

Disability Royal Commission  
GPO Box 1422  
Brisbane  
QLD 4001

21<sup>st</sup> December 2020

Dear Commissioners

I write in my capacity as the inaugural South Australian Commissioner for Children and Young People, an independent statutory position, established under the Children and Young People (Oversight and Advocacy Bodies) Act 2016.

My role includes advocating for systemic changes to policies, programs and practices that impact the rights, development and wellbeing of South Australia's children and young people.

This work is directed by the issues and experiences of children and young people themselves, with a specific focus on those who struggle to have their voices heard.

Nearly four years into my appointment as the Commissioner for Children and Young People, having spoken with thousands of children and young people throughout the state, I find myself searching still to hear the voices of children with disability.

I've spoken with children through student representative councils, youth advisory committees, Youth Parliament, workshops and forums. I've met many young people representing vulnerable and marginalised groups. Yet, despite reaching as far as I can within the parameters of existing participatory structures, my every day opportunities to connect with children with disability continue to feel limited.

Parents and advocates tell us there just aren't enough opportunities for children with disability to participate in decision-making processes, express their views, or be genuinely listened to. This gels with my own experience, and continuously prompts me to question, if I'm struggling to connect with diverse groups of children with disability to hear their voice directly, how are our systems and decision-makers ensuring that they listen to them?

Every child in South Australia has a right to actively participate in decisions affecting them. This exists at the individual, program, and system levels, to be implemented through practice, process and participatory structures. It's a right that is extraordinarily important to children and young people. It is also a right a majority of children feel least likely to have access to. Children with disability are even more excluded than other children and young people from this right. Our failings in this area is largely because we are not putting it into practice at practitioner, program or systems level.

Whilst our key policy documents and frameworks have adopted and included a range of terminology to describe children's right to participate in decisions affecting them, including 'voice', 'choice', 'freedom', 'participation', 'engagement' and 'active involvement' in decision-making processes, we have not moved far enough to make participation a reality.

Children's participation cannot be a tick-box exercise, rather, it must be meaningful and undertaken with a presumption that adults will respectfully listen and take consideration of children's best interests.

Given the backdrop of serious and systemic concerns in relation to the care and safeguarding of children with disability and ongoing service access issues and systemic exclusion from education, sport and recreation, and justice, the issue of engagement and participation can seem trivial. Many argue that our focus at this time should be on the deficits of our systems in meeting the fundamental care and protection needs of children and young people with disabilities.

I am currently engaged in conversations with children and young people with disability about how to increase their visibility and participation in every level of decision-making.

I am speaking with children and young people with disability about how they want to engage with adults and what structures will support us to gather the greatest breadth of perspectives. My aim is that in collaboration with children and young people, as well as specialist professionals experienced in working with children with diverse abilities and complex needs, we can develop inclusive methods of engagement designed to ensure every child's views can be expressed and understood.

I am asking children and young people with disability to tell us what issues and interests they want to elevate in our discussions, what they value and the things that need to change in order to build their participation and inclusion.

Through these consultations with children and young people with disability I will advise key stakeholders of practical changes required at the individual, program and systems levels to deliver on the participation rights of children and young people with disability.

Alongside rights of protection we must attend to the rights of participation to avoid repeating the same mistakes. In particular the systemic failures to recognise, respect and act upon the experiences, needs and wishes of the children these same systems were ostensibly created to serve.

We must ensure that future system improvements include, at a minimum, opportunities for children to exercise choice at every level, from day-to-day decisions to advising on the design and implementation of policies and systems which have the potential to impact on their lives and the lives of others.

It is said that sunlight is the best disinfectant. One of the ways we deliver this is by ensuring children and young people as consumers within systems, can be heard and are listened to. By putting children and young people with disability in charge of the decisions that affect them, we will educate ourselves and empower them to demand and receive the systems and services they have a right to.

I have attached to this letter some of the specific concerns that I hope you will be able to in some way incorporate into your deliberations and considerations as you prepare your reports. The importance of participatory service models and practices for children with disabilities that can be implemented by anyone, anywhere their views are entitled to be heard, from my perspective must be a critical part of system reform. I commend you for the work you are doing for the community and look forward to working on changing the systems that impact on children and young people with disability.

Yours sincerely,



Helen Connolly  
Commissioner for Children and Young People – South Australia

## Human Rights Covenants

As a signatory to the United Nations Convention on the Rights of the Child and the Convention on the Rights of Persons with Disability, Australia acknowledges and commits to enacting for children the rights they outline. This includes the right to participate in decisions on matters affecting their lives.

As such, the basis from which we should approach the issue of children and young people with disability's participation in decision-making is that it is their human right. These rights should permeate and be present in every interaction a child or young person has at the individual, program and systems level.

Combined, these establish the following rights for children and young people with disability in relation to choice and decision-making:

- autonomy, independence and the preservation of individual identity
- freedom to make their own choices and the right to be recognised as experts in their own lives
- free expression of their views on all matters affecting them, with appropriate assistance as required to achieve this
- the opportunity to be actively involved in decision-making processes about legislation, policies and programs, including those directly concerning them, and
- full enjoyment of all human rights, choice, inclusion and participation, equal to that of other children and young people.

South Australian children and young people with disability have contact with many services and systems. These operate in the area of disability but also include child protection, health, education, sports and recreation, law and justice, employment and more.

Whilst practice supporting the right of children and young people with disability to engage in decision-making processes is sadly limited, the available evidence demonstrates that the capacity to do so improves the design and delivery of systems and services, increases the confidence and capabilities of children, and also increases their physical and emotional safety.

Despite this, we continue to marginalise and ignore the voices of children with disability by failing to resource the work of participation and by assuming that they can't, or don't want to, express their views and make their own decisions. This speaks to a bias that is endemic to systems impacting on the lives of children and young people and becomes self-perpetuating over time.

Commitment is required to overcome the practical and attitudinal barriers to the participation of children and young people with disability. It will not occur through goodwill alone but requires dedicated, long-term investment at all levels of our systems and structures.

In November 2019 the SA government launched *Inclusive SA: State Disability Inclusion Plan 2019-2023*. This, the state's first disability inclusion plan, highlights the failure of current systems to engage people with disability, particularly children and young

people, in decisions affecting their lives. So much more needs to be done to investigate why this is the case. An essential part of system reform must be to create and fund opportunities for children and young people with disability to:

- build understanding of their unique perspectives and opinions through increased involvement in decision-making processes
- design prototypes for their engagement and participation that can be implemented by diverse organisations at all levels of decision-making, to ensure all children's voices are being heard where and when they should be, and
- advocate to governments and other key decision-makers to increase their participation through active involvement in dedicated and ongoing structures of decision-making.

## Federal and state legislation and policy frameworks

The rights of children and young people with disability are articulated and enacted at the state and federal level through a complex patchwork of legislation, agreements, frameworks, bodies, policies and programs. These have particularly emerged from the disability and child protection systems, where children with disability are highly represented.

Rights are further translated by government departments into their own policies, often mixed in with and diluted by other priorities and purposes. This process of filtering and translation continues to the program, practice and contracting level within individual departments and other agencies and organisations whose work intersects with these human rights.

Our experience shows that by the time this process is complete, rights such as voice and choice often become overtaken by and even subsumed into other rights, such as child safety and protection.

They may continue to exist in a technical sense, discoverable by tracking upwards through principle statements and governing documents, but when they are not given life through programs or practice they have very little meaning. Indeed in some instances, where rights don't correlate with a reportable activity or a measurable outcome, to all intents and purposes they may disappear altogether.

Throughout my work I have heard that children and young people with disability have many of the same issues as other children and young people. These include education and learning, jobs, family, activities, and friends.

However, children with disability also raise issues that reflect different priorities informed by their own lives and unique experiences, such as:

- transport that is accessible and affordable, which reduces their reliance on family members
- freedom to make choices, enact them and live with independence
- accessibility of community infrastructure to allow them to participate fully in their communities and the activities enjoyed by their peers, and
- safe, inclusive and accepting communities.

As such, whilst some of the perspectives of children and young people with disability are shared by others, they also include different views and needs reflecting their particular lived experience.

These views cannot be extrapolated or transposed from the experiences of any other group. Any service or system that presumes to understand the priorities, perspectives and wishes of children and young people with disability without undertaking the work required to collect them is guaranteed to fail in its purpose.

It is also worth noting the now-widespread acknowledgement that the safety of children and young people is enhanced in environments where they are listened to, involved in decision-making, and where their views and experiences are respected.

## The connection between engagement and empowerment

Despite the limited uptake of good practice participatory approaches designed to include diverse children and young people with disability, there is a growing body of evidence that shows their beneficial impact on child wellbeing and development.

We know from our own experience and the available research that children and young people with disability welcome opportunities for active involvement in decision-making processes, delivered within the right support frameworks. We also know that the more opportunities they have to participate, the more effective their contributions become.

Meaningful involvement in decision-making processes by children and young people with disability, conducted by capable and informed practitioners, has been shown to:

- support the acquisition of new skills
- promote confidence in capabilities and self-efficacy
- increase social experiences and socialising with others
- contribute to social and emotional wellbeing
- create a sense of belonging and inclusion, and
- promote active citizenship and support children and young people to feel valued.

It shouldn't be a surprise that providing children and young people with disability full access to their rights and presuming their capacity to participate would provide holistic benefits. The corollary is that when we refuse children and young people with disability the opportunity to engage in decisions on matters impacting their lives, we deny and diminish their feelings of confidence and capability.

When we assume that children and young people with disability can't, our actions communicate that assumption to them. These messages can become internalised and foster a lack of self-worth. As such, when we fail to involve children with disability in decision-making processes we create the conditions that allow us, falsely, to affirm our decision to exclude.



## Marginalisation of children and young people's views

Quite simply, there are too few organisations doing the work required to support children and young people with disability to actively participate in all levels of decision-making. Those organisations and agencies that should be elevating the voices of children with disability, including funding agencies, often aren't prioritising it sufficiently amongst their competing demands. As such, the voices of children and young people are being sidelined or ignored altogether.

Even where children and young people do speak up, at both the individual and systems levels, we find that the wishes, perspectives and interests of adults are consistently preferred and enacted over children's. This bias is endemic throughout all decision-making structures impacting on the lives of children and young people, comprising a systemic barrier at all levels to their participation, active involvement and access to freedom and choice.

Participatory practices need to be resourced. Participatory practices for groups facing access barriers, which includes all children and young people but particularly those living with disability, require more resources.

Whilst arguably the National Disability Advocacy Program should be enabling full participation for children with disability, I could find no SA-based programs delivered through the NDAP that supported children's ongoing participation in program, organisational or systems-level decision-making structures. We found only one specialist organisation with a dedicated purpose of working with children and young people with disability living in SA, but this is based interstate. There is only one organisation based in SA with youth participation methods embedded in their practices, however, this has a young adult focus.

This situation highlights a significant resource gap that will need to be filled if we are serious about changing the current situation.

## Structural and social barriers

Children with disability face all of the barriers to participation that other children and young people do. These can be attitudinal as well as practical, ranging anywhere from 'adultism' in which children's perspectives are inherently ignored and discounted, to logistical issues such as being unable to get to participatory events and activities without adult involvement.

There are also a number of extra physical, structural, and social biases and barriers that limit and prevent the participation of children and young people with disability, particularly those with complex needs. These include:

- a culture of 'ableism' and low expectations that presumes children with disability don't want or aren't able to engage in participatory processes and decision-making, resulting from stereotypes and assumptions about capability

- lack of opportunity, due to an absence of participatory processes, activities and events specifically designed to include children with disability which can also result in a feeling by children with disability that their views are not welcome
- inaccessible communication methods and other practices, including absence of the necessary supports and tools to engage with children and young people with diverse disabilities and complex needs, and
- a lack of skills, training, support and resources available to practitioners to implement participatory processes and practices through which children can be understood.

These barriers can become self-perpetuating, as a lack of opportunity for children and young people with disability to participate in decisions affecting their lives also excludes them from the opportunity to develop the skills, experience and confidence to participate in future.

First, we must design and implement the processes and practices by which children with diverse needs can express themselves. These should be developed in partnership with children and young people with disability themselves and implemented across all levels of decision-making.

Then, we must commit ourselves to acting upon the views and wishes of children with disability. This requires us to change attitudes and build cultures of listening and action within our systems, our organisations and our daily practice. Properly done, this will result in substantive changes to the way we support and work with children and young people with disability.

This is not something we will achieve overnight. It requires long-term dedication and a fundamental belief in the right of children and young people with disability to make their own choices, in their own way, for their own purposes.

## Failure to set targets and measure outcomes

Only a handful of the federal and state instruments relating to child and youth rights explicitly address the right of children and young people to participate in decision-making. Even less of these actually contain clear and measurable targets, regularly reported through accessible data sources, which quantify the extent to which children have access to this right.

There is no measure currently in use nor available data source which disaggregates outcomes relating to choice and decision-making for children with disability, making this impossible for us to quantify.

As measurements tend to drive outcomes, it's unsurprising that recent Committee on the Rights of the Child reporting by the Australian Human Rights Commission showed Australian children believe that participating in decisions affecting them is one of the rights they have least access to.