

National Disability Strategy Governance and Engagement Section

Department of Social Services

Lodged online at <https://engage.dss.gov.au/nds-stage2-consultation/make-a-submission/> and sent by email to disabilityreform@dss.gov.au

To the Department of Social Services,

Submission regarding a new National Disability Strategy

I write to you in my capacity as Chair of the ACT's Disability Reference Group (the DRG), and enclose with this correspondence a copy of our submission regarding a new National Disability Strategy.

DRG Members are appointed by the ACT Government to advise on matters of disability policy and action intended to promote greater social, economic and community participation of people with disability in Australia's capital city. We seek to give that advice within the context of action aimed at achieving the progressive realisation of outcomes set out in the UN Convention on the Rights of Persons with Disability.

A group such as the ACT DRG advises government on the needs and aspirations of people with disability with the aim – over time – to reduce (if not entirely eliminate) the need for persistent advocacy and reform because discriminatory barriers will be removed, attitudes will have evolved and people with disability will become truly equal, valued and fully participating members of the community. In our view, this objective is not simply a worthy goal but a necessity. But our DRG holds no illusions about the efforts that will be required by the whole community, working together to make this achievement real.

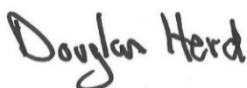
The will exists to work towards this goal. And as the consultation reports in our attached submission demonstrate, the ACT community is eager to embrace a new National Disability Strategy for all of Australia; one which sets out clearly the range of practical, meaningful and fully-funded measures that put people with disability and their supporters at the centre of the strategy's intent and its implementation.

Community expectations of the current NDS have been neither onerous nor unrealistic. Some progress has been made. But we note that progress has not been made in all areas. A new Strategy is, therefore, crucial to a better future. It represents a significant marker for all governments and their disability strategy intentions.

It is crucial, therefore, that governments listen to people with disability then lead concerted action. An absence of such leadership would reduce community confidence in Australia's commitment to act in the interests not just of people with disability and their families, but all people and all families.

We hope that this submission contributes constructively to discussion and action that leads to the realisation of a better and more just society for all. The DRG thanks the Canberra and ACT region's communities for their cooperation and willingness to respond to our call for their views. We are grateful for the opportunity to present these ideas to the Commonwealth and State and Territory Governments.

Regards,



Dougie Herd
Chair, ACT Disability Reference Group
Friday, 6 November 2020

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About the Disability Reference Group

The ACT Disability Reference Group (the DRG) is an advisory group that works to ensure the ACT Government, through the Minister for Disability, is aware of issues impacting upon people with disability, and the ways that the ACT can be a more inclusive community for people with disability. As members of the DRG we draw on our own experience of disability and our engagement with the community when we provide advice and guidance to government. Details of our membership and work plan can be found at https://www.communityservices.act.gov.au/disability_act/disability-reference-group.

The work of the DRG is informed by three foundational approaches to progressive reform:

- The UN Convention on the Rights of Persons with Disability.
- The social model of disability.
- Six policy outcome areas of the *National Disability Strategy 2010-2020*.

We believe the idea of an NDS has demonstrated the potential of such a broad framework for governments to engage people with disability in the development and implementation of policies and programs. The proposed new National Disability Strategy is of critical interest to us given the work we do in representing the interests of the ACT's disability community.

This submission about the new Strategy outlines the key themes and views of the ACT community arising from what they told us in response to our call for their stories. The examples and narratives in this submission outline the experiences shared by people with disability and supporters about what matters to them in the development and realisation of a new National Strategy. The DRG believes that the new Strategy needs to provide guidance for all governments about how to see and how to support people with disability in a fair and equitable way.

Who we spoke to

It is important to us to directly seek the views of people with disability on matters that affect them, and to ensure that their voices are heard, valued, and used to properly inform the development and implementation of policies and programs that affect them.

We reached out to our informal networks and sought conversations with groups of people who were meeting already. This document does not contain the views of all members of the ACT community but does reflect the views of the approximately 70 people we spoke with.

We spoke with people with disability, carers, parents of children with disability, students, people in prison, support staff and allies to people with disability. Around 40 of the people we consulted with and spoke to identified as a person with disability,

It is of great concern to us, however, that we were unable to gather and receive the views of the ACT's Aboriginal and Torres Strait Islander community about the proposed new National Disability Strategy. We have worked hard at ensuring that the views of the Aboriginal and Torres Strait Islanders are reflected in our advice and guidance to government, achieved through direct representation in membership and direct engagement with the community wherever possible. We acknowledge that this is not satisfactory outcome for these consultations, and have committed the DRG to making greater efforts to engage with the Aboriginal and Torres Strait Islander community for all future projects.

Despite this significant gap in obtaining community views, we are grateful to the ACT community for their willingness to engage with our consultations, and to trust the DRG with their stories and their experiences for the purposes of making this submission.

We extend our specific thanks to Imagine More, the ACT Council of Parents and Citizens Associations, the Alexander McConachie Centre, Confident Speakers and the ACT Down Syndrome Association, the Disability Policy network, Carers ACT, The Woden School, Wellways, and the ACT Office for Disability for enabling access to the people supported by these groups.

What we asked

The DRG felt that the submission questions proposed through both stages of the national public consultations did not really elicit responses from the community in a way that reflected their lives. The approach we took instead was to provide background information about the NDS, outline the six key priority areas, and then seek responses to four simple sets of questions:

1. What does a good life look like to you? What are the important parts of a good life to you?
2. Have you experienced fantastic inclusion before? Tell us more about these experiences and what made them special?
3. Have you come up against barriers where you were not included? What do you think could be done to address these barriers?
4. What role do you think government has to support you to have a good life?

Key issues for people with disability in the ACT

Our submission highlights the key issues raised in our consultations against each of the current six outcome areas, including sharing the experiences of people with disability about the elements under each of the outcomes, and also provides the feedback we received about improving community attitudes towards people with disability.

At the outset, we heard that there were many examples of good things that are happening in the lives of people with disability, and features of living in the ACT that created and enabled an inclusive community. For example, people spoke highly of their public school teachers, of the kids they go to school with, how great it is being employed in the ACT public service, the valued benefits of the Taxi Subsidy Scheme and the Companion Card. We are unable to include all of the great things that people have experienced in the community, and nor have we laboured and outlined all of the myriad challenges and barriers that were also brought to our attention.

Thematic feedback from our consultation with the community includes:

Education

- ❖ Access to inclusive education and teachers who have the skills to make inclusion happen and are disability confident makes a huge impact on the experience of children with disability and their families.
- ❖ Engagement with peers for younger people with disability makes all the difference to enjoying school or not. Bullying at school is a constant feature in the lives of both young people with disability and their families.
- ❖ Support around the transition from school to work is critical.

Jobs

- ❖ Having a job is valued by community and allows people to purchase both essential and non-essential items and services, which in turn moves them from living day-to-day to being able to plan for their future. To have a job is highly valued by both people with disability and by carers who are unable to work due to the absence of appropriate supports to allow them to economically participate.
- ❖ A job that pays a full wage rather than a supported wage or just volunteering is important to people with disability.
- ❖ Government has a key role in leading the employment of people with disability across public services and in encouraging and influencing business to do more to employ people with disability.

Inclusion in planning

- ❖ Planners – city planners, transport, housing, town, hospital planners – all need to engage with people with disability to ensure their needs are considered for the purposes of community infrastructure and services.
- ❖ The increase in mental health issues for people with disability needs to be acknowledged as well as the necessity of including people with psychosocial disabilities in the new National Disability Strategy.
- ❖ Health providers need to be confident in supporting people with disability and know what tools they can use to ensure that preventable causes of death are addressed.
- ❖ Health services need to be accessible both physically and financially to people with disability.

Home and independence

- ❖ The importance of independence to people with disability, including features such as having a driver's license, managing personal finances, having a home and a job, and having friends to connect with.
- ❖ The critical need of having a safe place to call home as an indicator of a successful life, and the absence of action in this area for people with disability.

Advocacy

- ❖ The essential role that advocacy plays when people are at their most vulnerable and the need for it to be accessible when it is required rather than having to wait for assistance.
- ❖ Many families asked for parent advocacy support – for somebody to sit with them in education meetings, advise how to complete forms and help them make often life-changing decisions.
- ❖ That the NDIS has offered more control and more support to more people but at the same time has increased the personal stressors and pressures on families and carers. The removal of a case management role has left families floundering and unsure of what to do and how to find support.
- ❖ The need to have the expressed voice of people with disability in a National Disability Strategy and in its reporting and evaluation. A “citizens’ jury” was suggested, to be composed of people who access services and supports; and lastly

Data

- ❖ The need to gather data from a whole range of sources – we count what we value – and include strengths-based data such as the benefits of early intervention, the number of children in inclusive settings, the number of people with jobs, the number of accessible homes etc.
- ❖ Governments need to be made accountable and more transparent with targets, actions and measures that are publicly reported.

Outcome 1 – Inclusive and accessible communities

It was clear from the views expressed by our community that there are serious and significant concerns about the inclusiveness and accessibility of services, supports and the ability to participate in community life for people with disability. The experience of people with disability of direct and indirect physical barriers, combined with unaware and biased community attitudes, send a clear signal to people with disability that they are not acknowledged, are not valued, and are not considered to be full and equal members of our community.

“Services expect people to be able bodied all the time. It’s a subtle way of saying, no, sorry, you are not welcome”

For example, a person with a mobility difficulty told us that they are part of a community choir that performs an annual Christmas concert for the community. But they can never participate in this experience because the choir performs on a stage that can only be accessed via a set of stairs with no railing, and no means of enabling them to perform with their fellow choristers despite repeated requests for the installation of railings.

Another participant in our consultations told us of their inability to traverse Canberra due to busses that don't cater for wheelchairs, limiting their ability to be in the workplace and to access services and supports.

"If we are seen as 'other' by enforcing that attitude through separate entrances etc, then we cannot expect community attitudes to change."

The DRG was made aware of inaccessibility issues for people with a vision impairment, who generally need to walk to access community services, due to simple, solvable issues that included:

- increased "clutter" associated with a rise in outdoor dining facilities, particularly due to post-COVID-19 spacing requirements, and shop signs limiting the ability of people with a vision impairment to use and access public spaces and walkways
- increased use of electric scooters and motor vehicles that, in comparison to other types of vehicles, are silent and often do not come within the range of person with a vision impairment's awareness – up to a third of people who are blind or have low vision have reported having had an accident or near miss with an electric scooter or vehicle, and
- issues with the use of improperly formatted electronic documents (such as portable document format material) that is incompatible with screen readers and other assistive technologies, leading to problems with studying or accessing simple information like café menus.

We were told that potential and possible solutions to these issues were relatively straightforward, and included signage provided at wheelchair height, large print material, and increased regulation of outdoor dining, signage and electric vehicle alert systems to better support the safety of people who are vision impaired or blind.

We are also aware of the specific and multi-faceted barriers experienced by intersectional people with disability who are marginalised within already-marginalised communities and groups. This includes repeated problems experienced with the accessibility of venues and the lack of forethought and consideration given to ensuring that people with disability are able to access the supports they need as an intersectional person.

"All access must be dignified and shared – no separate entrances or having to go the long way around to get to the same place – this is true from footpaths (kerb ramps at each road) through to public buildings."

Canberra is also a community that values its heritage and history, and the DRG is aware of continued problems with ensuring that when older premises are repaired or renovated that they are undertaken in a way that supports accessibility. The current approach lacks consistency with the relevant national standards, and appears at times to be (in the words of one of the people we spoke to) **"haphazard at best and deliberately neglectful at worst"**.

Small, simple changes are often all that are required to ensure that a person with a mobility impairment, a person who has a hearing or vision impairment, or a person who experiences the world differently due to their neurology, is able to access and enjoy the life of our community, and in doing so know that they are a part of our community.

Families talked about the need for inclusive playgrounds- where children can be safe to run around and participate. Sometimes when children are in segregated educational settings a playground is the only

place that they can play with children without disability. Fenced playgrounds can allow children to experience some independence and engage in free play with other children.

“Generally, we don’t have access issues, but we have to carry a ramp wherever we go.”

Repeatedly through the consultations our community representatives asked if the needs of people with disability were ever properly considered by city planners, transport planners, building codes and workplaces. The emphasis is on people with disability making changes to their communities based on their individual efforts and networks, rather than making the environment accessible to all people by design from the outset.

“Where is the co-design with community and people with disability?”

A family talked about the years their child had spent in a school, with regular, annual upgrades to school facilities. Each and every time following the upgrading and renovations work the family had to go to the school and ask for it to become accessible to their child. The school always agreed to make changes but never planned for inclusion and accessibility from the start.

Outcome 2 – Rights protection, justice and legislation

The DRG is proud to have played a role in the development of the ACT’s *Disability Justice Strategy 2019-29*¹, with a Disability Justice Reference Group², modelled on the DRG, supporting the Strategy by providing advice and guidance and ensuring that the experiences of people with disability are put at the centre of all Strategy actions. Our community consultations reinforced the value of this work and the benefits of taking a long-term approach to complex, cross-sector issues.

Having noted these positives though, there were experiences shared with us suggesting that people with disability and their carers are not having their concerns being taken seriously and that they are sometimes discouraged from exercising their rights.

One respondent shared their story about a family member who had been assaulted, resulting in a brain injury. This acquired brain injury in turn meant that the victim was not considered to be a credible enough witness for prosecution purposes, with the clear view that justice would not be possible for this person with a disability. Subsequent assaults and theft of personal property experienced by the person with disability were, in the views of the family member, also not adequately addressed by the justice system, with repeated complaints resulting in no redress or remedial action.

“They should make sure people coming out of prison are supported better. We need a bridge that helps us move back into the community. Everything in prison is structured but when you leave there is very little support. It makes everything hard and overwhelming.”

Prisoners with disability also told us that they experience considerable difficulty in accessing supports and with the continuity of the supports they need from the community to prison and from prison back into the community. Supports need to be established while in custody and then continued when they return to the community, and that building trusting relationships with support workers was crucial to their ability to know who to turn to in the community in order to help them to stay well and in community.

¹ Published online at https://www.communityservices.act.gov.au/disability_act/disability-justice-strategy.

² See https://www.communityservices.act.gov.au/disability_act/disability-justice-reference-group for more information including terms of reference and communiqués issued by the group.

Outcome 3 – Economic security

There were two key sets of experiences told to us relating economic security for people with disability – employment and access to housing.

“When I was in school I was bullied because I was different from everyone else, but I have proved them wrong, I am a fully independent woman with a job.”

People felt strongly that there is insufficient support to allow young people with disability to become job ready while they are at school, and that they are not being provided with the support they need to gain work experience. The expectation was instead that the families of young people with disability would coordinate and then provide the support to for that young person to access work experience. We were also told that there are insufficient opportunities to gain employment and then insufficient support to keep them employed once they’re in work.

“An increase in the number of people with disability in the workforce would assist managers to understand how to be an inclusive manager for people with disability.”

A key theme of the feedback we received from the community was that governments need to do more to show the rest of the economy how to effectively attract, recruit and retain people with disability across all workplaces. We heard that there are positive programs and examples of better recruitment and employment practices that all employers can learn from. Seeing Machines Ltd for example, winner of the *Inclusion in Private Sector Award* at the 2019 ACT Chief Minister’s Inclusion Awards, demonstrated how listening to people with disability and then making changes to the recruitment process meant that they were able to create employment opportunities for people who are neurodiverse.

“Not all disability can be seen, but if we were valuing diversity then it would be, people with disability wouldn’t have to hide and try to ‘pass as normal’.”

Our consultations also highlighted the importance of having people with disability in visible leadership roles within organisations, as a marker of the culture of that workplace as being one that values and supports employees with disability. This was singled out by those we spoke to as being of critical importance to longer-term change across workplaces.

“It seems that the workplace felt that reasonable adjustments just got in the way of how things were always done.”

The community told us that there are still significant problems with what should be simple and straightforward matters such as reasonable adjustments. We heard that workplaces don’t always understand what reasonable adjustments are and that there are inconsistencies in their application. If the adjustment is a hardware or equipment need then this seems to be simple to provide, but if the adjustment relates to communication and workplace flexibility needs that mean a person with disability is able to work to their full capacity then they are applied much less effectively by workplaces.

I think sometimes wages for disability is a slave labour – you have a car to pay for, groceries and bills.

The DRG heard that having a job is not just a valued social expectation, but provides financial security and independence to be able to pay for social activities and to engage in community. One man indicated that during the COVID-19 shutdown he was put on JobKeeper and he received such a significant pay increase that he could buy food in bulk and purchase some winter clothes. He is usually on a supported wage where he works three full days per week and earns \$200 per fortnight – which he referred to as his ‘slave wages’. In response to this comment other people we speaking to as part of the broader group also highlighted their concerns about the expectation that people with disability live on such a small income.

A group of people with intellectual disability also highlighted that the government had an obligation to ensure that people with disability could manage finances, to teach people how to manage money and then to ensure that they had the opportunity to earn it either through real waged jobs or increased income support payments.

“Being able to do the normal things that a spouse, mother, daughter, friend would do without a prohibitive personal or financial cost to myself that makes it too hard.”

For a person with disability living on a reduced income has an impact on the whole family, and is challenging and demoralising when transitioning between earning a wage to having to live on welfare payments alone.

“I can work, and I want to work, but I need this flexibility”.

Carers also identified that supporting their family member with disability often means they cannot work, or cannot work full-time, and that they, too, need support to find employment that is flexible, less hours, from home.

Housing

“Leaving home is important in a good life.”

The DRG believes that housing needs to be a separate outcome area under any new National Disability Strategy, and that the Commonwealth, State and Territory governments must, as a matter of urgency, commit and assign funding to this fundamental human need.

“When I was 21 I got a place in public housing. It wasn’t safe, I was scared for my safety, so I packed up my stuff and left. I haven’t had my own place since then. I’ve been homeless or couch surfing. I’m 32 now.”

Our community consultations highlighted that it feels as though there has been minimal progress on meeting the housing needs of people with disability under the current National Disability Strategy, and there is a strong sense that the community lacks confidence in any new National Disability Strategy that does not commit to direct, measurable improvements in housing support. Public housing support for people with disability, including ensuring that public housing was safe, accessible and appropriate to their needs, was the main concern raised by those we spoke to. We also heard about the impacts of insecure housing on a person’s mental health and wellbeing, and that the inability to find suitable, stable accommodation, particularly for those who may already be experiencing challenges with their mental health, affected a person’s ability to make progress in other areas.

Disability sector stakeholders told us that;

- there is a clear market failure in housing, and that governments should consider providing incentives for landlords to modify their properties to meet the needs of people with disability;
- there is also an obvious need to upgrade and reform existing housing stock, including in the private rental market; and
- changes to construction codes to provide a higher level of accessibility for people with disability are being actively resisted by the building industry as demonstrated by the submissions made to building code changes proposed by the Australian Building Code Board. This process appears to be listening to the voices of the people building the houses and ignoring the voices of people who have to live in them.

We did, however, have examples of positive progress being made in the building and construction industry drawn to our attention, with some construction companies focussing only on building or

modifying homes to the highest accessibility standard. Those companies that take this approach are then realising the economic benefits of being able to meet the needs of this emerging market.

People indicated that having a home and a place to live is a critical part of having a good life. People also identified that finding that home is one of the barriers to being included in community.

We heard that people cannot find homes in the private rental market that are accessible and that they are not eligible for public housing, and so are unable to live an independent life when they do not have freedom in their own homes. They can't afford to purchase a home in the Canberra market and so are constantly struggling with simple acts of daily living.

Many people commented on access to public housing, with some focus being on the difficulty of getting housing that feels safe and meets the needs of their family.

“Public housing is a crock of When you come out of prison the only places there are to live for single men are full of drug users and drug dealers. It sets you up to fail.”

Housing also presents specific challenges for prisoners with disability, with a lack of stable, available and suitable accommodation – this then ties into the cycle of recidivism and reoffending because being homeless or living somewhere unsafe leads to risk-taking behaviour. Minimal amounts of support are provided to them which leads to the perception that their rehabilitation and community reintegration is not worth the required degree of investment.

Other Canberrans want to see more opportunity to live in a home on their own rather than in shared accommodation.

“Most [public] accommodation – especially short-term accommodation – is communal. I wish there was an option to live by yourself but not have to be on a housing list for years.”

A support worker in a community mental health program said he has noticed the most challenging issue for participants in the program is the ability to find suitable accommodation. He said this impacts people's mental health, causing anxiety and stress, which is particularly difficult for people who are already facing challenges with their mental health and wellbeing.

One person shared a positive experience getting suitable accommodation in a short time. They told us when they were a young adult, conflict with her family home lead her to be kicked out of the family home. She said she applied for housing and was contacted within a week. She moved into a brand-new apartment that was close to services. She said it was a great place to live and she stayed there for over 18 years.

Outcome 4 – Personal and Community Support

The majority of views we gathered relating to personal and community support concerned the NDIS, with a mix of positive and negative experiences in accessing personal support. The DRG holds serious and significant concerns about many elements of the NDIS that could form the basis of a separate and sizable submission. For the purposes of this paper we note that:

- many people told us that getting appropriate supports through the NDIS is very challenging, with a lack of guidance about applicant rights and reasons for decisions made about supports.
- There were inconsistencies in support plans and decisions affecting the credibility of the NDIA in the eyes of people with disability and their families.
- The volume of paperwork required to be undertaken was overwhelming leading to a number of people consulted indicating that they have just given up and stopped asking for support and let their plans lapse.

- The absence of a case management type role has increased the pressure and stressors on families many times over as has the lack of a clear communication when LACS and planners will not support people to access providers or provide advice about how to find support.
- People feel lost and helpless when engaging with the NDIA.

“Having to justify needs at every step of the way to get to services we need – it’s like two full-time jobs to work and to care.”

We also heard about a lack of consistency in support providers, with a fatiguing element to the experience of people with disability and their carers having to retell their story over and over again to different people at each stage of the process in arranging or changing supports.

“I was respected as a carer, and [the person with disability] was respected as a person. ...The bar has been set.”

There were positive experiences shared with us as well. One person told us that she wasn’t aware of the extent of support for people experiencing mental illness until she was linked into services following a hospital admission, and another consultation participant describing the inclusive practices and culture they experienced in another medical setting.

The differences and inconsistencies between the aged care and disability support system were another concern expressed to us about community support.

A number of people spoke about the difficulty in accessing disability supports or services when over 65 as the aged care system – even level 4 packages- does not provide enough support hours or funds for equipment making it incredibly difficult to have a good life or maintain any quality of life at all. This increases the pressure on carers and funnels people into nursing homes.

Before the NDIS the equipment loan scheme was amazing and responsive and now they keep pushing us to find other people to pay for the equipment- but there is no one else to pay.

Many people indicated getting appropriate supports through the NDIS is very challenging. One person, talking about NDIS support stated “It’s hard to find guidance about what is a right and when your application is rejected they don’t specify why – it’s not transparent or clear”.

Another person explained they require a ramp to help them access their parents’ house where they were currently living. The person explained they had a plan for a ramp that would suit them, shaped to provide manoeuvrability, and that would be affordable according to the NDIA. However, building regulations dictated a different design that was less desirable to the participant and too expensive to be approved by the NDIA.

“From a carer’s perspective three meals, a shower and a decent sleep is a good day- is that okay or should I be able to want or expect more?”

Outcome 5 – Learning and Skills

The DRG’s consultations included sessions conducted with parents of children and young adults with disability, students with disability, teachers and disability sector representatives with experience in education and training people with disability.

“Schools are microcosms of society, if we can’t get it right there how will we do it.”

We heard about the importance of keeping children with disability engaged and supported in mainstream schooling. We heard that the examples of being most included were generated through peers in inclusive

class settings. The everyday contact with each other created a comfort and an ease that allows real inclusion and connection to occur. Engagement with peers for younger people with disability makes all the difference to enjoying school or not.

We heard that access to inclusive education and skilled teachers who are disability confident makes a huge impact on the experience of children with disability, their families and on peers.

“Where I am most hopeful for my child is when I see peers who expect to have my daughter in their class. When my daughter can stand up in assembly and present because another student stands next to her and whispers the prompts in her ear so she can say an acknowledgment of country.”

It was unfortunate to hear that bullying at school is a constant feature in the lives of both young people with disability and their families. This bullying or exclusion happens when peers are not informed, where there is not a culture of acceptance and educational support staff are not confident in engaging in inclusion. At the same time it is very small acts of inclusion – such as being invited to birthday parties, walking to class with peers or having somebody to chat with at lunch – that have been identified by young people at school as indicators of being welcome and included.

“Inclusion is everybody’s business, if we want it to work everybody needs to take an interest.”

We heard that there is a need to explicitly teach inclusion at schools, so that both teachers and students are confident in the daily acts they can undertake that welcome and include all others. Some discussion was had around the Everyone Everyday resource developed in the ACT for primary schools and the confusion as to why it was not mandatory for all staff and all schools given the level of children with disability in ACT schools.

“Working in partnership with schools is where the magic happens - that has been our success.”

Support around the transition from school to work is critical. Parents discussed that sometimes schools didn’t seem to see beyond the boundary of the school, as if they viewed transitions as “someone else’s problem”. Parents saw that the way their children were set up for life during school would impact the success of the rest of their life. They discussed the need for students to learn interview skills. Young people with intellectual disability discussed the difficulties of being expected to source their own work experience opportunities, while at the same time sharing the value that work brought to their lives. Early in their lives it is unclear if they will work and what contribution they will make to community.

“Investment into opportunities for social connection to grow is everybody’s responsibility. In schools we know when kids have a sense of belonging (friends) then they are more likely to engage academically.”

We talked to high school students who had no vision of their future beyond food and video games. The students needed support to explore what opportunities might be available to them and encouragement to dream big.

We heard that kids and young people do not have regular ongoing social support networks- that school holidays don’t have peer engagement and on weekends only a few of the people we spoke with initiate contact with friends. At the same time we heard from families who are supporting children with disability through the education system that they are exhausted from engaging with the system and have no energy to access sport or recreational activities that assist in building social connection for their kids. This is isolating for both parents and children.

“Where is the evidence for segregation?”

There were many conversations about the why and how of segregated schooling versus inclusive education. We heard that some families place their children in segregated settings not out of choice but

out of concern for their children being bullied and excluded or because they were funnelled there through the system. Largely we heard from parents who had fought hard to have their children in inclusive school settings and continue to struggle to keep their children in mainstream, inclusive education. As one mother said – **“Inclusion leaves battle scars.”**

Parents told us about some of the positive experiences, they have had with teachers who speak to their child with disability with a genuine sense of respect, and how this reflects an inclusive school environment and culture. This was nearly always connected to having a Principle who is willing to engage to ensure that their child is included.

“Schools should be required to demonstrate that they are being inclusive rather than families proving that they are not.”

Our community told us that there are inconsistencies across the education system in the way that teachers work with parents to support students with disability, with a perceived lack of accountability, transparency and bureaucratic barriers working against the providing of supports. Parents shared their frustration that there seemed to be no mechanism to measure whether a school was meeting its aspirations for inclusion. Families feel frustrated with the burden of effort involved in engaging with the process of obtaining support, with a sense that the more they try to engage the more disincentives they encounter in doing so.

“Only when we are all included will we have better expectations.”

We were told that the Australian education curriculum should include all learners so that children with disability learn what all the children learn - just make adjustments. We heard that low expectations of students and young people at this critical life stage changes the likely outcomes of their lives. We also heard about students completing their learning with their therapists rather than at school because their teachers could not make the learning and assessment accessible for them.

Nearly every parent and student could think of at least one educator, if not many, who had made a difference in their lives and the common thread seemed to be that they had high expectations and were willing to champion the changes and adjustments needed- this made all the difference.

“The best thing I have done in my life is getting my reading up to date. I can read a lot better than most people in my ilk. I can do a lot more things, I can do more physical work. I can read instructions and things like that.”

Parents talked about the struggle between trying to keep the school accountable and meeting their obligations, yet at the same time, striving to maintain a positive relationship with the staff. One family described fighting hard to have their school spend disability specific funding on the purpose for which it was provided. The students involved were about to transition from one educational setting to another, and due to the redirection of funding, were not receiving the support they required to make a smooth and successful transition.

This decision by the school affected a number of students in that year and one parent described feeling that trust had been eroded. The parent also shared their concern over a proposal that their child be moved from an inclusive integrated setting with peers, to a segregated classroom with only other students with disability.

“It feels like our kids have been thrown under a bus by putting at risk this most critical year.”

We heard from parents and sector representatives that when they try to resolve issues through the complaints process that this, too, feels like it presents barriers. There is no real sense on the part of the people we spoke to that complaints information is collected, tracked and then used to inform systemic changes in policies and processes.

“The complaints system is broken and it’s totally unacceptable.”

Quite a few families, parents and allies suggested the need for a Parent Advocate to support families engage with bureaucracy (not just Education systems, NDIS was also cited). An independent person who can help parents and students *navigate* the system to get the supports they need, while also working to *influence* the system to achieve more consistency in the way that different schools meet the needs of students with disability.

Outcome 6 – Health and wellbeing

“I want to be thriving not just surviving.”

Our community consultations emphasised the importance of seeing health and wellbeing as more than physical health, instead improving the emotional and psychological health of people with disability needs to be part of the overall goal. This broader sense of health and wellbeing includes having dignity, being seen and being included in planning. We heard that community attitudes towards people with disability play a big role in a person’s wellbeing, and that it is connected to and contributes towards improvements across the other outcome areas.

People with disability feel that they are included when planning includes them from the beginning-without having to retrofit. We heard from a number of people who had experienced the indignity of no planning for their situation in a health care setting. For example, there was no plan for people with sensory issues and COVID testing. If people with disability are not considered and their situation understood they do not feel valued or included.

“A good life is when a plan made early on, is acted on.”

The experience of being seen (or not) is also reflected in the accessibility of health services and the way that they treat people with disability, another key theme arising from our consultations. Those working in health services need to understand how to effectively listen to a person with disability. A common experience among those we spoke to was that of feeling as though they were being told that they did not know their own body as well as the medical practitioner or specialist. There was also a lack of awareness on the part of health sector workers regarding the specific practices, or reasonable adjustments, associated with different types of disability, such as ensuring that they announce themselves when entering a room where a person with a vision impairment is present.

Participants discussed other experiences of their disability not being understood. There are no adult changing facilities in Canberra Hospital so there is no way to attend to personal care if you have high physical support needs and are not an inpatient.

In the health system, if someone uses wheelchair, their height and weight are not measured because it is considered too difficult- but is it still important? Having a hoist available would show that the needs of people who use wheelchairs have been considered.

A further example is the lack of breast-screening options for women with mobility impairments, and no information about how to get help or where to go for assistance. A lack of access to this kind of service, that is designed to help prevent serious illness, can have significant consequences for a person’s health and wellbeing.

“I wasn’t listened to, was made to feel unsafe and undignified by having to ‘try’ things that I knew wouldn’t work. Staff are trained in clinical care and not complex disability needs, and they aren’t told to listen to the person who knows best.”

Participants linked their experience with the need for a change in community attitudes:

“If the culture around people with disability changes so that the intent is to give the same care as others receive, that would be significant.”

When asked, participants had no awareness of any resources or supports provided by Health, GP's, hospitals or emergency services that catered to the needs of people with disability. There was no awareness of useful tools to assist with better health care such as Health Passports or the Comprehensive Health Assessment Program (CHAP).

“There needs to be explicit reference to psycho-social disability in the strategy because otherwise they will get forgotten.”

The experience of people with both psychosocial disability and people with disability and mental illness needs to be acknowledged and addressed in the strategy. Advocacy organisations now work with more people with psychosocial disability than before. As such, mental health training has had to be accelerated. The new strategy needs to reflect that mental health needs to be prioritised where inclusion is not on the same trajectory of outcomes.

There were positive experiences shared through consultation, albeit with one example relating to a service outside of the ACT. One participant's son has been attending the Developmental Disability Health Unit in Sydney, where a clinic was being run by doctors whose whole careers have been about people with disability – especially complex disability – and who conduct comprehensive proactive health reviews. These doctors are able to provide referrals to specialists because they know which ones are good with people with disability and their needs. We were told that despite this being an effective and even 'wonderful' service, the funding for this service will be phased out because they are not assessed by the government as a necessary service.

Another example in the ACT from a respondent described how they had recently experienced great inclusion in a medical setting, with a doctor advocating for the carer's support for the person with disability in the context of the COVID-19 restrictions.

“I was respected as a carer, and [the person with disability] was respected as a person”.

The respondent continued that while many things went wrong the team was always accommodating and respectful, understanding that the person with disability couldn't communicate the way they were used to. The respondent advised that they (the carer and the person with disability) still talk about the event and compare other places to that example with the sense that the **“the bar has been set”**.

Outcome – Community Attitudes

The DRG believes that governments need to support and promote changes in community attitudes towards people with disability over the short, medium and longer term if there is to be any progress against any of the outcome areas. We know that cultural change can be difficult to achieve and that the benefits that arise from changes in community attitudes can take generations to be able to realise, which makes it critical that we invest in improvements now.

We also note and endorse the view put forward in the Interim Report of the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability about community attitudes. This report noted that attitudes towards people with disability is a key area of importance to the independence of people with disability and their right to live a life that is free from violence, abuse, neglect, and exploitation³.

“A good life is the opposite of being isolated, being free from pain, good relationships, acceptance of differences, and children with differences and disabilities having voices, not being branded as naughty and instead being seen as good people.”

³ p365 of the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability Interim Report published 30 October 2020 at <https://disability.royalcommission.gov.au/publications/interim-report>

We asked people in our consultations to tell us about what a good life looks like, and ensured that they had the freedom to tell us in their own words and in their own way. The need to make real, substantive improvements in community attitudes towards people with disability was a constant, common thread in the stories we heard and the experiences that were shared. People with disability in the ACT told us that community attitudes affected nearly everything, be it their ability to access and use services, to participate in community events, to engage in education and training. We heard that true progress cannot be made for people with disability until they are seen as truly equal and valued members of the community, recognised for their contributions and supported in their aspirations.

One person spoke about community attitudes and the different experience two of his children have had growing up in different regions –

“One of my sons lives in the country. All my son wants to do is play footy. He has autism and dyslexia. The local footy club won’t let him play. I have another child who plays footy in Canberra. There are two kids with Down syndrome on the team. Those kids are treated like any other kid on the team.”

The role of governments in changing community attitudes

“They have a lot of principles right, but the execution doesn’t match up with the needs”.

The DRG also asked our community what they saw as the role of governments in changing community attitudes. Governments were seen as having good intentions, but that when it comes to actual implementation there are clear failures and problems, not least with relatively simple issues like providing information that is relevant, accessible, and easy to find for people with disability and their supporters.

Community feedback emphasised the importance of ensuring that people with disability were directly involved in the development and implementation of programs intended to assist them (“nothing about us without us”). We were also asked to tell government that people with disability needed to be visible in every campaign and in every brochure, and to tell advertisers that including people with disability in their marketing often said more about their store than their prices did.

It was of particular interest to us that the National Disability Strategy was not really something that the people we spoke to were aware of. The majority of those in our consultations didn’t know about the outcome areas or the way that the Strategy is designed to guide the actions of Commonwealth, State and Territory governments. The feedback we received was that a Strategy, however described, does not matter unless it’s being practically implemented at the ground level with actual, tangible benefits for people with disability and their families.