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Disability Discrimination Commissioner
Australian Human Rights Commission
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**Melbourne City Mission's response to
The Australian Human Rights Commission National Consultation
*Shaping our Future: discussions on disability rights***

Melbourne City Mission wishes to thank you for the opportunity to submit a response to the Australian Human Rights Commission National Consultation, *Shaping our Future: discussions on disability rights*.

About Melbourne City Mission

Melbourne City Mission is one of Victoria's oldest and largest community services organisations. Our vision is to create a fair and just community where people have equal access to opportunities and resources.

Melbourne City Mission has significant expertise in providing support to people with disabilities. Our services:

- span the continuum of early intervention, care and respite, and community participation
- are accessible to people of all ages and life stages
- are part of a broader, integrated service platform that includes Early Years, Education, Training, Employment, Family Support, Housing and Homelessness, Justice Services and Palliative Care.

Our one-on-one work is complemented by the work we do at the systems level to try and mitigate structural inequality. This work is underpinned by a human rights framework, and has a strategic focus on capacity building and social inclusion.

About this submission

This inquiry presented an opportunity for people with a disability engaged with Melbourne City Mission's programs to share their experiences and have their stories put on the public record. Our intention with this submission was to collect first-person accounts of the people we support who wished to express their opinions and insights and feed these directly back to the Commissioner.

The feedback throughout this submission comes directly from the diverse people with a disability we work alongside, including:

- members of the [Compass Clubhouse program](#) – a service operated by and for adults who have experienced an Acquired Brain Injury (ABI)
- adults with disabilities and carers of children and young people who took part in a series of Melbourne City Mission focus groups in regards to their experiences of the NDIS.

As part of this submission response, we are also pleased to include a stand-alone piece of advocacy work developed by the members of the Compass Clubhouse, '*Headz Up – What's Next? Life After an ABI*'. This publication is a guide of experience written by, and for, people who have experienced an Acquired Brain Injury.

Feedback from the people we work alongside

On the theme of education

Background

The ABS notes a significant gap between students with disability and those without, notably in the attainment of Year 12 or equivalent, vocational education and training qualifications, and participation in university studies¹.

Commonwealth-State data on the 'support needs of service users', cited by the Australian Institute of Health and Welfare in 2007, showed that 'service users' with an ABI were most likely to need help with activities related learning and working than other 'life areas' (more than three-quarters of service users needed assistance with learning and working activities).

Gaps in specialist support means that: there are some students in mainstream schools who are *"just getting by"* and not genuinely learning and participating and there are some students who are only able to attend part-time.

Insights from the Compass Clubhouse members on education

David



- *"I want to do another degree but I'm not sure how I'd go until I started doing it. I'd probably have to study online. I don't want people judging me in a classroom."*

Frank



- *"It's difficult for me to read and I have difficulties with my memory. I can't do education with the way it is now. Impossible."*

¹ See <http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/4446.0main+features102009>

Geoff



- *“Affordability stops me from education. The Government will only fund one Certificate III and I have one in business, but if I can’t do that and need something else, I can’t get another Certificate III as they won’t fund another one in a different discipline.”*

On the theme of employment

Background

ABS figures show that the labour force participation rate for Victorians with disability is significantly less than the rate for Victorians without disability (54 per cent compared to 82 per cent, respectively).

VicHealth research shows the relative income of people with disabilities in Australia is approximately 70 per cent of those without disability (the lowest in the OECD) and that 45 per cent of Australians with disabilities live in poverty or near poverty, a situation that has worsened since the mid-1990s². As a result of changes to eligibility for the Disability Support Pension (DSP), there has been a drop in successful claims from 53 per cent in 2011 to 33 per cent in 2014. The result is that many people facing significant barriers to work due to disability or caring responsibilities are now forced to rely on the lower \$37.00 per day Newstart Allowance, most for more than a year³.

There are less people with disability in the workforce now than there were 20 years ago. Families caring for a child with a disability also experience economic vulnerability. In the VicHealth research, two-thirds (64 per cent) reported that the main financial impact of their caring role was a decreased income or an increase in their expenses⁴.

Insights from the Compass Clubhouse members on employment

David



- *“Coming from being a professional, it was so hard being told after my injury, “all you are capable of now is pushing trolleys”. I was a paramedic. I want a job that is meaningful to me again.”*
- *“It would be great to have like a liaison, a career adviser, specifically for people with a brain injury. I’m legally blind and have attempted to work, but as much as my last employer tried – he didn’t really understand my disability and so the things he asked me to do – I couldn’t do them the way he wanted me to.”*

² Victorian Health Promotion Foundation (2012), *Disability and health inequalities in Australia research summary*, accessed at www.vichealth.vic.gov.au

³ Australian Council of Social Service (ACOSS), *Budget Priorities Statement 2016-17*
<http://www.acoss.org.au/acoss-budget-priorities-statement-2016-17/>

⁴ *ibid*

- *“We need aware workplaces, where employers understand disabilities and what people are actually capable of.”*

Frank



- *“It’s difficult for me to find work doing what I do with computers. The market is very competitive and I’m up against lots of ‘healthy’ people.”*
- *“I need support in the job. If there was a support person who was paid to support me in the workplace and advocate for me, that would be great. Because of my injury, people think I can’t do the job anymore.”*

Geoff



- *“I’ve been working but it always comes to an end at some time. It’s always things like I don’t work fast enough, or I don’t meet KPI’s and it’s not because I don’t want to, it’s because I actually can’t in the ways employers want me to.”*
- *“I’ve tried working in manufacturing, business administration and a call centre – everything is so fast paced. I also have to deal with depression and anxiety. I know I am physically capable of working and I want to work, but I don’t know what role would suit me and that wouldn’t be so fast-paced.”*

John



- *“I was told by my Disability Support Pension (DSP) provider, “no-one will employ you” and put on the pension. As soon as employers find out I have a brain injury, there’s no chance for me.”*

Peter



- *“It seems to me that for people with a brain injury or mental health condition, lowly jobs are offered. As if there’s a presumption that’s all people with a disability are capable of. Although it’s good to have opportunities where we can contribute to society, we also need to be able to choose work that’s meaningful to us.”*
- *“We’ve had our knocks and for some, what’s also knocked out of us is self-confidence.”*

Susie



- *“For me, my injury has reminded me of what’s important. The opportunity to work is great because it’s a way to have independence with having a wage. I felt so bad when friends offered to pay for my coffee. It’s so degrading.”*

- *“I felt really good being able to go to work as a receptionist but I had this drive to be what I was before my injury – an account manager. But, I had to accept that I’m a new Susie now.”*
- *“It was pretty much like they [employers] didn’t have time for someone who can’t talk or walk straight.”*
- *“Sometimes, for me, the best thing is for someone to tell me I can’t do something. I finished a degree with a brain injury because I was told I couldn’t work in business.”*
- *“We’re still the same person underneath, but certain capabilities have changed and this is different for each person with a brain injury.”*
- *“Work gives people skills you can also use in your everyday life, like working out processes.”*

Warren

- *“Everyone’s experience is unique. We’ve all made different meanings of what we’ve been through.”*
- *“Finding employers who are aware and accepting of people with disabilities and their capabilities is like finding hen’s teeth.”*
- *“It takes a bit more care, a bit more patience and a bit more nurturing, but we can still work. It’s a case of being there for me.”*

On the theme of housing

Background

VicHealth, citing Beer and Faulkner, reports that it is common for people with a disability to 'fall out of home ownership' due to the costs of their disability, with 32 per cent of people with a disability who are rental tenants reporting that they used to be homeowners with a mortgage.

In 2012, almost 250,000 people receiving a Disability Support Pension also received Commonwealth Rental Assistance (CRA)⁵.

Despite receiving CRA, about three in 10 persons receiving the Disability Support Pension were still spending more than 30 per cent of gross household income on rent after CRA. The widely accepted measure of 'housing stress' is the proportion of lower income (first and second quintile) renter households for whom spending on rent accounts for more than 30 per cent of income.

Insights from the Compass Clubhouse members on housing

Erin



- *“My husband and I re-designed our house to have wider doors and a more open plan for my wheelchair. Other houses I’ve had had too narrow doorways.”*

David



- *“Access to affordable housing is very difficult without having to live far away.”*

⁵ See the AIHW analysis of the Australian Government Housing Data Set June 2012 published at <http://www.aihw.gov.au/WorkArea/DownloadAsset.aspx?id=6442453666>

- *“I was shown a studio apartment and it was very small. I didn’t want to live with the people around there either – inappropriate conditions. I need to be around people with self-respect and who respect others. I live with my family at the moment and it’s not ideal – it’s very far away. For me to get here [Compass Clubhouse], I have to take a bus, two trains and a bus from Wheelers Hill.”*

Peter



- *“The upkeep of a home is very hard to keep up with. When there’s things that need to be done – you just put them off and try to get help left, right and centre. It’s a constant juggling.”*

On the theme of the NDIS

Background

4,200 users of disability support services under the National Disability Agreement (NDA) transitioned to the National Disability Insurance Scheme (NDIS) in 2013–14. A further 1,900 transitioned in 2014–15⁶.

There is a large increase in demand for services, with over 27,000 participants in Victoria growing to 105,000. The level of annual expenditure is projected to grow from \$2.6 billion to \$5.1 billion in Victoria by 2020⁷.

Insights from focus group members on the NDIS

The following quotes have been extracted from a series of NDIS focus groups we have convened with adults with disabilities and carers of children and young people.

“It’s all about money for you. I said I’d like to do pottery, bowling and mini-golf. I got everything in the package, I couldn’t have done any of this before.” – Kay, existing residential client.

“He [the pre-planning advisor] came around and had the form! He constantly reminded me of how you need the best for your child – you have to put everything down, all the little things need to be included. You get a package of money based on the info you put on the forms. The NDIS tells you where you can spend it. The therapy has been gold. Already she has stopped spitting and started walking for the first time.” – Christine, grandmother of a school – aged child with a disability.

“I want to have more activities for him. It all costs money and I have to budget with the other children in the family.” – Rowia, carer of an adult with a disability.

“They got home at 4:00pm and are home for the rest of the day. No activities like movies or going out, like the rest of the kids. Not acceptable for a 23 year old. I want him to go dancing and come home at 11:00pm!” – Nancy, carer of an adult with a disability.

“I want him to be happy, to be independent and to have a job – there is so much he can do, he is already doing work experience filing for an after-school program. He is doing well.” – Sel, mother of a school – aged child with a disability.

“I can’t remember how we got here, it’s all a blur. In the beginning, we were placed on a waiting list for speech therapy for a year, then she had speech therapy for a year.

⁶ Australian Institute of Health and Welfare (AIHW), ‘Disability’
<http://www.aihw.gov.au/disability/>

⁷ NDIS Market Position Statement, April 2016

<https://www.ndis.gov.au/html/sites/default/files/documents/Market%20Position%20Statement/Victorian-MPS.pdf>

We then got a referral to a paediatrician she wasn't overly concerned but gave us a referral to the Children's Hospital. We were on that waiting list for a year. Elise is now five and half years old and has just been diagnosed with Autism. The official interventions could have started earlier. In some ways it's been gratifying, in others, frustrating." – **Alex, parent of child with a disability.**

"It's been great for her to have interaction in a smaller social group. At kinder, she can use the skills she is learning here – go up to someone, tap them on the shoulder, look them in the eye . . . her social skills, confidence and language is getting better. She was even invited to her first birthday party." – **Carmeletta, parent of child with a disability.**

"I am a single mother, I moved here from China. Patrick had a lot of tests, everyone was very worried about him. Funding has been very difficult. DHHS is very difficult. I work twice a week, I get respite care. People at work are not happy with me choosing my shifts. I work to be part of a community. I could sit at home and wait." – **Liya, parent of school – aged child with a disability.**

"I found the information all by myself, because if you wait it's too late. To start, I go to community health centre and neighbourhood house, read every paper – I say, 'I want help there is something wrong with my child.' They all help in different ways – I want all the help I can get. I tell everyone, they are Vietnamese and they don't know – their children are sometimes not diagnosed until 13 years old. Australians are different. You want help by having your children cared for by someone else. My husband and I work hard – so on the weekend we want to spend time with our two daughters, not take them away. It would be better for us to have support to allow us to work less and spend more time caring for our children ourselves." – **Kim, Vietnamese carer of school – aged child with a disability.**