work* report and contains targeted general measures for increasing workforce participation, including addressing structural workplace barriers. This includes setting a quota for public service employment of people with disabilities, including specific quotas for people with developmental disabilities, that reflect the natural proportions in society.

Recommendation 10

That the Royal Commission recommend the Australian and State/Territory Government's put the interests of people with disability over the vested interests of services such as Australian Disability Enterprises, Day Services and Disability Employment Services. This means a plan be put in place to end segregated settings such as ADEs, to significantly overhaul Day Services and support the transition of workers to regular employment settings and this includes equal remuneration - real jobs for real pay.

Recommendation 11

That the Royal Commission recommend the overhaul of the Disability Employment Services for more innovative and effective pathways that have appropriate supports, information, on-the-job training and skill development to ensure people with developmental disability receive a fair days work for a fair days pay. Some examples of these models are customised employment, and micro-enterprises.

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[23] http://microboard.org.au/

[24] Family Advocacy, *Josh's Story,* YouTube, 24 November 2019. <https://www.youtube.com/watch?v=OTdRgyh1dV0>

Inclusion and Housing

People with developmental disability should have choice and control over where they live and who they live with in accordance with Article 19 of the UNCRPD. There is a well-established link between appropriate housing and health, employment, and community involvement.

We acknowledge that a lot has been done to close institutions but there is more needed to realise the initial aims of independence for people with a disability. More than 5.2% of people with disability live in cared accommodation such as group homes,[25] with a further 2.8% living in supported accommodation facilities.[26] This data is not disaggregated. People with disability in residential care die at least 25 years earlier than the general population.[27]

Access to appropriate, available, accessible and affordable housing remains a major issue for people with disability, becoming more evident with the roll out of the NDIS. There are more than 200,000 people on waiting lists for public and social housing across the country.[28]

One funding stream that has recently being offered by the NDIS and has potential to support inclusion is the Independent Living Options model, and we share the explanation on the NDIS website:

Where we live, who we live with and the supports to live the life we want are very important to everyone.

Individual Living Options (ILO) are focused on working with the participant and their family to consider their needs and preferences, and design a flexible package of supports. Implementation often happens in stages and the package includes a primary support approach and supplementary supports. Once established the living arrangement is closely monitored and fine-tuned.

The following describe a variety of living arrangements under the ILO heading.

Host Arrangement - *You live full time with a person or family (host) who is not related to you. The host provides a safe and welcoming home and the help you need. The amount of support provided by the Host is negotiated and they receive a 'payment' in lieu of that support e.g. rental subsidy paid from ILO.*

Housemates - *You live full time in your own home with one or more people who provide an agreed level*

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[25] Australian Institute of Health and Welfare 2017. Australia's welfare 2017. Australia's welfare series no. 13. AUS 214. Canberra: AIHW. See also: Australian Government, Australia's Combined Second and Third Periodic Report under the Convention on the Rights of Persons with Disabilities, 1 September 2018.

[26] ibid.

[27] NSW Ombudsman (2018) Report of Reviewable Deaths in: 2014 and 2015, 2016 and 2017, Deaths of people with disability in residential care. NSW Ombudsman, Sydney.

[28] Australian Institute of Health and Welfare 2017. Australia's welfare 2017. Australia's welfare series no. 13. AUS 214. Canberra: AIHW.

of personal care, household assistance and companionship. Housemates receive either a payment or reduced or subsidised rent depending on the type and intensity of support provided. Previously 'Co-Resident'.

You live in your own home with one or more people (with or without disabilities) that you have chosen through existing relationships (friendship, familial or intimate). There is no payment incentive for other people in the home unless both residents have disability supports in which case some supports may be shared. Previously 'Living Together'.

Mentors - *You live in your own home and choose to live alone with a package of formal supports including a high level of flexible drop in supports, supplemented by on-call or other supplementary supports and/or informal supports. You have a small team of exclusive paid supports that provide you with direct and indirect support, for an extended period of time*

Individual living options aims to be a viable alternative to a group home.

The NDIS encourage and support the introduction of ILO models in participant plans and is currently developing an ILO policy. Current ILO arrangements will be maintained in participant plans.

It is still early days to know the success of this program, as it is yet to be evolved to indicate the outcomes of the model, however we are hopeful it will support independent living. We draw the Royal Commission's attention to another one of Family Advocacy's ILC projects called "Individualised Housing Options", through its membership with the National Alliance of Capacity Building Organisations (NACBO, more fully explained later in "Inclusion and Community Attitudes" section). This project aims to support individuals and their families to plan towards and move into individualised living arrangements through the ILO.

Quotes from Jac's Place

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. – Jac's support worker

"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". – Melanie, member of Jac's circle of support

One positive example of independent living is from one of our families, and we recommend the Royal Commission watch a video produced by Family Advocacy, 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.

Recommendation 12

That the Royal Commission recommend the Australian and State/Territory governments develop a national plan to promote independent living and address the many housing issues faced by people with disability so they can maximise their level of independence and freedom; and allow people with disability to control the resources they require to live with dignity in the community, ensuring that people with disability are able to choose where and with whom they live.

Inclusion and Community – examples of good practice

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 creating booklets and film are ways of changing mindsets by showing families and the general public what is possible and challenging stereotypes. Below are examples of some of the community booklets and videos Family Advocacy has produced to promote inclusion:

Family Advocacy / Resourcing Inclusive Communities booklets promoting inclusion

- All students learning together
- Developing Community Connections
- Life Long learners
- Harness the possibilities

Family Advocacy Films promoting inclusion

Below are examples of films promoting inclusion 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.

Lee Oliver (Principal) - “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.

Annette (Jacob’s mum), “…something that we really would encourage that people think about their child's life holistically, as a whole going beyond school because school is only just one part of their whole life but it certainly sets them up for having a good life after they leave school”.

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.

Melanie (Circle of Support member) - "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.

Sarah (support staff) – "When I first started with her, she was a lot more quiet and not as capable and confident in everything. So these last two years, she's blossomed heaps. She's out there more. She's cooking in the kitchen. She's pegging out her washing. She's out doing archery and swimming and horse riding and pole-dancing, and it's amazing how well she's developed and grown. And happy to do what she's doing, not just forced to do something because it's that day."

Luci (support staff) - "She just continues to surprise us every day with the leaps and bounds that she makes. Self-management means that Rachael has a happy individual life doing things that she's choosing to do."

Jo (mum) - " From a very early age, I realised that Rachael was going to have different needs to her peers. But I still wanted her to have the same outcomes as her peers and have a life of her own, so I was very strategic in setting goals, working with things that she was interested in… I'm watching my daughter thrive, doing what she wants to do."

We strongly recommend the Royal Commission visit our Resourcing Inclusive Communities website to see more ideas, stories, resources and event information that support people with disability to lead a meaningful life as valued members of the community.

Recommendation 13

That the Royal Commission recommend a commitment be made at national, state and local levels for funding projects and initiatives focused on changing community attitudes towards disability, and that these initiatives be co-designed and implemented by people with the lived experience of disability and their families and supporting organisations.

Inclusion and Community Attitudes

“Unconsciousness is the enemy of devalued people.”

John Armstrong

Community misunderstanding, stigma, prejudice and discrimination impact significantly on people with disabilities in all areas of their life. Community attitudes must change as a general concept but this should extend to those working within government. First and foremost, attitudes need to be addressed within each government department at the national/state/territory/council levels. All levels of government need to model the change they wish to see in the non-government sector if they are to engage with business and community on the topic.

Government needs to be a role model and lead the way for community. We strongly encourage the Royal Commission to investigate international examples where good practice exists as potential models to follow rather than reinventing the wheel. It is important to identify that many of the systems designed by government perpetuate the ongoing discrimination, prejudice and low expectations through segregated schools, ADEs, accommodation services and day programs and until this is seen as a pressure point that needs alleviating, then authentic inclusion will not be realised.

Another important step towards shifting mindsets, is for the Royal Commission to meet with the National Alliance of Capacity Building Organisations (NACBO), who are:

“A national network of not-for-profit, values based, capacity building organisations. We have a shared vision and belief that all people with a disability are valued citizens and have the right to contribute to society through social and economic participation.

We acknowledge that many people with disabilities are shut out from the richness of many ordinary experiences through outdated practices that limit people’s lives. To shift this paradigm, members of the alliance provide information, education, mentoring, planning, peer support and leadership development.

Our aims as an alliance are to:

- Build people’s knowledge, shift mindsets and strengthen values-based leadership so that Australians with a disability are empowered to have full, meaningful and inclusive lives that are rich in relationships and
- Support and safeguard not-for-profit organisations in Australia who do this work, and
- Strengthen people’s skills and competencies to enable social and economic contributions.

Collectively, the Alliance has an impressive online national presence that contains high-quality materials on global and local best-practice of community inclusion.

In 2017-18 year, NACBO worked with 20,000 people directly and had connected with 250,000 Australians online."

We strongly recommend the Royal Commission investigate the NACBO website here, and meet with NACBO to gain insights as to how to shift community attitudes and strengthen values-based leadership so that people with a disability are empowered to have full, meaningful and inclusive lives.

Social Role Valorisation

Any attempt to address both government and community attitudes needs to intentionally address the inherent devaluation of this group and the unconscious bias that exists in both community members and our systems. For an in-depth discussion on how to tackle the unconscious bias within community and improve community attitudes, please refer to Family Advocacy's Submission to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability Submission No.3 - Rights and Attitudes Paper.

Briefly, for rights to be respected, promoted or realised, a person 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) [29] comes into play.

Currently, we are not living by the standards set by the UNCRPD, 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 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[30]. SRV explains that people with disabilities experience heightened vulnerabilities to relation to their rights being disregarded and experience violence, abuse, neglect, and exploitation due to their devalued status (such as segregated "special" student, unemployed, living in a group home).

To counteract this and prevent violence, abuse, neglect and exploitation, people with disability need to have socially valued roles such as student in a regular classroom (as learners, not just being present),

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[29] 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.

[30] 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.

employee in a regular working environment (able to work and contribute), and living independently with people they choose to live with (as flatmate or owner). 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.

On this basis, we invite the Royal Commission to 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, and we direct the Royal Commission to the Australian Social Role Valorisation Association. There are various touch points such as the family directly, the medical profession, allied health professionals, educators, bureaucrats and parents at school environment. In this way, over time we can close the gap in society's 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.

Media

Another powerful tool for changing attitudes towards people with disabilities is media. We refer the Royal Commission to Starting with Julius' media toolkit, Disability Royal Commission – Our Guide for Media Reporting as well as the Attitude Foundation, who work to ensure increased and authentic representation and inclusion of people with disabilities across all forms of media. Through media, they want to " improve Australia's understanding of disability, including by striving to challenge the common misconceptions regarding:

1. the portrayal of people with disabilities as objects of inspiration, pity, burden, menace or tragedy;
2. the belief that an individual's diagnosis or impairment is the main barrier to their participation in society. Instead, we promote a "social model"[3] perspective of disability, which recognises that everyone is different, and that society needs to be organised in a way that ensures that all people can participate on an equal basis; and
3. that all impairments have obvious physical characteristics, when in fact many impairments are invisible, for example, psychosocial or mental health conditions, intellectual or sensory impairments, and hearing and vision impairments."

Independent Advocacy

Disability advocacy organisations such as Family Advocacy also play a key role in promoting inclusion. Family Advocacy promotes inclusion through raising awareness, sharing information, providing representative advocacy, systemic advocacy and building the capacity of families in order that they may advocate with, for, or on behalf of the person in their life with a disability. We have shared some of the resources and videos we have produced throughout this submission.

The NSW Ageing and Disability Commissioner recently stated, "The need for advocacy will continue to be an important part of the lives of people with disability to ensure the continued promotion, protection and security of their rights, and enable their genuine participation in the community."[31] Adequately funding the advocacy sector is a step in the right direction in contributing towards addressing community attitudes.

Because the needs of individuals are complex, a suite of many different 'forms' of advocacy are 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.

Recommendation 14

That a commitment be made at national, state and local levels for funding projects and initiatives focused on promoting employment and improved community attitudes towards disability, such as the National Alliance of Capacity Building Organisations (NACBO). Such an investment must be across the life of the National Disability Strategy and needs to recognise this goal will require an ongoing and sustained effort.

Recommendation 15

As tools to influence changing attitudes, that the Royal Commission recommend our governments at State, Territory and National level, do the following:

- formulate a plan to ensure comprehensive theories such as Social Role Valorisation are known and understood by those involved more closely with people with disability and the community at large
- investigate the influence of media as a tool to challenge stereotypes, and
- fund independent advocacy.

Inclusion and the NDIS – Valued Citizen versus Service recipient – the dangers of clienthood and the value of informal supports

We bring the Royal Commission's attention to the dangers of clienthood, where the person with disability is seen as a client rather than as a regular citizen. 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. Human service providers are often run without considering the real needs of people, or how they are going to be of benefit to this person, but rather are driven by staffing schedules and a focus on making a

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[31] Dr Robert Fitzgerald, *Review into Disability Advocacy in NSW: A report by the NSW ageing and Disability Commissioner,* 19 December, 2019.

profit. 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[32].

For example, those running day programs tend to believe 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 at these times. Services are often coming up with solutions on how people with disability can spend their time instead of supporting the individual’s strengths, interest and possible contributions or 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. This only serves to reinforce the parallel life for people with disability living alongside but separate from community which leaves them at heightened risk of harm.

Further, there appears to be a perception generally that responsibility for inclusion of a person with developmental disability sits solely with the NDIS. It does not. Inclusion is everybody’s responsibility. The NDIS is not the panacea to inclusion, but simply a funding stream to provide supports so people with a disability can have economic and community participation in society. It is necessary to improve the capacity of the community and all systems that engage with developmentally vulnerable people to adjust and respond to the needs of those people and their families.

The introduction of the NDIS has had the unintended consequence of impacting the delivery of informal supports and community centred services. Evidence shows best practice to consist of both formal therapy supports and community focused supports. Informal supports for the family are considered to be a better predictor of child outcomes than formal supports. Some families have reflected that an individualised service model through the NDIS has built up a transactional service system alone rather than support based on freely given relationships, which has led to poorer outcomes.

Many families have shared stories over the years in various settings where the paid formal supports are valued more highly than the informal supports provided through community. For example, the teacher’s aide is “velcroed” to the student with disability, which we know has a detrimental effect on academic and social outcomes for the student. Similarly, support workers are glued to the person with a disability in community or in employment which blocks the opportunity for potential friendships to emerge. These examples illustrate the dangers of clienthood, where the person with disability is seen as a client rather than as a regular citizen.

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[32] E Cocks, Normalisation and social role valorisation: guidance for human service development, East Asian Archives of Psychiatry, Hong Kong J Psychiatry 2001;111(1):12-16

We draw the Royal Commission's attention to another ILC project Family Advocacy is running through its Resourcing Inclusive Communities initiative, called *Inclusive Lives: Possibility to Reality*, a state-wide, multi-layered project to strengthen the knowledge, skills and confidence of people with disability and their families so that many more people with disability across NSW experience typical pathways experienced by most Australians.

Within this project, we highlight and strongly recommend the Royal Commission watch "Person-Centred vs System-Centred" (3.04 minutes) by Beth Mount, from Open Future Learning:

"System-centered planning comes from the idea that the people we support are defined and treated through the idea of what the system needs in order to run efficiently. The system believes it is their job to "fix" people so they define and create a treatment plan and hope to get it correct before even meeting the people who they support and for who these systems are put in place for.

A major contrast to that is person-centered planning. People don't belong to systems; they belong to themselves, their families, and their communities. If we can see them in a different light, in the capacities that they can bring to a community, then our thinking shifts dramatically from how to fit people into a system to how do we support people to live good lives in communities. Furthermore, how do we take things we need from systems and services and use them in a more responsive way.

Quotes from Beth Mount PH.D –

"people don't belong to systems….they belong to themselves... their families... and their communities"
"services are not bad, they just tend to be wired for their own purposes, for their own self-interest"
"a good person-centred planning process calls into question the way we use services"

Inclusion and the role of family advocacy to heighten expectations and support their family member into typical and ordinary settings

As a general rule, the parent or family member has a natural authority for the person with disability in their life as they are the constant in people's lives, the setter of expectations, and the repository of knowledge. They tend to care more, have greater responsibility over their family member's wellbeing, they know them the most fully and for the longest period of time, have a stake in outcomes, and are granted a degree of independence which call into question the credibility of other parties.

In addition, families are often best positioned to see how everything, in its entirety, adds up to a person's life and for this reason, they can often see the incongruences of different interventions in early childhood, in education and employment. Utilising this relationship and familiarity with the person enables all options to be explored that are sustainable in the long term. In this regard, we refer to "The Natural Authority of Families" by Michael Kendrick.

When we hear of the successful inclusion stories already shared throughout this submission, the key element was the parent having a clear vision for their child, thinking ordinary and typical, being included in mainstream society, high expectations in the long term, and good collaboration. With this in mind, it is vital that the Royal Commission recommend to support the capacity building of the family to have the skills, knowledge and confidence in order that they can support or advocate for, with or on behalf of the person with a disability in their life.

Recommendation 16

That the Royal Commission recommend to support the capacity building of the family to have the skills, knowledge and confidence in order that they can support or advocate for, with or on behalf of the person with a disability in their life.

Inclusion, strengthening of accountability of the National Disability Strategy and improving systems

> *I don't know what I'm looking for and I don't know what I need. The system is so complex and unclear. When things go wrong, it's always on me to figure it out.*
>
> (Source: Disability Employment interviews, conducted by Services Australia, August 2020)

There has been a lack of accountability in relation to the National Disability Strategy which has impeded the realisation of good inclusion for a person with a disability over the last decade. One of the impediments to implementing inclusion is the silo-ing effect that can happen to a person with a disability trying to navigate the layers of bureaucracy that occur within the 3 tiers of government. The idea of the person at the centre, as a whole person, gets lost in the bureaucracy, and this needs to change. There needs to be a focus on the impact on the person with a disability and the supports they need. Systems must be simplified to enable a person with a disability and their family supporters to confidently navigate and access supports and services that address them as a whole person.

Not only is there confusion, but we also hear stories where one Department passes the buck to another Department and vice versa and people fall "through the cracks".

Recommendation 17

We recommend the Royal Commission call for reform to streamline existing services and supports between various levels of government to make them easier to use and more person-centred. For example, improve linkages between key systems/agencies to reduce duplication.

Strengthen the protocols around collaboration

To promote inclusion, collaboration is key. It requires a commitment and a planned approach by all parties working towards a common goal by sharing responsibility and expertise. For example, the successful inclusion of a student with disability, collaboration in schools takes many forms and involves multiple stakeholders working together to support the teacher such as the student, parent, teachers' aides and other professionals. For collaboration work to be effective, time and space need to be allocated for collaborators to develop a working relationship, establish roles, plan, implement, and reflect.

In this way, all governments need to collaborate internally and externally with their own departments, with other departments and between state and federal governments as well as local councils. We invite the Royal Commission to ensure commitment from all sectors to establishing cross-agency collaboration as a key approach.

Create an independent administrative body funded to oversee the National Disability Strategy

It is clear that whilst government will always have a primary role in ensuring people with disability are included as citizens, inclusion at the community level as expressed in the UNCRPD is often dependent on the attitudes and values held across the private sector.

We invite the Royal Commission to recommend the National Disability Strategy place a greater emphasis on the role of the non-government sector in facilitating inclusion for people with disabilities. In an ordinary day, it is very likely that a person with disability will engage with a range of public and private entities.

It is essential that support and information is provided to help the private sector to understand the benefits of inclusion and fulfil their responsibilities. We suggest an independent administering body be funded to achieve the same. This body could also be a point of contact for feedback from people with disability as well as to assess and evaluate the National Disability Strategy, provide education and training, information and advice.

In terms of good role models, it would be helpful if those positive exemplars within early childhood education, education, business and housing were supported by this independent administering body to run workshops to educate the government and non-government agencies. It would be good to set up a central body to be funded to take charge of educating the government and non-government agencies and the community at large.

Further to this, examples must be aligned with the principles and implementation practices of the CRPD, that is, segregated settings cannot be used as examples. This administrative body could also take carriage of the data collection, measurement, monitoring and reporting requirements to act as a 'check and balance' to hold the National Disability Strategy accountable to its intent to achieve an inclusive society.

The need for proper consultation and deep engagement by people with lived experience and their families

The National Disability Strategy must proactively engage with people with disability, advocacy and community organisations as well as external experts with evidence based practices to ensure the lived experience of people with disability is heard, understood and the effective strategies applied. We do not feel our families have been consulted in a meaningful way other than feeding in their input/ information/ opinions. Having all stakeholders part of the design and of the monitoring process is essential.

The success or otherwise of the National Disability Strategy will depend on how it ends up being implemented 'on the ground'. We believe it critical that an ongoing steering committee be involved in the implementation and monitoring process to feed in with proper guidance and the lived experience sought from students, parents of students with disability, and the organisations that support them such as Family Advocacy and other disability advocacy organisations. We are invested in getting this right and must all work together towards realising this.

Recommendation 18

That the Royal Commission recommend require greater accountability of the National Disability Strategy with the need for:

- establish cross-agency collaboration within and between federal and state/territory government
- establish a central administering body to facilitate both the government and non-government sectors to take carriage of consistent and long term data collection, measurement, monitoring and reporting requirements to hold the National Disability Strategy accountable to its intent to achieve an inclusive society.

- proper consultation where people with disability, their families and supporting organisations are involved in co-design the implementation, measurement, monitoring and reporting of the National Disability Strategy

Inclusion and data collection

A nationally consistent approach to collecting data around people with a disability is required across all settings. There needs to be an evidence-based measurement framework in each of the areas discussed above such as early education, secondary and tertiary education, employment, housing and community to track the success of the National Disability Strategy.

Transparency and clear communication on the National Disability Strategy's progress generally to the public is needed, at least yearly combined with longitudinal progress reports, and tabled in Parliament. It is imperative that all governments and local councils take on a transparent, collaborative approach to the continued development of the National Disability Strategy.

In NSW, there has historically been a poor collection of disaggregated data regarding people with disability across all settings. In education, there is little known in mainstream/support units/segregated settings about educational attainment/completion, tertiary study, employment upon leaving for students with disabilities. In employment, little is reported about the efficacy of Day Services and ADEs leading to long term employment in mainstream society.

This needs to change and there is no excuse not to do so as the technology exists to support it. The purpose of this data will shine a light on differences both positive and negative to enable shared learnings of good practice as well. It will also inform where there may be 'hot spots' or whether certain schools, employment providers or regions need more attention, training and support, and also whether any systemic changes need to occur. For transparency, all of this data should be publicly available and easy to access. Hence, data collection should be a priority generally. Any data collected should be consistent across departments/ councils/ industries to enable comparison, which can be helpful in ensuring all jurisdictions are held accountable.

We note that a National Disability Data Set is in the process of being developed. Such a resource will without doubt have significant usefulness in terms of understanding the needs, service usage and service delivery for people with disability. It would make sense to consider the use this Data Set, once it is developed, as a guide and also for consistency between state and federal jurisdictions.

Another suggestion is to consider the NDIS reporting system, under s.174 of the *National Disability Insurance Scheme Act 2013* (Cth), which provides a good reporting framework template which we consider should be adopted in determining the success of the Employment Strategy. The NDIS reporting framework provides national, state and territory progress reports against key outcome areas as well as a breakdown of spending across each jurisdiction.

Additional aspects of the NDIS reporting scheme which would have benefit in the context of tracking the success of the Employment Strategy include:

- **Reporting on participant satisfaction** – a similar evaluation could be made in relation to the satisfaction of people with disability regarding progress for example, across the National Disability Strategy and National Disability Employment Strategy's key outcome areas; the six pillars of the Australian Coalition for Inclusive Education's 10 year roadmap to achieving Inclusive Education
- **Assessment of participant outcomes** – this is vital to determine the actual effectiveness of strategies, and should therefore be part of the evaluation of any project/scheme under the National Disability Strategy;
- **Longitudinal tracking** – the National Disability Strategy 2021-2031, with broad application across the whole of society - it is important to track progress against the key outcomes over its life span to ensure that progress is being made across long term projects as well as tracking whether incremental progress is being met as part of these long term objectives.

Recommendation 19

That the Royal Commission recommend the Australian and State/Territory governments commit to both annual and longitudinal reports across the life of the National Disability Strategy and that such reports be tabled within parliament.

Recommendation 20

That the Royal Commission recommend robust data gathering is required to maximise public accountability. Investment in a national system, with built-in accountability is required.

Appendix: Choice does not equal “informed choice” around inclusive education

Catherine & Andrew McDonald, Australian Institute on Intellectual and developmental disabilities, Volume 28, 2/2014, pp 21-24

“First we make our choices. Then our choices make us.” - Anne Frank

Almost from the moment Sofia, our first born was diagnosed, we told ourselves and the very few people we could trust that we would give her back in an instant if that meant she could avoid the isolation, loneliness and sense of purposelessness that we believed would define her future. We truly believed that at best we could hope to perhaps trick her somehow into having some sense of belonging. We wondered what sort of band-aid we would be able to find to make life bearable for her. No one had told us otherwise in those early days and we had both grown up in worlds that gave us no reason to expect that anything more than this was possible. We had no way of knowing that our “not quite whole” baby would grow into a young girl with such gifts to share with all she encountered…that Sofia with her ‘intellectual deficit’ would become the teacher and we the students.

School was always going to be a daunting prospect. Handing over our tiny “June” baby at the tender age of three and a half to complete strangers and trusting that they would do the right thing by her was a leap of faith that felt like a free-fall from the international space station. The fact that Sofia was born in June meant that she would be the youngest in her class, but we wanted to give her exposure to her typically developing peers from as early as possible. Our theory was that the peer modelling of children with age-appropriate development was likely to push Sofia along or at least drag her along in its wake.

We started thinking about school shortly after Sofia turned one years old, researching our options and trying to grasp just what ‘Inclusion’ meant, what it would look like when it was working, how “do-able” it was and how the costs and benefits stacked up. Little did we know the answers would remain elusive for another five years. We visited multiple schools, attended a number of Education Options Forums and spoke to the director of the Centre for Inclusive Schooling, several teachers, therapists, a school psychologist, our Disability Services Commission Local Area Coordinator, parents of children with similar diagnoses who had already been through the schooling process, tapping into every imaginable source of information. The overwhelming focus of all of these was the level of funding and resources available and the rights of parents and children. We most often left these encounters feeling none the wiser and somewhat numb. Reflecting back on it now, it all makes sense.

We were tourists and each sector was a rudderless ship. Some ships were plain and without frills, some had bells and whistles. They were all doing their best to get us on their manifest…but ultimately there was no talk of a destination. They all believed their way was the best — though some pointed out that our daughter was clearly not cut out for what they had to offer.

Eventually, we ended up choosing the local government school around the corner from our house. A constant theme from our research was that government schools had by far the biggest pool of funding and, in the absence of a reason not to go there, it seemed as good a choice as any. The school had an Education Support Unit (ESU), although we were not overly clear on what that meant. We felt however that there were professionals with years of experience teaching children at risk who by now must be pretty good at navigating the ‘system’ — and surely they had to know how best to teach a child like ours. We were very willing to collaborate, to offer all of the support we could, to learn from them and we hoped they would reciprocate.

Our first two years at school were reasonable, but not without problems. Importantly though, Sofia was in the mainstream class and was adored by her classmates. She loved going to school and her teachers were generally capable and enthusiastic. Sofia’s Kindy teacher in particular was very approachable, very willing to work with us and great at sharing information - which made the world of difference. Interestingly, she was in her first year of teaching.

When Sofia started Year 1, we were told it would be best to move her into the ESU. Our preference was for Sofia to stay in the mainstream class full time, but it was stressed to us that she would lose much of her support and that the school would be less willing to extend its best efforts on our behalf. Inexperience and fear got the better of us and we reluctantly agreed.

The year started with Sofia's name being left off her Year 1 class list. It may have been an innocent oversight, but it certainly set the tone for what was to come. Sofia was "allowed" to spend afternoons with her mainstream peers. Initially the seating was carefully arranged to include her within a group, but very quickly she was shifted to a corner desk with another ESU child, an Education Assistant (EA) and none of her mainstream peers. Sofia began to withdraw from interactions with her old classmates and preferred to spend playtime with other, mostly older children from ESU.

As the year went by, we got increasingly marginalised. Information around how Sofia's day had gone, what kind of work they had done and how she had responded to it was not forthcoming. There was no opportunity or time allocated to discussing Sofia's week, never mind her day with teachers – mainstream or ESU. We were instructed to not approach the EA's with questions and they were in turn forbidden to provide any information to us. If there was anything to discuss we were asked to make an appointment with the teacher.

There were justifications and reasons for the way things were done but, no matter how rational, the feeling could not be shaken that Sofia was in the wrong place.

Sofia of course was delighted to join the ESU class. There were new friends, one-to- one attention, loads of positive reinforcement, a greater focus on life skills and generally lower expectations. Not just lower academic expectations, but lower expectations across the board — physical, emotional and social. With the threat of her support being withdrawn, we felt completely trapped.

Six fairly dreadful months into Year 1, Catherine stumbled upon what became for us a life changing paper by Prof Bob Jackson[33]. It was a literature review that looked specifically at studies over the last 40 years that compared the benefits of segregation and inclusion, as well as the impact of segregation and inclusion on teachers and other students. We were amazed to find that not a single study concluded that there was a benefit to any form of segregation – both for the children at risk, as well as their normally developing peers. The academic and social outcomes for children in fully inclusive settings, even without any support, were consistently better than in the segregated or partially segregated environments; and, importantly, including children at risk, had no impact on the academic performance of normal developing children, but brought marked social benefits to these children. All of the doubts we had, the reasons and justifications that were presented to us over the last six months were vaporised in an instant. Then and there, we decided to move Sofia back to where she belonged.

In a bold statement of destiny, it turned out we lived in the same city as Prof Jackson. We attended a workshop where he was presenting the research on inclusion together with PLEDG CEO, Darrell Wills and family members who shared their experiences of inclusion – from earliest interventions through high school. PLEDG specialises in parents learning about evidence and then incorporates evidence-based teaching strategies to facilitate curricular and social inclusion. Together, they helped us to vastly change our perception of our daughter, her abilities, her (and our) potential and her place in the world.

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[33] Jackson, R., 2008. Inclusion or Segregation for Children with an intellectual Impairment: What does the research say? (http://www.include.com.au/wp-content/uploads/2011/11/ Inclusion_Seg.pdf)

With research and examples of how we were finally “informed” about our choices, we were confident that the situation at our current school was not salvageable. We moved all three of our children to a private community school at the beginning of Term 4 that year. Sofia’s support funding allocation was much lower than it was at the government school, but the school more than made up for it in attitude. We were reliably informed “that will precedes skill and this school had that will”. There was a principal who was always available, unlimited access to teachers and a central ethos that welcomed parental involvement in education.

Our daughter, now 7 years old, continues to grow and amaze not only us but also her teachers and peers. We were told that reading would be a challenge (she is now advanced), that she would not be able to write (she now types) and that she would not be able to do maths (she now does sums). Furthermore, she is having a very real impact on the lives of people all around her – in her class, her school, in her family and beyond. We can unreservedly say that the world is an infinitely better place for welcoming her into it.

The sad reality is that this path of discovery and possibility very nearly never existed for her or for us. The even sadder reality is that there are thousands of stories just like ours that will never be told or written because “choice” has so quickly swept aside “informed choice.” The question has to be asked why this vital information was not forthcoming, despite our exhaustive search and questioning.

It is truly astounding how quick we are to limit what we believe others are capable of. Our professionals and policymakers appear to ignore the evidence and develop strategies and institutions that foster and develop these low expectations and give us choices based not on “what works” or “what is possible” but what gets the most resources and is easiest to manage. We segregate people who are different under the auspices of giving them a greater chance to learn skills that will help them to live out in the world one day. But what chance do they have to function in a world that they were not allowed to experience and learn from during their formative years and therefore know nothing of?

We are infinitely lucky to have been able to alter our path. It is however not the “easy” path and not without its challenges. The lessons we have learned have been hard learned and are not easily found along any of the paths offered up, but in the uneasy search beyond the beaten track.