10 years of DisCo:

The Past, Present and Future of Disability Rights

Speech by the Disability Discrimination Commissioner, Mr Alastair McEwin

The changing landscape of human rights in the disability area

I acknowledge and pay respects to the traditional Aboriginal people of the Gold Coast and their descendants. I also acknowledge the many Aboriginal people from other regions as well as Torres Strait and South Sea Islander people who now live in the local area and have made important contributions to the community.

Master of Ceremonies, Angela Catterns, the Hon Ken Wyatt, Rae Lamb, fellow speakers, colleagues and friends.

It's a real honour and pleasure to be with you today, and share the stage with such an esteemed panel of speakers. I also acknowledge your keynote speakers from yesterday – the Hon Michael Kirby and Professor Rosalind Croucher and I pay tribute to the outstanding work they have done for human rights in Australia.

As Disability Discrimination Commissioner, it is my job to promote and protect the rights of all Australians with disability. Nothing quite gets me out of bed in the morning like the prospect of making sure the 4.2 million Australians with disability can enjoy their rights on an equal basis with others. I'm a self-confessed disability rights nerd.

From the moment I wake up in the morning until the moment I go to sleep at night, I see examples and reminders all around me of how far the disability rights movement has come.
I’m encouraged when I turn on the TV and can watch the news with captions instead of staring at the screen and hoping that they will have the news presenter in the shot so I can lip read what they are saying.

I’m encouraged when I walk out of my building and walk towards the train station, and see that the City of Sydney street signs are in braille.

I’m encouraged when I get to the train station and know that, thanks to my predecessor Graeme Innes risking his house to pay Sydney Trains’ legal defence bill, there are both visual and audio announcements to let people know what station they are at.

I’m encouraged when on my way to work, I see advertisements for accessible performances of popular shows, including sensory friendly performances.

I’m encouraged when I get to the Human Rights Commission office and there are both visual and audio cues of what lift to take up to my floor.

I’m encouraged when I see written information on the walls of the building that are in easy English.

I’m encouraged when I turn on my computer and navigate to a website that is fully accessible to screen reader technology, user friendly and has all media transcribed or captioned.

I’m encouraged when I hear stories of how the National Disability Insurance Scheme, the NDIS, is enabling people with disability to do the things they never thought would be possible.

And, perhaps most significantly, I’m encouraged when I meet with ordinary Australians with disability doing ordinary things – getting an education, advancing their careers, living in housing of their choice and participating in the community.
But at the same time, I am very aware of how far the disability rights movement still has to go. How far we still have to go to give people with disability in Australia a fair go.

If you have a disability, you are more likely to be uneducated, unemployed, homeless, living in poverty, experiencing violence abuse and neglect, isolated and denied your rights to make decisions and choices about all aspects of your life than those who do not have a disability. I share these insights not to provoke a response of pity, but to set the scene for what needs to be done to ensure a more positive future for disability rights in Australia.

Today I would like to take you on a journey through the disability rights movement in Australia and 10 years of DisCo. Not Donna Summer, the Bee Gees, Sister Sledge, KC and the Sunshine Band, Earth, Wind and Fire and Michael Jackson, but the United Nations Convention on the Rights of Persons with Disabilities – DisCo for short. I’m going to reflect on the past and present of disability rights and share with you some insights from national consultations I have been conducting on issues that matter the most to people with disability. And I’m going to share some thoughts on what the future might look like for people with disability in Australia.

Throughout history, we know that people with disability in Australia have been ignored, hidden and denied their fundamental human rights. 1981 was a turning point in the history of the Australian and international disability rights movement, with the International Year of the Disabled Persons. In 1986 we saw disability rights advocacy recognised as a program area to be funded under the Disability Services Act. And I know I said there wouldn’t be any Michael Jackson, but I think we can agree that after this point the mantra in the disability rights movement became – Don’t Stop Til You Get Enough.

In 1991, we saw the introduction of the Disability Reform Package which reformed the Commonwealth income support payments for people with disability with a view to encouraging their integration into the workforce. We then saw the passage of the Disability Discrimination Act – an Act to eliminate discrimination on the ground of disability, ensure equality before the law for people with disability and promote
community acceptance of the rights of people with disability – which was passed in 1992 and commenced in 1993.

In March next year we will celebrate 25 years of the Disability Discrimination Act. There is no doubt that in almost 25 years of the Disability Discrimination Act there have been achievements in the disability rights movement. Some of the examples I mentioned earlier are a testament to this. And there are many more examples where ordinary Australians with disability trying to live ordinary lives have found themselves unable to do so because of barriers and discrimination, and have been able to make change through the provisions of the DDA. We now also have standards under the DDA, which provide more detail on rights and responsibilities about equal access and opportunity for people with a disability in relation to transport, education and access to premises. But I think we can agree that the legislation and standards alone are not enough to provide the attitudinal, cultural and social change we need to ensure people with disability are enjoying their rights to the fullest extent possible.

10 years after the commencement of the DDA, negotiations began for DisCo. As many of you in this room will be aware, the development of DisCo was a long time coming. The negotiation process itself spanned five years, which seems like a long time, but DisCo was, and remains, the fastest negotiated human rights treaty ever. It was also, in UN terms, revolutionary as it involved the highest level of participation of representatives of organisations of people with disability of any human rights convention, or any other United Nations process, in history. At this point, I want to acknowledge the work of Graeme, Rosemary Kayess and countless other Australians with disability whose tireless work saw the development of a DisCo that puts the rights of persons with disability at the centre of everything that affects them.

DisCo is made up of two documents – the Convention, which contains the main human rights provisions expressed as a series of Articles, and the Optional Protocol, which is a more limited document that sets up an individual complaints procedure. Through the Articles, DisCo sets out general and specific obligations for states in relation to specific human rights and fundamental freedoms.
DisCo contains traditional human rights concepts that are general protections found in other thematic human rights conventions. It outlaws discrimination in all areas of life, including employment, education, health services, transportation and access to justice. But DisCo has added, modified and transformed traditional rights concepts to give them a more specific disability focus. It has added detailed disability-specific interpretations to some of these traditional human rights concepts. Although DisCo does not establish new human rights, it tells us what governments must do to ensure that people with disability enjoy their human rights to the fullest extent possible and on an equal basis with others.

The text of DisCo unequivocally recognises the inherent dignity and human rights of people with disability. The text is more than just semantics. At the time it was adopted, and today still, it represents an acknowledgement that all people with disability must be empowered to enjoy their fundamental human rights on an equal basis with others. It positions people with disability as equal and active members of society who not only want to exist in society like anyone else but also have important contributions to make, yet are prevented from achieving their potential and enjoying their rights because of the attitudinal, environmental and social barriers that society imposes.

This position is indicative of the social model of disability. It is important to acknowledge this because it is a fundamentally different position to the historically dominant medical model, which characterises disability as a health problem and focuses on prevention, cure and symptom management. In many ways, DisCo has a very important ideological and symbolic significance, as a show of strong international support for the rights of people with disability and commitment to removing the barriers that prevents people with disability from full participation and inclusion in society. But, as is true of a lot of international human rights law, it’s meaning and practical impact is derived from the extent to which it is incorporated into domestic law and policy. Or to put it in another way, it’s all icing and no cake unless the promises at the top are matched by the commitment and practice at the ground level.

Given Australia’s federal structure and longstanding arrangements about which level of government funds what portfolio, it was inevitable that successful implementation of DisCo across Australia would require a co-ordinated national approach across
mainstream and disability specific areas of public policy. Enter the National Disability Strategy – a 10 year plan to promote the rights and inclusion of people with disability and guide activity across six key outcomes – health and wellbeing, economic security, learning and skills development, rights, protection and justice, inclusive and accessible communities and personal and community support.

Initially, at least, hopes for the National Disability Strategy were very high. The NDS promised to be the Donna Summer of DisCo – the “Queen of DisCo.” Finally, a national co-ordinating mechanism that promised to drive not only disability policy change, but change in mainstream systems and services to ensure better outcomes for people with disability.

But in late 2009 and early 2010 when the NDS was in the early stages of development, there was general agreement in the disability community that the NDS would not be successful unless it was supported by processes of policy and program development, implementation and monitoring. It was flagged very early on that there was a critical need for detailed implementation plans for the NDS, including timelines, performance measures, indicators in key areas and reporting requirements. It was feared that without these, we would have policy, but no practice.

We are over half way through the implementation time-frame for the National Disability Strategy - Australia’s mechanism for implementing DisCo. I also promised no Bee Gees, but I think it’s appropriate to describe the current state of NDS implementation with reference to one of their most popular songs – unfortunately it’s not “You Should be Dancing,” and fortunately it’s not “Tragedy” - it’s more like “Stayin’ alive.”

We know that there is agreement that attitudes need to change, society needs to be more inclusive and accessible and people with disability need to be empowered – but we aren’t seeing the ongoing commitment and practice that we need at the grassroots level to deliver real change for people with disability. At present, there are examples all around us of recognition of disability rights and willingness to make changes to ensure that people with disability enjoy their rights, but we haven’t seen the steps towards the kind of change we need in areas such as employment, education and
housing. The disability rights agenda has, as it has been at so many times in Australian history, been overshadowed by other agendas.

As I said earlier I have been conducting national consultations with people with disability, their families, carers and the community. I have been to every capital city and some regional centres, asking people about the issues that matter to them the most.

People have told me that implementation of the NDS has been slow and inconsistent. They have told me that although Australia has made some progress in advancing the rights of people with disability over the last 10 years, the basic challenges and issues that people with disability face haven’t changed – equality, rights, full participation and equal standing in society.

As they did 10 years ago before DisCo and the NDS, some people with disability continue to work in disability enterprises and face barriers to open employment, live in congregate and/or inaccessible settings, learn in segregated schools, experience violence and face barriers in their interactions with the criminal justice system. People with disability continue to have limited opportunities for representation and meaningful participation in all aspects of society.

I heard consistently that people with disability still face many barriers to meaningful employment, inclusive education, equality before the law and their right to choose where they live and with whom. People told me that in employment, education, housing and the criminal justice system, practice rarely matches policy, and more needs to be done to ensure mainstream systems and services have the resources, incentives and in some circumstances, the regulation and accountability requirements, to provide better opportunities and outcomes for people with disability.

There was general agreement among the people I spoke to that the time has passed for good intentions and high-level policy – it’s time for action to spark the cultural, attitudinal and practical changes that are required. I am hoping that in the final three years of implementation of the NDS we will see a renewed commitment to the actions
required to ensure the rights enshrined in DisCo become everyday reality for people with disability in Australia.

One small, but significant, part of the NDS which we have seen action on during the past few years is the NDIS. The NDIS is one of the most significant social reforms to take place in Australia and its impact on the lives of people with disability and our society will be immense beyond measure. It has been compared to the introduction of Medicare, and it represents one of the most significant advances in the disability rights movement in Australia.

Unlike the existing disability service system, it is a system based on rights where people with disability are empowered to have choice and control over their services and supports. It is designed to ensure that all people with disability have the supports they need to achieve their goals and actively participate in the community. It brings with it a fundamental shift in the way governments approach and fund supports and services for people with disability.

The NDIS represents an acknowledgement that it is not a person’s disability that prevents them from accessing opportunities to study, work and participate in the community, but rather the barriers imposed by discrimination, lack of understanding and insufficient supports and services. It starts from the central premise that with access to the right supports, the supports that they have chosen and have control over, people with disability will be able to overcome the barriers they face to full, equal and active participation in society.

Although there have been some challenges and issues during implementation of the NDIS, the stories of change from the NDIS highlight how this once in a generation reform is working to address the environmental, economic and social inequalities experienced by Australians with disability.

Like Vanessa’s story. Vanessa is an avid cheerleader, and is now in her second year of Journalism at Edith Cowan University in Western Australia. She is passionate about human rights and wants to travel the world, get a job as a journalist and continue to compete as a cheerleader.
Vanessa also happens to be deafblind. She is able to participate in her lectures at university and learn her cheerleading routines because her NDIS plan includes funding for the support of tactile Auslan interpreters and communication guides. She also has a Braillenote device with a keyboard attached that helps others to communicate with her.

On paper, she is the sum of specified amounts of money for improved daily living, increased social and community participation and core supports. But for Vanessa, those dollars allow her to be a regular 19 year old - socialising with friends at the Uni bar, cheerleading - and maybe attending a few lectures and tutorials too.

And in late 2016, Vanessa was named Western Australia’s young person of the year.

We are seeing how the NDIS is enabling people with disability to get out and about, get an education and be part of the workforce, and empowering them to be in control over what supports they receive and who provides them.

The common thread is how the NDIS empowers people with disability to get out and about in the community and enjoy life just like anyone else. People who have been told their whole lives that they have to be “special” – go to special schools, have special jobs, attend special activities, live in special homes – can just be ordinary because of the NDIS.

We are seeing how the NDIS is making dreams a reality for some of the most marginalised and vulnerable people in our society, and contributing to the realisation of the rights of people with disability.

And we are hopeful that the increased number of people with disability actively participating in their communities and contributing to society will contribute to a more positive public discourse and higher expectations about people with disability and their potential.
The NDIS also plays a broader role in helping people with disability to access mainstream services like education, housing and health, access community services like libraries and sports clubs and maintain the informal support of family and friends. Through the Information Linkages and Capacity Building component of the NDIS, people with disability will receive information, linkages and referrals to connect them with appropriate disability, community and mainstream supports, and some work will be done to build the capacity of mainstream services to be more inclusive and responsive to the needs of people with disability. Some work will also be done to increase awareness and build the capacity of communities to be more inclusive and accessible.

Realising the vision of the NDIS is critical to the present and future of disability rights in Australia.

But it’s important to remember that most people with disability will never have access to the NDIS. At last estimate, only around 10% of the 4.2 million people with disability will receive NDIS supports.

Even in a NDIS world, people with disability will still need access to health care, they will still need somewhere to live, to go to school, to go to University, to go to work and to socialise, to go shopping, visit websites – in short, they will still have to do all the tasks of daily living. And as we all know, many of these tasks are, and will continue to be, out of reach for many people with disability, because of physical barriers and the barriers imposed by discrimination and low expectations.

Throughout my national consultations, I’ve heard a lot about the barriers that people with disability still face to enjoying their rights to employment, education, housing, equality before the law and safety and freedom from violence.

I’ve heard that people are very concerned about the systemic and persistent barriers to employment that people with disability face and would like these to be addressed through attitudinal change and work to increase expectations of people with disability. I’ve heard the challenges people are facing in finding meaningful employment are great and not enough is being done to help people with disability overcome them. I’m working
with my colleague Kay Patterson, the Age Discrimination Commissioner, on ensuring the recommendations from the Willing to Work Report are implemented.

I am really concerned about the prevalence of discrimination against students with disability in schools and universities, and as I have been conducting my consultations it has been disheartening to hear just how many people share my concerns. I have consistently heard that there will be no change for students with disability until there are systemic changes to ensure every student has the right support and positive education environment that will enable them to do their best and learn effectively. I have also heard that action is urgently needed to facilitate a more inclusive culture in the education system and equip our teachers and lecturers with the tools and skills to provide more positive education experiences for people with disability.

It has become clear from my consultations to date that the shortage of accessible and affordable housing severely limits choice and opportunities for people with disability. This of course is no surprise, as where you live and who you live with often determines many other aspects of your life, including where you work and the kind of social, community and cultural events you participate in. I’ve heard very strongly from the consultations that the lack of affordable and accessible housing must be addressed through regulatory change to increase the supply of accessible housing and innovative housing models that give people with disability greater choice over where they live. And I’m hoping this is something I can work towards throughout my term.

I am saddened every single day by the persistent discrimination and hardship people with disability face in their interactions with the criminal justice system. There is a real lack of appropriate support available to help people with disability to reduce the disadvantage they face and the risk of offending behaviour, and to effectively participate in the criminal justice system. I’ve also heard very strongly that these issues are likely to be compounded by the NDIS which is unlikely to provide the support that people with disability in the criminal justice system may need.

I have also heard that violence against people with disability, and particularly women with disability, is a very serious issue that has not received the same coverage and response as other violence issues.
All of these insights present a strong case for a renewed push for the government and community to make good on the promises of the NDS and DisCo. Change is unlikely to occur for people with disability unless there is a collective effort across government and society to tackle the persistent causes of discrimination and inequality.

What we know is that education, awareness and attitudinal change are some of the strongest tools we have in the struggle to overcome the prevailing culture of disempowerment of people with disability and low expectations about their ability to contribute to society and make decisions about how they would like to live their lives.

Cultural change takes time, and resources, but it can happen. Well focused and sustained community education and awareness campaigns can and have changed entrenched attitudes and behaviours.

We know that until there is an expectation that people with disability participate in schools, in workplaces, in sport, in cultural activities, in social and recreational activities and generally in the community in the same way that people without disability do, people with disability are likely to continue to face attitudinal barriers to the full enjoyment of their rights.

We also know that if we can raise expectations, and tackle the inequalities that exist in the circumstances where people live and work, we will be much closer to the full realisation of the rights of people with disability.

Reflecting on 10 years of DisCo, I think it’s clear what we should expect and strive towards for the future of disability rights in Australia.

I would like to see an Australia world where stigma and discrimination do not prevent the full realisation of the rights of people with disability.

An Australia where a person’s disability does not define their opportunities for participation in society and employment.
An Australia where people expect people with disability to participate in schools, in workplaces, in sport, in cultural activities, in social and recreational activities and generally in the community in the same way that people without disability do.

An Australia where people with disability have the right support and live in a community that anticipates and expects them to participate and contribute to all aspects of community life.

An Australia where people with disability aren’t heroes or victims, but are just people enjoying equal and included lives in the community.

And we will know we have reached equilibrium when it’s not a news story for a person with disability to succeed in school or at university, or to be employed in a job they love for a decent wage, or to be a member of parliament. We will reach equilibrium when people with disability can just be who they are and participate in all aspects of society just like anybody else.

Borrowing the words of Sister Sledge, from their disco chart topping song “We are family”:

Living life is fun and we've just begun
To get our share of the world's delights
High - High hopes we have for the future
And our goal's in sight
We - no we don't get depressed
’Cause here’s what we call our golden rule
Have faith in you and the things you do
You won't go wrong