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Office of the Advocate for
Children & Young People

The Voices of Children & Young People with Disability.

Key Findings

*A consultation undertaken by the Office of the
NSW Advocate for Children and Young People.*

Introduction

With the support of a number of agencies, schools and disability organisations, The Office of the Advocate for Children and Young People (ACYP) led face-to-face consultations with over 370 children and young people with disabilities throughout metro and regional NSW over 6 months spanning 2019 and 2020. The aim of the consultations was to ensure that children and young people with disabilities in NSW had the opportunity to express their voices, opinion and experiences in line with the principle of participation emphasised in the United Nations Convention on the Rights of the Child (CRC), the Convention on the Rights of Persons with Disabilities (CRPD) and ACYP's own legislative mandate.

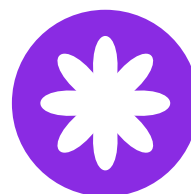
Forty-five groups of children and young people were asked the following questions¹:



What is working well for you and other children and young people in NSW?



What is not working well for you and other children and young people in NSW?



What would you like to change to make NSW a better place for children and young people?

These three questions are purposefully phrased as open questions to encourage the sharing of information, opinions and experiences as well as initiate impromptu group discussions. Where necessary, the language used to ask these questions was adapted to ensure that the communication needs of the participants were taken into account.

¹ ACYP asks the same three questions in each of their general consultations. Other consultations that ACYP have conducted can be found <https://www.acyp.nsw.gov.au/dod/map> ²

Analysis of the consultations with children and young people with disabilities revealed seven major themes as determined by the frequency with which these topics were raised. These are;



Education



Health and the National Disability Insurance Scheme



Access and Inclusion



Voice and Participation



Employment and Training



Bullying and Discrimination



Mental Health

More information on other topics that were also raised during consultations will be briefly detailed in the complete Disability Consultation Report and includes cost of living, the environment, recreational spaces, recent natural disasters and technology.

It is important to acknowledge the purpose of this report is to reflect the views, experiences and needs of children and young people as they were expressed to ACYP. Children and young people speak about both positive and negative personal experiences. It is not to say that government and non-government organisations do not undertake significant and substantial work in these areas. Rather this report documents how children and young people perceive these actions - it is a reflection of their lived experience and is the truth according to them.

Further to this, it is an overarching principle governing the Advocate's work to reflect that truth according to children and young people. We hope this exploration of the perceived successes and potential gaps in facilities and services available to children and young people with disabilities is useful.



IMAGE DESCRIPTION - NSW Acting Advocate Zoë Robinson sits at a table with a group of students in a classroom conducting a consultation. There are 9 students sitting around the table and she is taking notes.

Key Themes

Education



Children and young people spoke most readily about Education, with responses referencing topics including access to learning, support and development. The topic of Education featured in responses to all three questions, suggesting the majority of children and young people regard Education as a particularly significant factor in their lives and have a diverse array of experiences in that space.

Many children and young people spoke about how Education was a positive experience for them and told us they valued:



Supportive and experienced teachers and support staff that helped them meet their education and general support needs;



The choice to attend a school dedicated to addressing challenges associated with learning with a disability that offered personal care and one-on-one support when necessary;



The choice to attend mainstream schools and schools that encouraged acceptance of diversity within the student group;



The opportunity to learn life skills and skills that could be directly transferred to the “real world” such as shopping, road safety and travel;







Access to work experience opportunities; and



Access to extra-curricular activities such as music, art, sport and community programs.

Children and young people with disabilities told us that they confront the following challenges in the education space:

-  Some students felt their education had been negatively impacted by discrimination, and their schools lack of inclusivity and adaptability to their special needs;
-  Students spoke about their needs not being met and that schools needed to be better supported to, in turn, support student with disabilities. They specifically mentioned that school buildings and classrooms needed to be adjusted to allow for easier access for children and young people with a physical disability and that more school learning support officers were needed in the classroom, particularly in circumstances where multiple children required intensive support at once;
-  Students spoke about the lack of direct consultation with them when decisions were being made about their education, emphasising the importance of speaking to them directly, and not solely to their parents or carers and;
-  Children and young people with disabilities also echoed the concerns of their peers regarding health and safety issues such as excessive heat and lack of soap and other accessible sanitary facilities at schools.

Children and young people suggested that an increase in resourcing, disability awareness training for both school staff and students, and buildings that provide for people with physical disabilities should be considered essential. They also emphasised the importance of ensuring that children and young people, regardless of disability type, have the opportunity to directly participate in decision making in matters impacting them.

Health and the National Disability Insurance Scheme



Children and young people with disabilities face unique and sometimes complex barriers to accessing appropriate services and supports. Many participants spoke about the impact of the National Disability Insurance Scheme (NDIS) on their lives².

Children and young people spoke about the experience they had with the NDIS and how it had improved their lives:



Children and young people valued the NDIS for supporting them to access and participate in community activities such as group events, excursions, sports and other activities;



Children and young people with positive experiences of the NDIS often referred to the dedication and skill of their support, respite and case workers and the long term relationships they built with them and;



Children and young people appreciated being able to direct what kind of support and guidance they needed, feeling it gave them a voice and provided relevant services.

² The NDIS is designed to provide direct funding to individuals with disabilities to source supports and services specific to their needs, for further information see <https://www.ndis.gov.au/understanding/how-ndis-works>

Children and young people also spoke about difficulties they and their families had accessing appropriate services and supports, including:



Needing to rely on their parents and families to “fight” for them to get support, even if those supports were featured in their NDIS plan;



The complexity of the NDIS system and that it could be repetitive and difficult to navigate. They said their level of funding and access to supports was often dependent on how well their parents could research and negotiate the NDIS, and how effectively they could advocate for their child and;



Their frustration with the disparity between services, delays, availability and quality subject to their location, the capacity of their family to advocate for them and their relationships with key individuals such as the Local Area Coordinator (LAC) or their school support officers. The particular vulnerability of children and young people who have a dual diagnosis of mental illness and disability was also raised in light of there being a lack of services that would accept these young people as clients.

Children and young people suggested all professionals working within the disability sector be trained in methods of best practice for working with children and young people with disabilities. They called for more equitable access to services for people in rural and regional areas of NSW and systems that enabled more efficient plan approval that did not repeatedly require them to provide evidence of permanent disabilities. Children and young people also advocated for more youth dedicated health services such as Headspace and increased services for young people with complex vulnerabilities such as comorbid disabilities and mental health concerns.

Access and Inclusion



Children and young people spoke about access and inclusion in many different contexts including services and events, buildings and facilities, information, quality of service, consultation processes and employment.

When speaking about the things that worked well in facilitating access and inclusion, children and young people referred to:



Infrastructure that was designed to accommodate wheelchairs, such as purpose built board walks and paths in National Parks and the recently installed elevator on the Sydney Harbour Bridge;



Schools that provided Community Access Courses aimed at helping children and young people with disabilities feel confident and comfortable in accessing and navigating their community;



Organisations, clubs and teams that supported their participation and made them feel included, respected, valued and listened to;



Professionals and services who made the effort to speak with children and young people directly and listened to their responses and;



Support from friends, family and school to participate in mainstream social and community activities.

Children and young people emphasised how difficult it was to access services and participate in the community making them feel ignored, isolated and excluded. Contributing factors included:



Physical barriers and limited accessibility to educational and public spaces such as schools, TAFE's, cinemas, recreation centres, shopping centers and parks for those with physical impairments;



Challenges navigating public transport due to the lack of accessible information regarding schedules as well as assistance or support to board buses, trains, trams and other modes of transport. This was particularly important as children and young people spoke about inadequate disability parking, particularly in and around hospitals, and the costs associated with parking;



Difficulty accessing Auslan interpreters which left some children and young people unable to communicate and participate in activities;



Mainstream organisations and services not offering the appropriate support for children and young people with disabilities to be able to participate in activities that were available to their peers.

Children and young people suggested that training and education be made available to raise awareness about both the needs and capacity of people with disabilities and that ramps be made available in NDIS plans to allow people with wheelchairs to access their friends places. They also suggested that services such as Auslan be mainstreamed to enable children and young people with hearing impairments to more easily participate in the community and that more effort should be put into hearing the voices of children and young people with disabilities.

Employment and Training



Access to employment and training was seen by children and young people as a crucial factor in their quality of life, their capacity to become financially independent and their ability to participate in their community. Additionally, on a personal level, they spoke about how important securing employment was to build their confidence and support themselves financially. Most children and young people said getting a job is their number one aspiration for the future.

Children and young people told us that many positives came from opportunities to access jobs and training support:



Participation in school career development, work experience, accredited training and hands on learning in a work environment were among the most important and valuable things children and young people said they learnt at school;



Work experience and ongoing work placements in areas such as hospitality, farming, national parks, retail outlets, horticulture and cleaning contributed were valued for helping inspire confidence and build employment skills;



Training and support programs such as vocational skills courses designed specifically for people with disabilities and similar work and vocational education programs run by organisations such as Northcott, Key Employment, Youth Connection and Macarthur Disability Services , were highly valued for providing an opportunity to learn new skills, develop self-confidence and self-esteem and prepare participants for future employment and;



Disability Employment Services were mentioned as a useful service that assist young people with a disability to seek a job and maintain their employment, although participants spoke about their different experiences with some left feeling confused and unsupported.

Many children and young people struggled to access these same opportunities or had found some employers reluctant to engage a young person with a disability. They told us:



There was a lack of opportunity to access training and support programs in their area, leaving them feeling they did not have the skills or qualifications to participate in a workplace;



It was difficult for any young person, but especially a young person with disability, to find employment due to lack of job opportunities, particularly in rural and regional areas, even where job providers or supports are available;



That they were sometimes only given the opportunity to participate in volunteer work, rather than paid work, or they were placed with unsuitable employers. Some mentioned that they had to repeat the same training or skills courses because nothing else was available to them and;



They sometimes felt confused about what was expected of them in a workplace once they commenced a role and some referred to experiences of bullying in the workplace that caused them to leave the job.

Children and young people suggested that they needed more opportunities to train and work, particularly in rural and regional areas. They also thought that, to encourage businesses to provide more meaningful employment opportunities, employers should be encouraged to undertake awareness training to assist them adapt to the needs of employees with disabilities and learn how to provide ongoing support in the workplace. Children and young people also recommended that Centrelink be made easier to navigate and be more client friendly and training be given to Centrelink staff to better assist people with disabilities.

Discrimination and bullying



Children and young people spoke to us about their experience with bullying and discrimination and the impact it had on them. When they reflected on their experiences with discrimination, children and young people spoke about experiencing difficulties relating to their disability. When they reflected on their experience with bullying, children and young people seemed to regard some of those incidences as relating to their disability but also considered it a common experience of all children and young people.

There were few positive examples associated with this topic, however children and young people recognised:



The importance of education and awareness raising efforts around the impact that discrimination and bullying can have on children and young people with disability;



The importance of having a trusted adult that would believe them when they needed help and;



The value of having online assistance as well as places to go to in person when they were seeking help.

Children and young people spoke about the environments where they experiences bullying and discrimination and the negative impact that it had on their wellbeing:



Children and young people talked about experiencing discrimination in many aspects of their lives including when seeking to access education, training, employment, accessing services and navigating systems, and when trying to participate in events and general community activities and;



Bullying was a major concerns for children and young people and they spoke about experiencing bullying at school, on public transport, in the community and online.

Children and young people spoke about the importance of increasing knowledge and awareness in the general community about the negative impact that ignorance, fear and discrimination based on disability can have on individuals. They suggested widespread promotion of the idea that diversity and difference is something to be valued and that people with disabilities have the same rights and needs as everyone else. Children and young people also spoke about the importance of services that could help them respond to bullying and discrimination.

Mental health



The children and young people we spoke to during consultations told us that it was important to recognise the significance of mental health issues affecting them and their peers. They discussed the importance of awareness, of youth specific services and services that were equipped to assist children and young people that had complex or comorbid conditions such as mental health and disability concerns.

Though the focus of the feedback on this topic was on what needed to be improved, children and young people recognised that:



The increasing recognition of good mental health was a positive step forward;



Services specifically catering for children and young people that were easy to access and were supported by non-judgemental and friendly staff were of significant value and;



Increasing awareness of mental health at schools, and the training of teachers in how to respond to young people with mental health concerns, was acknowledged and appreciated.

Children and young people also spoke about the stigma that still surrounds issues of mental health and what more needed to be done to provide greater mental health support to them and their peers. They told us that:



It means a lot when adults take the mental health concerns of children and young people with disabilities seriously and help them access services that deal with chronic and complex issues;



Services needed to ensure they are “youth friendly”, that they listen and take young people seriously, that they understand that children and young people with disabilities could have co-morbid mental health concerns, and that they are available extended hours;



More effort should be put towards making children and young people aware of local services they can access;



Schools should play a more active role in mental health education and building positive mental health strategies and;



Peer to peer education was particularly valuable, as was hearing real life experiences and advice from people their own age.

There was general acknowledgement that efforts to address mental health concerns are increasing but that more needs to be done. Children and young people that participated in these consultations said further awareness raising was needed to ensure that teachers and mental health professionals better understood the potential interaction between mental health concerns and disabilities and ensure services were equipped to assist them.

ACYP key learnings from working with children and young people with disabilities during this consultation:

Facilitating the voices of children and young people with disabilities is critical to satisfying the rights of children and young people to be heard in matters affecting them. To do so effectively, organisations may need to consider what techniques need to be adopted to ensure ease of participation and clear communication. With this in mind, the Office of the Advocate for Children and Young People adapted our consultation techniques to ensure as many young people as possible could participate in whatever way they felt able to do so.

In organising these consultations, ACYP ensured that it provided information about the purpose and format of the consultations to agencies and schools through the provision of documents detailing:



The role of ACYP, the reasons for undertaking the project, the aim of the consultation and the format the consultations could take;



How the consultations would be organised and facilitated by ACYP and what support was needed from schools or organisations on the day; and



The information to be given to children and young people about the consultations and their consent requirements in a child friendly and easy to read format (when written material was appropriate).

By providing this information, ACYP sought to overcome concerns from schools and agencies with respect to potential interruption to their schedules, new challenges or practices that may be encountered by the children and young people and the ability of ACYP to adapt their practice to suit the needs of the children and young people in the consultations.

Each of consultations was specifically tailored to ensure all children and young people felt comfortable to participate. ACYP adapted the consultation sessions using the following techniques as required:

- Verbal consent permitted in place of written consent forms
- Smaller group numbers
- Shorter sessions with more breaks
- Adapted presentation techniques and record keeping options (large font screens, hand written notes, use of iPads, verbal records on REV software)
- Informed and supported the presence of support workers
- Adapted communication techniques and language depending on the communication needs of children and young people
- Provision of and cooperation with Auslan interpreters.

Acknowledgement

The Office of the Advocate for Children and Young people wishes to extend its sincere thanks to all the children and young people who participated in this consultation as well as those parents, carers, teachers and support workers who offered their support during this process. We look forward to widely promoting the voices and experiences of children and young people with disabilities with government agencies, non-government organisation and the wider NSW community.

Please visit www.acyp.nsw.gov.au for more information about this and other ACYP projects with NSW children and young people.



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