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Acknowledgements and Dedication

We acknowledge the traditional custodians of this land, the Ngunnawal people. The PWD ACT offices, where we publish and distribute *The Canberra Disability Review*, is on the traditional land of these people.

Thanks to the ACT Council of Social Service for supporting this edition.

This edition contains accounts of health events, places and situations which are confronting and upsetting.

We dedicate this edition to the people speaking out about quality of care and all people with disabilities who have suffered poor care including in clinical and institutional settings
<https://whiteflowermemorial.wordpress.com/>





Welcome to this fourth edition of *The Canberra Disability Review* where we dive deep into disability and health.

This is the fourth edition of the review and in previous editions we’ve included facts and data and long form interviews with advocates and experts.

And we’ve got some detailed feature articles in this edition, looking at the rights, barriers, issues and responses for people with disabilities across the world and closer to home here in Canberra.

But one of the things we heard over and over again is that too often debates and decisions about the health care of people with disability are offered about people with disabilities by doctors, professionals, academics, researchers, substitute decision makers and others.

So we have largely turned over this edition to the voices that matter: YOU – patients, users, citizens and consumers of health care.

We asked people five questions going to their experiences – the what, why and how of disability and health – and held a social media forum on 13 November 2017 to hear those voices and we’ve largely turned this edition over to many extended extracts of personal stories from people who have come forward.

Thank you for speaking out. You told us that:

- That you can’t afford the care you need on a pension or on a low income
- Your health wasn’t valued as people with disability and you felt you weren’t receiving the same quality of care as people without disability in the same settings
- That people didn’t listen to you, take you seriously or understand your conditions
- That you don’t get the information you need
- That you feel the health system is an ableist system
- That people don’t take the time to listen to you and disability loses out in a rushed system
- That some of the services you need are not here in Canberra or are hard to travel to
- That you fear hospitals and there is a lack of natural and NDIS supports available
- That access to transport, physical and digital barriers stop you maintaining health and accessing health services
- That the digital, physical and social infrastructure in the health system wasn’t accessible, affordable and fit for purpose.

Change is needed. The facts and stories speak for themselves.

Craig Wallace
Editor

PS. Some of the material in this edition is sad and confronting. Most of this is in the first part of the edition so give yourself time, especially with the facts and stories.

WHAT IS HAPPENING TO US?

In which we ask about the experiences of people with disability in accessing preventative, primary and tertiary health services

Five Questions

Too often debates about the health care of people with disability are conducted about people with disabilities by doctors, professionals, academics, researchers, substitute decision makers and others. So we asked local people with disability to answer five questions about disability and health in our city – here are some highlights.

1. To what extent do people with disability encounter barriers in preventative, primary and tertiary health services in Canberra?

Karen:

In my experience health care systems are set up for the average white middle class non-disabled person. The Bureaucrats who plan and design health services base their decisions on their own life experiences which largely reflects this same majority ableist centric view. This viewpoint is entrenched further because of the underemployment of persons with disability in the healthcare sector.

Marietta:

My son (now age 28) has been experiencing the symptoms of post-concussion syndrome since he was injured at work in January 2015. It was discovered that he also has a Chiari 1 malformation (brain herniation). It has been frustratingly difficult to find anyone in Canberra with knowledge and experience of these conditions (and Sydney is much the same!). GP & specialist knowledge is extremely poor. Allied health professionals such as neuro-physios seem to be best. Medical expertise regarding concussion and TBI seems to be concentrated in the elite sports and the military, with no cross-over to mainstream health.

Peter:

The key failing in the ACT Health system is a lack of information voluntarily provided by health professionals and bureaucrats. Let me give a few personal examples.

In 2014 I started to develop a hand tremor and made an outpatient appointment at Canberra Hospital. The specialist

consultant outlined four possible causes, including Parkinson's, but would not choose one or recommend treatment. Frustrated, I arranged to see a different consultant at the hospital. This was in November. In February I was told I was 147th in line and my appointment was scheduled for August. When August ended I rang and was told that other individual cases had been pushed in front of mine and it would still be several months before I got an appointment.

The reason I was dealing with the hospital was because I expected I couldn't afford a consultation with a neurologist in private practice. Somehow I found out I could see one and be ed. I had my appointment a week later and within 10 minutes had a diagnosis of Parkinson's and the start of treatment. No-one at the hospital had considered telling me I could do this and my health declined over some 16 months when I could have been getting treatment.

At the same time I was gaining weight due to a drug intended to stabilise my mental health. However, protracted use of it was damaging my renal system. A podiatrist told me about an alternative drug, which I then discussed with my psychiatrist and adopted. Since then I have successfully dieted, lost some 17kg (okay, regained a few) but my GP has reversed my diagnosis of Type 2 diabetes and says my kidney function is now normal. Again, the health professionals didn't discuss news and options with me – I had to find out for myself and ask.

Would my psychiatrist continue insisting I take the renal-damaging drug until I needed dialysis or a transplant?

My next example is about preventative medical care. I do not have private health cover, it's unaffordable. So I have paid cash for dental care on a needs basis. Everyone is aware of the appalling waiting lists for public dental care. My previous dentist used to light up when I visited – the cash cow had arrived for milking. I think my last filling was \$200. Belatedly discovering I probably had a hole in a front tooth, I recently visited a dental surgery near my GP. This surgery told me I could call a hotline, get triaged over the phone, pay \$42 for an Emergency Voucher from a government health centre and a week later I was fixed for 20% of the cost of visiting my previous dentist. My point is, that dentist was quite happy to take my money and leave me ignorant of how to get the care I needed cheaper. Had he done so, I would still recommend his services to others. But now, he can go whistle.

Jean:

Neither Mum's disability (caused by spinocerebellar ataxia) nor her chronic illness (ME/CFS) were taken into account when she was being treated for other conditions in hospital.

Most of the staff (doctors, nursing staff and allied health) were not interested in how her disability changed the support she needed to recover. Despite repeated explanations, most of the staff just did not get it. I could understand that not everyone's heard of spinocerebellar ataxia but seriously health people, google is your friend. Also, you have an expert in how it affects her right in front of you. I tried showing them videos on youtube to give them some idea of how the illness can affect movement

Nurses for example expected her to be able to get herself to the loo using a walker (that wouldn't have been safe one for her normally, let alone when she had a broken ankle).

It was hard to get help setting up meals so she could eat (she needs help opening stuff and cutting up meat).

Physios wanted her to do stuff beyond her ability and labelled her as non-compliant (lazy/malingering) when she tried to explain why. When she was at a point where she could safely start doing stuff, they were slow to provide that support. Their attitudes influenced how the nursing staff viewed her too.

Many of the staff seemed resentful of any extra help mum needed because of her disability.

Mum has difficulty using IT (so no phones and computers) which made her feel more isolated and vulnerable. Even with me visiting lots, providing support and advocating for her, it was a really traumatic and disheartening experience for her to spend 9 months in hospital over the last year.

I shudder to think what it's like for people without any outside support.

2. What do you think are the most visible barriers?

Karen:

Physical access to health services for those with disabilities is poor.

Public transport is poor in Canberra ;leaving those who don't drive with significant barriers to accessing emergency and after hours services in particular. Both tertiary and preventative Health services are often planned around car parks with public transport an afterthought. This means the most vulnerable put off attending to their health because they are just not well enough to make the often arduous journey to a health services.



The hurried nature in which both primary and tertiary healthcare is delivered means that patient centred care is just rhetoric and those with complex or multiple health issues cannot possibly receive the appropriate preventative holistic care.

The way in which healthcare information is shared is one dimensional and poorly accessed by those with special needs.

The doctor/nurse knows best attitude is still alive and well with people with disabilities and their carers more often than not seen as partners in decisions about their own care.

3. What are some barriers we might not consider?

Gavin:

Most staff display a poor understanding of disability.

Some doctors refuse to talk to people with disabilities even when we have normal cognition.

We face a high danger of picking up antibiotic resistant infections.

Inability of nurses to do personal care for people with high or complex needs. This is made worse because under the NDIS participants are not supposed to take the support workers with them to hospital.

Never-ending amounts of paperwork, all of which is on paper and inaccessible. Nurses and junior doctors seem to have trouble understanding medication regimes thereby creating a risk of under dose or overdose.

Lengthy hospital stays create significant social isolation.

4. Why is this happening? Can you think of any reasons that health services or systems might not be responsive?

Karen:

Just like with many other issues, until people with disabilities are employed in the healthcare sector in representative numbers they will continue to be seen as “other” and an afterthought in planning and decisions.

Sam:

There are huge issues nationwide around systems which are siloed between health, mental health and disability. None of these systems interact. Disabled people also regularly have contact with drug and alcohol and homelessness authorities as well as other mainstream systems. The onus is on an individual to 'engage' with a system, usually a system which has a huge waiting list – if they do not, they are dropped off. There is nothing that looks like case management and there is an expectation that people who use drugs, are homeless or who have severe alcohol addiction issues will self refer or have the capacity or resources to manage their health issues.

5. How do you think we can start to make a change?

Karen:

Professional development for all staff where they have to spend a day accessing health services by public transport in a wheelchair/blindfolded and then once at the health service they have to communicate with staff with nonverbal communication aids.

Sasha:

Others with ME take a fact sheet explaining ME and what they can't do/tolerate. Good idea, esp when lose ability to speak.

PERSONAL STORY

Taking me seriously

Hi, I'm writing this in Comic Sans type font because it gives anyone reading it the feeling that whoever wrote anything using the comic sans type font either doesn't feel that anyone takes them seriously or, they i.e, me (the personage writing this piece) doesn't take whoever is reading this seriously. In fact, by using comic sans, I'm really saying that I care for you so much that I don't care for you at all. I guess what I'm saying here is, is this statement about care and lack of care such a horrifying statement to make in the year 2017. To me, it's a statement of fact.

This is because, if like me you've experienced shoddy and frankly disrespectful service rendered by the ACT Government health system, then you'll know the word care is a much operated on word. You will also know that being taken seriously is seemingly not anyone's concern.

Who do I blame for being treated like a boil on the governments Butt? I think it would be easy to blame the nurse, doctor, receptionist, dentist, psychiatrist, duty officer, etc for all my problems. Watching other people suffer at the hands of unprofessional staff too would be the easiest way of rolling all that shared disgust I feel into one big ball of hate wouldn't it? But again, falling into that emotionalized state for more than a few days is only going to cause me more health problems and pains in my butt, too.

I don't want to go into specifics too much. I deal with Government provided health care by not partaking in it very often. Luckily, for now I can get away with that. If you try to get what help you're entitled to, then you will be treated, but only sparingly and after you have waited eighteen months to two years. When you do get in to be treated or see, you will be made to feel it is a luxury not a right to be treated at all. Asking questions is fine. Just don't expect any answers or don't come back too soon or preferably at all. The rest is all too painful to speak of. And that, in the end creates perfect health consumers, who are always silent and cowering.

My name has been comically sansed out and unrespectfully omitted by me.

International Evidence

Key facts from the World Health Organisation¹

A factsheet from WHO provides a picture of disability and health around the world

- Over a billion people, about 15% of the world's population, have some form of disability.
- Between 110 million and 190 million adults have significant difficulties in functioning.
- Rates of disability are increasing due to population ageing and increases in chronic health conditions, among other causes.
- People with disabilities have less access to health care services and therefore experience unmet health care needs.
- People with disabilities report seeking more health care than people without disabilities and have greater unmet needs. For ex-

ample, a recent survey of people with serious mental disorders, showed that between 35% and 50% of people in developed countries, and between 76% and 85% in developing countries, received no treatment in the year prior to the study.

- Health promotion and prevention activities seldom target people with disabilities. For example women with disabilities receive less screening for breast and cervical cancer than women without disabilities. People with intellectual impairments and diabetes are less likely to have their weight checked. Adolescents and adults with disabilities are more likely to be excluded from sex education programmes.

Two studies: UK and Ohio

People with disabilities also have less access to care and

worse health outcomes than individuals without disability in the UK and US, two recent studies suggest with common issues being a lack of training, practice and awareness of disability accommodations.

One study found that people with disabilities in the UK have worse access to care largely due to struggles with transportation, costs and long waiting lists for appointments.

The other study was done in the U.S. state of Ohio and found people with disabilities were more likely to have unmet medical needs and less likely than others to have a primary care physician.

Roughly one in five people in the UK live with a disability, researchers note in BMJ Open.

To see how disability influences access to care, researchers examined survey data on access to care for 12,840 people over the age of 16 who didn't live in institutional settings like nursing

homes. This included 5,236 people with disabilities.

The most common obstacle for all people – whether they had a disability or not – was long waits for treatment, the study found. This was more common, however, for individuals with disabilities and impacted more than one in four people with severe disabilities.

Researchers also found that people with severe disabilities were more than four times as likely to lack treatment for mental health problems as individuals without disabilities.

In addition, women with disabilities were more than seven times more likely to have unmet health needs due to the cost of care or medication than men without disabilities.

This might be due in part to women having lower incomes than men, or more hurdles like the lack of transportation or insuffi-

¹ WHO Factsheet, Disability and health, Updated November 2016 | <http://www.who.int/mediacentre/factsheets/fs352/en/>



cient time to seek care due to responsibilities caring for kids or other relatives, Sakelariou said.

For the Ohio study, researchers examined survey data on almost 43,000 adults and more than 10,000 children with and without developmental disabilities.

Overall, they found that 14 percent of children aged 18 and younger with disabilities had problems receiving needed care, compared to 2 percent of kids without disabilities.

Among adults 65 and older, half of people with disabilities and 17 percent of individuals without disabilities

reported having one or more unmet healthcare needs, researchers report in the *Annals of Family Medicine*.

Adults with disabilities were also less likely to have a primary care physician that spends enough time with them or to have clinicians who explained things well.

Neither study was a controlled experiment designed to prove whether or how disabilities may influence access to care.

But previous research has documented significant health disparities for people with disabilities, and the findings suggest that lack of access is one reason why, researchers in-

involved with both studies said.

A lack of training for healthcare providers is another problem, said Susan Havercamp, a co-author of the U.S. study and researcher at The Ohio State University Wexner Medical Center's Nisonger Center in Columbus. "Healthcare training programs have not changed much in the past 100 years," Havercamp said by email.

"In contrast, the lives of people with developmental disabilities have changed a great deal," she said. "A century ago, babies born with developmental disabilities were not expected to survive childhood."

Now, many of these babies will grow up and require lifelong care that's tailored to their specific physical and mental health challenges.

"The best way to reduce health and healthcare disparities in people with developmental disabilities is to include disability training in all healthcare training programs," Havercamp added.

Sourced from Lisa Rapaport (Reuters Health) – SOURCE: [bit.ly/2gFXpdo] BMJ Open and [bit.ly/2zSpIha] *Annals of Family Medicine*, online September 11, 2017.

Australia

Australians with disability locked out of health – AIHW

Work by the Australian Institute of Health and Welfare¹ has found people with disability experience poor access to a range of health services including dental and GP services. Issues included cost and a lack of support and coordination services.

In 2012, 95% of people with disability living in the community saw a general practitioner (GP), 22% saw a GP for urgent medical care, 59% saw a medical specialist and 49% visited a dentist.

One-quarter (26%) visited a hospital emergency department (ED). One-third

(32%) saw 3 or more different health professionals for the same health condition and 22% received assistance for coordination of their care provided by 3 or more different health professionals.

In that year, 1 in 5 (20%) people with disability who saw a GP waited longer than they felt was acceptable for a GP appointment; 17% who needed to see a GP delayed or did not go because of the cost.

Nearly one-fifth (18%) of people with disability who saw a medical specialist waited longer than they felt was acceptable to get the appointment. One in 5 (20%) people with disability did not see a medical specialist when they needed to, mainly because of the cost.

More than 1 in 10 (11%) people with disability who needed to see a dentist had been placed on a waiting list for an appointment at a public dental clinic, as with many other Australians.

Of these, 32% were still waiting for the appointment at the time of the survey. Some 30% of people who needed to see a dentist delayed or did not go. Of these people, 67% delayed or did not go because of the cost.

Of people who saw 3 or more different health professionals for the same health condition, 16% had difficulties caused by a lack of communication or coordination among different health professionals.

About 13% of people with disability who report-

ed a need for ongoing help or supervision with healthcare activities (such as taking medication, manipulating or exercising muscles or limbs) had no source of assistance.

Intellectual disability – NSW study reveals poor health, avoidable deaths

A new study finds higher mortality and avoidable deaths amongst people with intellectual disability

A new study has found that compared with the general population, people with intellectual disability experience very poor mental and physical health status and

¹ Access to health services by Australians with disability – AIHW 29 • June 2015

Australia and disability – a snapshot

- There were **4.3 million** Australians with disability in 2015
- Around **16.4%** of Canberra people have an ABS defined disability or around **62,000** people
- The likelihood of living with disability increases with age, **2 in 5** people with disability were 65 years or older
- Almost **1/3** of people with disability had a profound or severe disability
- Around **3 in 5** people with disability* needed assistance with at least one activity of daily life
- Around **1 in 5** people with disability said their main longterm health condition was a mental or behavioural disorder

Indigenous Australians

- Almost **1 in 4** Indigenous people reported living with disability in Australia* in 2015
- Higher rates of disability were experienced across all age groups when compared to non-Indigenous people
- Experiences of discrimination due to disability were almost twice as likely than non-Indigenous people

Source: (ABS SDAC 2015)

substantial barriers to accessing quality health services, with tragic consequences including higher death rates and even avoidable deaths.

The study notes that people with intellectual disability experience high rates of common disorders with known associations with mortality, including mental disorders, respiratory disorders, gastro-oesophageal reflux disease, epilepsy and obesity.

Poor access to health services and an under-skilled medical workforce amplifies the potential for poor outcomes in this population group.

A New South Wales study released in November provides death statistics and details of potentially avoidable deaths in adults with intellectual disability (ID) who received disability services in that State¹.

Of 19 362 adults with an intellectual disability 732 (4%) deaths occurred at a median age of 54 years.

Overall the comparative mortality figure was 1.3, but was substantially higher for the 20–44 (4.0) and 45–64 (2.3) age groups.

Cause of death amongst people with intellectual disability was dominated by respiratory, circulatory, ne-

oplasm and diseases of the nervous system.

After recoding deaths previously attributed to the disability, 38% of deaths amongst people with intellectual disability and 17% in the comparison cohort were potentially avoidable.

The study provides evidence of higher mortality amongst people with intellectual disability compared with the general population.

The high proportion of potentially avoidable deaths for people with intellectual disability indicates an opportunity for the development of possible preventative strategies according to the study authors.

Double whammy – dual disability and chronic illness

AIHW analysis of the health status and risk factors of people with a disability has found people are more likely to experience other health and wellness issues ranging from diabetes to heart disease to mental illness as well as being more like to attempt suicide².

Among people aged under 65 years with severe or profound disability and mental health problems, the proportion who had behavioural and emotional problems with usual onset in childhood or adolescence was 14%, compared to 7% of those without disability.

Among people aged 15–64 years with a specific long-term health condition of NHPAs, the comparisons between people with severe or profound disability

and those without disability showed that:

- the proportion who had diabetes or a high sugar level before the age of 25 years was 23% versus 7%
- the proportion who acquired arthritis before the age of 25 years was 14% versus 6%
- the proportion who first experienced osteoporosis before the age of 45 years was 43% versus 31%.

About 69% of adults aged 18–64 years with severe or profound disability were overweight or obese, compared with 58% for those without disability.

People aged 35–64 years with severe or profound disability who were overweight or obese were more likely than those without disability to report both cardiovascular diseases and diabetes (9% versus 1%).

Compared to people without disability aged 15–64 years, people of the same age with severe or profound disability were more likely to do a very low level of exercise or no exercise (43% versus 31%); to be current daily smokers (31% versus 18%); to start smoking before the age of 18 years (38% versus 22%); and were less likely to have never smoked (42% versus 61%).

About 42% of people aged 16–64 years with severe or profound disability had seriously thought about committing suicide, including 18% who had attempted suicide. This was associated with their high prevalence of mental and behavioural problems.

1 Julian Trollor, Preeyaporn Srasuebkul, Han Xu, Sophie Howlett, *Cause of death and potentially avoidable deaths in Australian adults with intellectual disability using retrospective linked data* | 22 November 2017

2 Health of Australians with disability: health status and risk factors, AIHW September 2010

Vox Populi

(n) “the voice of the people.” (L)

PWD ACT asked people with disabilities to describe their experiences of healthcare services and systems. Here are some of the comments we received (some names and details have been changed to protect the identity of respondents).

ON AFFORDABILITY

Ryan:

“If you're like me, I'm on the DSP and have been for over 11 years now, I can't get an appointment with a psychologist because I can't get my mental illness under control. That being medicated. To see a psychiatrist, it's about \$300 a visit. I can't afford that every fortnight/month”

Gina:

“(there is) minimal reimbursement for specialists”

ON ACCESS

Aine:

“I went months without getting even basic GP care (due to access)”

Tom:

“I use a wheelchair due to Spina Bifida and have trouble transferring to the exam bed at my Dr's cause its really high and the winder is broken”

Jackie:

“Nursing staff are not taught how to do manual handling with the disabled hospitals, have a no lift policy but we're

are the lifters for us guys I was taken to emergency department in nsw years ago the staff was not all allowed to transfer me into a bed from my wheelchair I was told to go home and call an ambulance”

Sam:

“Issues like access to testing equipment, accessible rooms and even basic standardised equipment like height adjustable beds prevent disabled people accessing basic health care”

ON NURSING CARE

Wilma:

“During the time immediately following his injury, (my family member) was cared for very well at our local regional hospital. The ambulance staff, nurses and doctors at our hospital adapted their provision of service to suit my brothers needs.

When my brother was transferred to the [major] hospital the following day or two, it was pure hell.

The nature of big city hospitals meant that a lot of the nurses were agency nurses. Which meant no team approach. No continuity of nursing care. No rapport building. Most were simply there till the clock chimed, then they ran.

They did not have any disability training..and they didn't care to ask any questions as they knew they would probably never see my brother again.

My mother and myself took turns staying with my brother 24/7.

He was there for 6 weeks.

There were several near misses with his medication, and when we picked them up, they didn't really care.

A lot of them did not follow the protocol of checking patient name, allergies, etc before dispensing meds...it seemed that my brother was not worth that basic effort.

A lot of them also failed to wash their hands ...and we made a point of noticing if they washed their hands before tending to patients without a disability ... and they did. That made us feel so sad and angry.

Basically, the nurses were not professional ... it was very distressing. The doctors were amazing.

We felt that they not only offered my brother the same care they offered to all patients...but they seemed to take extra care to be gentle with him.

Some other staff in the hospital were great too”

ATTITUDES

Lena:

“(Hospitals are) Dangerous. Too many assumptions about quality of life to make it safe for a disabled person”

Jean:

“Physios wanted her to do stuff beyond her ability and labelled her as non-compliant (lazy/malingering) when she tried to explain why. When she was at a point where she could safely start doing stuff, they were slow to provide that support. Their attitudes influenced how the nursing staff viewed her too

Many of the staff seemed resentful of any extra help mum needed because of her disability”

If my mother or myself had not been able to stay at the hospital, sleeping on a camp bed in my brothers room, we dare not think how it would have ended.

ON SUPPORTS

Peter:

“Many people also lack support systems, including friends and carers who can help them, take the pulse of their pro-

gress and give the patient and their medical team independent feedback. In short, ensuring they don't feel alone and aren't alone”

Briony:

“Last year I took a friend to The Canberra Hospital and she couldn't physically walk at the time. I parked, went in to ask for a wheelchair to go back to her with and they just glanced around, said they couldn't see any and asked why she couldn't just walk to the ER. Took 45 minutes to get a chair located, and once we got to ED they asked for the chair back while we were in the waiting room!”

Wilma

“...During the 6 weeks at [the hospital with a family member with a disability], the social worker made an appearance in week #5.

She did nothing more than give coffee vouchers. There was no specialized support.

If my mother or myself had not been able to stay at the hospital, sleeping on a camp bed in my brothers room, we dare not think how it would have ended.

We feel he wouldn't have survived...”

MAINTAINING HEALTH

Tom:

“It can be hard getting gym access – many of them tend to be downstairs or upstairs in Canberra”

Kel:

“Plus the equipment can be inaccessible (also on gyms)”

Sam:

“Dentistry is also a huge issue and poverty and the cost of health related tests preclude preventative treatment. So does fear, because doctors and hospitals are not our friends”

NDIS

Peter:

“Please don't mention the NDIS – the National Disability Insurance Scheme. I was told it would take four months to be registered. When I went back four months later, they initially claimed I'd never applied and later agreed I had. Nonetheless, they chose to recognise my second “application date” as my “initial application” because it looked bet-



ter for them. They then asked for more information, and again the clock restarted every time this happened. I am still waiting and it will shortly be a year since I applied. What makes my blood boil is that it's my money yet they hold onto it as if I'm demanding money with menaces"

Wilma:

"My brothers current service provider wanted to update some parts of his care plan. They advised us that a review by an OT was part of the update. They went ahead and booked an OT assessment appointment with their own OT, who is a good OT, but pretty general. They did not consult with us.

(My parents are still my brothers legal guardians)

My parents had researched and found an OT that specialises in spinal injuries, and said they would be seeing this person instead.

This was met with A LOT of resistance from the service provider. They really don't like sharing my brothers funding with other professionals...despite my brothers best interests. ..This sort of thing happens a lot"

Lew:

"Has been a major year for our adult son who is now fully supported by the NDIS. His mum is a trained nurse and has

been instrumental in passing on her skills and now gradually letting go with the NDIS being in his life. He has complex needs, health and to many others to count.

Two key aspects of his NDIS personal plan have impacted on him now being more secure health wise.

- He has enough funding for emergencies including two on one for these occasions. Hospital visit recently when he seized and went through a glass window. He had two workers with him at the hospital sharing the load and supporting him and hospital staff overnight at the hospital.
- We recently employed a support worker who is a registered nurse. She's going to lead the team. Empowering them in ensuring his health and wellbeing is up to scratch. The NDIS support him at the higher needs rate. That gives him that little bit extra to cover the nurse who works one full shift a week and a few hours extra for record keeping, checks and meetings with his local doctor and staff as needed"

ISSUES WITH COMCARE

David:

"... have suffered from RSI related problems in both arms since 1985. I have had to go to the tribunal twice. Once to stop Comcare from cancelling my claim and secondly to get a 10% permanent impairment approved.

Currently I am 64years old, medically retired because of the side effects of pain medication since approximately 2001. Comcare is now in the process of removing all forms of physical treatments because they are passive treatments, remedial massage, manipulative physiotherapy and hydrotherapy.

I hate putting things into words. Even this much hurts my arms"

LACK OF CONSULTATION

Sam:

"...prescription drug regulation systems are being widely discussed in the absence of any discussion with disabled people, who are often people who are the primary stakeholders. For example, codeine will soon be unavailable without a doctors prescription. This is a huge issue for those who cannot access medical treatment and who use 'soft' non prescription drugs for pain management. The proposals to introduce 'real time' monitoring of prescriptions through systems such as DORA are being discussed right now, with some worrying trends like 'opt out' e-health, where your private information will be shared without your consent unless you know to say no. Nobody is discussing these issues out loud"

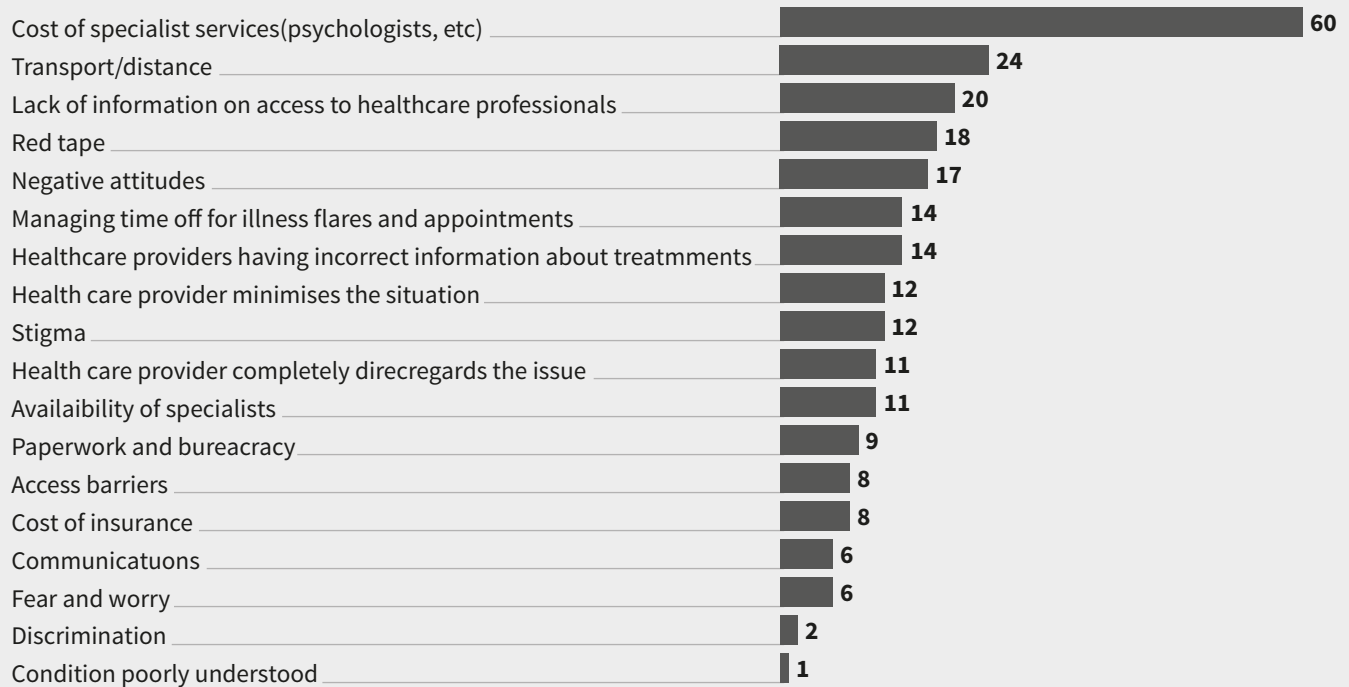
WHY IS THIS HAPPENING TO US?

**In which we ask why are people with disability
locked out of parts of the health system and
experiencing poor health**

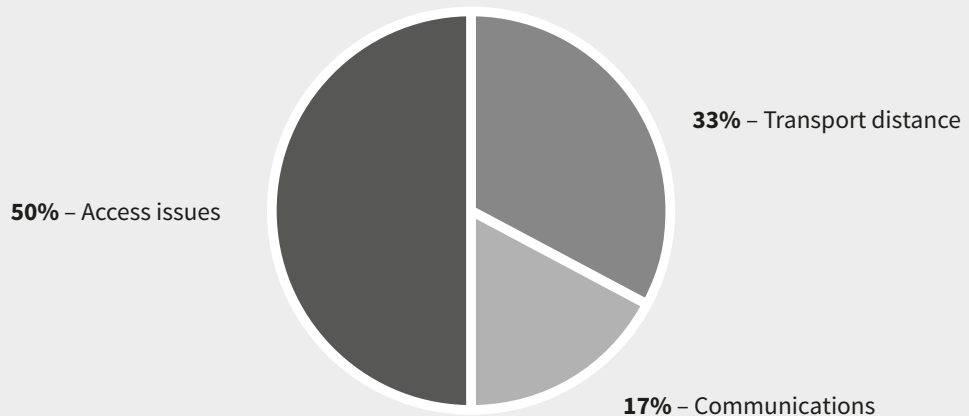
Snap poll

At our #pwdhealth Social Media Forum on 13 November 2017 we invited people with disabilities to nominate the biggest barriers to access in the health system via on online polls on Facebook and twitter. We invited people to respond to set issues but also to nominate their own

This is what people said on Facebook:



Over on twitter a smaller group of people said:



A failure of human rights

Doorstop: We invited Therese Sands the Director of Disabled Peoples Organisations Australia to discuss health, disability and human rights in Australia

All human rights are interdependent and interconnected. It is well understood that the right to health is dependent on the realisation of other human rights, such as the right to housing, education, employment, life, non-discrimination, privacy, information and the right to be free from violence and exploitation. Violating any human right will impact on the right to health and vice versa.

Evidence shows that the physical and mental health of people with disability is much worse than people without disability, and that this situation is not the result of the individual's disability, but the social and economic circumstances that people with disability experience. People with disability are more likely to live in poverty, be unemployed or underemployed, have insecure or inappropriate housing, experience higher rates of violence and exploitation, have lower life expectancies, face daily discrimination and lack access to community and essential services, such as health care. The exclusion and marginalisation of people with disability means that many people with disability can live, work and be educated in segregat-

We face a higher risk of being subjected to non-consensual medical treatment, such as forced sterilisation and contraception, and a range of restrictive or behaviour modification practices

ed environments, with little to no genuine access to community life, services, or decision-making.

There are many barriers to living a healthy life, such as the cost of health care, and the lack of accessible health information and education campaigns about healthy eating, anti-smoking or exercise etc. Within the health system, there is often a lack of accessible medical locations and facilities, and an inappropriate focus on a person's impairment or health condition, confining people with disability to medical 'fixing' or 'managing'. This means that health issues can go undiagnosed or be poorly managed, and preventative health checks, such as breast screening and pap smears, may not be made available.

Autonomy and life choices can be limited for people with disability, with decisions made on behalf of a person, rather than the person being provided with decision-making supports. As a consequence, we face a higher risk of being subjected to non-consensual medical treatment, such as forced sterilisation and contraception, compulsory mental health treatments, and a range of restrictive or behaviour modification practices, such as chemical, physical and mechanical restraints, seclusion and solitary confinement.

Australia does not have a Bill of Rights, so the implementation of international human rights, such as the Convention on the Rights of Persons with Disabilities (CRPD) is largely focused in

national policy frameworks. The National Disability Strategy 2010-2020 (NDS) is the national policy agreed by all Australian governments to implement the CRPD and to report to the UN against progress in achieving human rights for people with disability.

Although the NDIS is an important reform under the NDS, parallel reform in other areas has been limited, with successive implementation plans under the NDS being limited to existing priorities within the remit of the Department of Social Services.

Cross government reform across a full range of responsibilities, including in health, aging, housing, education, employment and justice is critical to ensuring the right to health for people with disability.

Much more needs to be done to commit coordinated investment, concrete actions and accountability mechanisms across all the six NDS policy outcome areas; to establish a high level executive mechanism to drive and leverage reform across government and between jurisdictions; and to actively include representative organisations of people with disability in NDS governance and advisory structures.

Contributing our voices – hearing from women about health

A report written and compiled by Jenni Gough for Women With Disabilities ACT in September 2015 saw 36 women from a broad range of disabilities, ages and socio-economic backgrounds contribute to a consultation about their lives. We review it here:

“When I ended up in the hospital ... [the nurses] said I should go home with my parents because people with a disability shouldn't be in the hospital system, it's wasting their time and taking up beds.”

“I have to go to Sydney quite often because there's no-one in Canberra who can manage what I have and it gets quite expensive going up there all the time.”

“From my perspective and the Deaf community perspective, there's a lot of mental health issues that are around, mostly depression... Because of [lack of] access to communication.”

(Participants in the 2015 WWDACT publication, Contributing Our Voices)

Focus areas identified included health and wellbeing with some key themes as follows:

- **Assumptions about disability:** Participants identified that some health professionals held a range of assumptions about women with disabilities. This included initial assumptions about

the life of the person presenting, the level of disability a person had and also what supports and benefits they were receiving as a result.

- **Access to health and wellbeing services:** Overwhelmingly, participants reported concern about the lack of linkages between the health, disability and aged care sectors. This affected the accountability of services and the quality of care that participants received. Inevitably, this also affected overall health outcomes and the fulfilment of health goals
- **Access to Allied Health Professionals:** Participants identified that five ses-

sions with allied health professionals under the Chronic Disease Management Plan was insufficient. This was identified as a “vicious cycle” which left women accessing only a few of the services that they needed to improve their health, wellbeing and ability to participate in the community. It was also reported that having to return to the doctor to adjust the plan, particularly in regards to referrals, was both time consuming and an additional cost.

- **Access to specialist care:** Participants identified the lack of specialists in Canberra as a barrier to maintaining good health



and wellbeing, as well as the long waiting periods and the expense. Attracting more specialists to the region was considered an important part of filling the gap in service delivery in the ACT. Other considerations included the need for use of e-health or telehealth services to assist in reducing the transport costs.

- *Access to complaints mechanisms:* Participants showed a general lack of awareness and understanding about the existence and role of the ACT Human Rights Commission and the ACT Health Commissioner, as well as being ignorant of alternative forms of mediation and individual advocacy. At the same time, those accessing complaints processes felt that it was an exhausting experience which often led to no action, which left them with feelings of powerlessness.
- *Mental health and wellbeing:* Mental health and wellbe-

ing came up strongly as issues in both the forum and the interviews. This included not being able to access the adequate support and treatment needed to obtain and sustain positive mental health and wellbeing

- *Aged Care for women with disabilities:* Participants raised concern over the lack of information on aged care for women with disabilities, and the accessibility of available information, particularly for women who are Deaf, hearing impaired or have a hearing disability. Participants felt that people who will not have access to the NDIS because of their age will therefore fall into a gap of limited and inaccessible information
- *Skills of support workers:* Concerns were raised over the suitability, skills and lack of training of support worker staff. Several participants felt that they or their family members had been put at risk or blamed

for injuries sustained under the care of a support worker. This was particularly related to unqualified staff delivering support that they were not trained to do, and staff being paid to provide support without adequate knowledge or skills to provide that support. Participants identified that some support workers had arrived at their homes without knowledge of what supports they were there to provide.

- *Information provision:* Lack of information provision and pathways both generally and specifically for women with disabilities in the ACT was identified by participants as an issue. This related to knowing where and how to access certain health services, programs and information, particularly in accessible formats.
- *Waiting times:* Waiting times when admitted to ACT hospital emergency departments was high-

lighted as a concern by some participants. Lack of understanding of the interaction of the emergency condition with the existing disabling condition meant triage was not done appropriately and resulted in poorer health outcomes. This was particularly an issue when combined with a lack of understanding and provision for people with specific health needs and medication regimes.

- *National Disability Insurance Scheme (NDIS):* The NDIS was continually raised as an issue affecting women with disabilities' health and wellbeing. This included issues around maintaining established care arrangements and gaining access to services that were still integrating the NDIS requirements into their service delivery. There was a lack of understanding by both consumers and within services themselves about the NDIS and what would be available under the scheme.

OUT OF REACH... THE STORY OF EXAMINATION BEDS

Back in 2003 a community advocacy group, Access for All Alliance, undertook a survey of all general practices around Australia to identify which provided access to adjustable-height examination beds. The survey showed that of the 3,553 response there were just over 14,000 fixed height examination beds and only 719 adjustable-height examination beds.

An open letter from the Human Rights Commission found that in many situations patients, particularly women with disability do not get a service at all because of the inaccessibility of fixed height examination beds. One woman had not had a Pap smear for 10 years because her doctor could not transfer her onto the fixed height examination bed.

In 2009 then Disability Discrimination Commissioner, Graeme Innes, today called on the Royal College of Gen-

eral Practitioners (RACGP) to ensure equality in access to medical care for people with a disability by making it mandatory for GP surgeries to have height adjustable examination beds.

Commissioner Innes made the call for changes after receiving a report from the Physical Disability Council of NSW (PDCN), which showed that most patients with a physical disability visiting their GP could not get a full examination or screening for possible conditions because they could not get onto the examination table.

Despite ongoing calls for change and regulation many people with disability still report issues around a lack of access to exam beds.

The story continues...

Cultures of misunderstanding

Have you ever heard about the debates between a social and medical model of disability? Isn't disability the same as illness? Does this mean disability rights is anti-medicine? What do these concepts mean and what do they have to say about disability and health?

What is the medical model of disability?

The Medical Model sees the disabled person's impairment or health condition as 'the problem'. The focus is therefore on 'fixing' or 'curing' the individual.

'Disability' is seen 'to be a problem of the individual. From the medical model, a person with disability is in need of being fixed or cured. From this point of view, disability is a tragedy and people with disability are to be pitied. The medical model of disability is all about what a person cannot do and cannot be.

The medical model of disability, or medical model, arose from the biomedical perception of disability. This model links a disability diagnosis to an individual's physical body. The model supposes that this disability may reduce the individual's quality of life and the aim is, with medical intervention, this disability will be diminished or corrected.[1]

The medical model focuses on curing or managing illness or disability. By extension, the medical model supposes a "compassionate" or just society invests resources in health care and related services in an at-

tempt to cure or manage disabilities medically. This is in an aim to expand functionality and/or improve functioning, and to allow disabled persons a more "normal" life. The medical profession's responsibility and potential in this area is seen as central.

What do all the different terms mean?

In 1980, the World Health Organization (WHO) introduced a framework for working with disability, publishing the "International Classification of Impairments, Disabilities and Handicaps." The framework proposed to approach disability by using the terms Impairment, Handicap and Disability.

Impairment = a loss or abnormality of physical bodily structure or function, of logic-psychic origin, or physiological or anatomical origin

Disability = any limitation or function loss deriving from impairment that prevents the performance of an activity in the time lapse considered normal for a human being

Handicap = the disadvantaged condition deriving from impairment or disability limiting a person performing a role considered normal

in respect of age, sex and social and cultural factors

What is the social model of disability?

The social model of disability is a reaction to the dominant medical model of disability which in itself is a functional analysis of the body as machine to be fixed in order to conform with normative values.[1] The social model of disability identifies systemic barriers, negative attitudes and exclusion by society (purposely or inadvertently) that mean society is the main contributory factor in disabling people. While physical, sensory, intellectual, or psychological variations may cause individual functional limitation or impairments, these do not have to lead to disability unless society fails to take account of and include people regardless of their individual differences. The origins of the approach can be traced to the 1960s; the specific term emerged from the United Kingdom in the 1980s.

What about trying to "cure" disability?

Disability Advocates have historically criticized the extent

of spending on impairment prevention policy rather than measures which would build the health and wellbeing of people with disability.

However, as Tom Shakespeare has pointed out, not all impairment prevention policy is bad, and most disabled persons actually are in need of this kind of public health policy.

In fact, the 2011 WHO World Report on Disability gives evidence that disabled persons experience poorer level of health due to a variety of factors, such as inaccessible health care services, risk of developing secondary conditions, higher risk of being exposed to violence, increased rates of health risk behavior ([90],pp. 57–60). This is also recognized in the CRPD in the context of the rights to health.

There prevention is addressed not with relation to primary prevention but to secondary prevention programs to "prevent further disabilities including among children and older persons" ([1], art. 25 (b)).

Article 25 CRPD is an example of framing the right of health of disabled persons in a human rights context. It demands equal access to general and specialized health care services for disabled persons.

Services must be community based and sensitive to freedom rights and to the dignity of disabled persons. Discrimination through provision or denial of health care must be prohibited and prevented. As the WHO Report underlines: *Viewing disability as a human rights issue is not incompatible with prevention of health conditions as long as prevention respects the rights and dignity of people with disabilities, for example in the use of language and imagery...Preventing disability should be regarded as a multidimensional strategy that includes prevention of disabling barriers as well as prevention and treatment of underlying health conditions [90], p. 8).*

What did the Shut Out Report say?

In 2010 the then National People with Disabilities and Carers Council published the report of a widespread consultation with people with disabilities and families undertaken in every capital city in Australia as well as regional centres. It included a scathing assessment of access to healthcare and a call for cross-jurisdictional action

People with disabilities require the same access to health care as all other Australians, yet experience considerable difficulties receiving appropriate care. More than 29 per cent of submissions identified problems with health care. At consultations across the country many people passionately argued that the gaps are so considerable and care so compromised that people with disabilities experience not only a poor quality of life, but also threats to their very lives. These participants strongly argued that poor health care is contributing to a reduced life expectancy for people with disabilities.

Submissions argued that many in the health and allied health sector receive very little training regarding disability and therefore have little understanding of the health needs of people with disabilities. More disturbingly, some

argued that myths and misconceptions regarding disability are affecting clinical decisions and compromising quality of care.

There's a lot of 'she's in a wheelchair, take an aspirin and go home'.

Health professionals who were considered poorly trained to work with people with disabilities included doctors, nurses, specialists, pharmacists, community health care workers, and allied health professionals such as audiologists.

They need clear signage, awareness and education for people in the hospital system for deaf people, especially when you are sick and unable to convey your needs.

Submissions argued that despite their training, health professionals hold the same beliefs and misconceptions about disability as the rest

of the community. Ironically, because of their training they are often less likely to acknowledge this. As one respondent noted,

Those GPs who have myths about disability and sexuality may refuse to give women with a disability a pap smear.

One submission noted that there appears to be little awareness of the mental health needs of people with intellectual disabilities, particularly as they age. This was seen as a pressing issue for future planning.

A number of submissions also noted the lack of availability of early intervention, particularly for children with disabilities. These submissions argued that while early intervention is essential to ensuring children with disabilities grow up to reach their full potential, most children re-

ceive only a few hours of support a week. With such limited availability, the burden falls on parents to source and pay for other kinds of support or carry out the work themselves. While parents clearly expected to be active participants in meeting the additional needs of their children, there was considerable stress, resentment and anger at the perceived transfer of responsibility of early intervention to parents. And as these submissions noted, investment in early intervention not only ensures optimal outcomes but reduces costs associated with support over a lifetime.

Ideally, early intervention should be a one-stop-shop for parents and carers seeking support in the early years of a child's life, this period typically being one of the most stressful in the journey of a family with a disabled member.

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Contact the office on **6286 4223**
or email pwdact@shout.org.au for information
about rates and specifications.

Disability and health

RIGHTS...

WHAT WAS PROMISED

EVERYONE HAS THE RIGHT to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control¹

STATES PARTIES RECOGNIZE that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability²

THE STATES PARTIES TO THE PRESENT Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health³

STATES PARTIES SHALL TAKE ALL appropriate measures to eliminate discrimination against women in the field of health care in order to ensure, on a basis of equality of men and women, access to health care services, including those related to family planning...⁴

STATES PARTIES RECOGNIZE THE RIGHT of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health...⁵

1. All health service providers (including hospitals, general practices, specialist services, allied health, dental health, mental health, population health programs and ambulance services) have the capabilities to meet the needs of people with disability
2. Timely, comprehensive and effective prevention and early intervention health services for people with disability
3. Universal health reforms and initiatives address the needs of people with disability, their families and carers.
4. Factors fundamental to wellbeing and health status such as choice and control, social participation and relationships, to be supported in government policy and program design.⁶

1 Universal Declaration of Human Rights, Adopted and proclaimed by General Assembly resolution 217 A (III) of 10 December 1948 (Australia was one of the founding 8 states that drafted the declaration)

2 UN Convention on the Rights of Persons with Disabilities Article 25, ratified by Australia 18 July 2008

3 International Covenant on Economic, Social and Cultural Rights Article 12

4 Convention on the Elimination of All Forms of Discrimination Against Women Article 12

5 Convention on the Rights of the Child Article 24

6 Policy directions from the National Disability Strategy signed for and on behalf of the Australian Capital Territory by Mr Jon Stanhope MLA, Chief Minister of the Australian Capital Territory, 13 February 2011

...AND REALITY

WHAT'S HAPPENING IN 2017

"In my experience health care systems are **set up for the average white middle class non-disabled person**"

– Karen

"I went **months without getting even basic GP care**"

– Sasha

"Public transport is poor in Canberra leaving those who don't drive with significant barriers. Health services are often planned around car parks with public transport an afterthought. This **means the most vulnerable put off attending to their health** because they are just not well enough to make the often arduous journey to a health service"

– Karen

"It has been frustratingly **difficult to find anyone in Canberra with knowledge and experience** of (my sons) conditions (and Sydney is much the same!). GP & specialist knowledge is extremely poor"

– Marietta

"I use a wheelchair due to Spina Bifida and **have trouble transferring to the exam bed at my Dr's** cause its really high and the winder is broken"

– Tom

"I'm on the DSP and have been for over 11 years now... To see a psychiatrist, it's about \$300 a visit. **I can't afford that** every fortnight/month..."

– Ryan

"I am concerned by the inability of nurses to do personal care for people with high or complex needs. This is made worse because **under NDIS we can't take support workers with us to hospital**"

– Gavin

"Most of the staff (doctors, nursing staff and allied health) were not interested in how her disability changed the support she needed to recover. It was hard to get help setting up meals so she could eat. Many of the **staff seemed resentful of any extra help mum needed because of her disability**. I shudder to think what it's like for people without any outside support"

– Jean

"When my brother (with disability) was transferred to the [major] hospital the following day or two, **it was pure hell...** A lot of (the nurses failed to wash their hands ... and we made a point of noticing if they washed their hands before tending to patients without a disability ... and they did. There was no specialized support. If my mother or myself had not been able to stay at the hospital, sleeping on a camp bed in my brothers room, we dare not think how it would have ended. We feel he wouldn't have survived..."

– Wilma

"I've heard from people with **intellectual disability barriers** include inaccessible info, health staff not listening to you, finding your way to the place & people not explaining things"

– Aine

"... until people with disabilities are employed in the healthcare sector in representative numbers they will continue to be seen as **"other" and an afterthought in planning and decisions**"

– Karen

"I do not have private health cover, it's unaffordable. So I have paid cash for dental care on a needs basis. Everyone is aware of the **appalling waiting lists for public dental care**"

– Peter

(Thanks to PWD ACT members and friends for your stories. Names and some details changed to ensure confidentiality)

***HOW CAN
WE MAKE
A CHANGE?***

Co-ordination not Conflict

There are many things which need to be done to address the poor health outcomes and access to health services which many of us as people with disabilities have experienced all our lives says Robert Altamore, Executive Officer, People With Disabilities ACT.

The observation which I want to add to this discussion is that for far too long, the administrators and policy makers have seen health and disability as conflicting opposites.

The social model of disability which we support requires that this approach, which has failed for so long, be dispensed with.

If people with disabilities are to achieve better health

outcomes and improved access to health services, the health system and the disability system need to be co-ordinated and not pitted against each other in a mutually destructive conflict for supposedly scarce resources.

We see all too often that the health and disability service systems are separated. Policy makers decree, with no rhyme or reason that a particular type of disadvantage is either a health problem or a disability problem.

Similarly people seeking services are told, with no understandable explanation, that their need is either a health need or a disability need. You have to get your help from either the health system or the disability system and if you get help from health, you can't get support from disability. The two systems do not work together. Access to health precludes access to disability or vice versa. You tell the same story of your needs but the health and disability systems place their own spins and interpretations on your need. For your part what is important is that your support need is met. But for the system the big issue is does your need get met and funded from the health buck-

et of money or from the disability services purse.

Unfortunately, the NDIS has sharpened this health/disability divide because COAG Governments see disability as funded by the Commonwealth through the NDIS and health as funded by the States through both State revenues and Federal taxation. Our hope was that the NDIS would facilitate a co-ordinated approach to health and disability but this has not happened.

The way forward starts with us to communicate to the community that for us as people with disabilities, health and disability services must be co-ordinated to produce health outcomes for people with disabilities which give effect to our health related human rights as set out in Article 25 of the UN Convention on the Rights of People With Disabilities. When a person with a disability needs to use a health service the question is not whether the money comes from the health budget or the disability budget, the question is how can the person be best supported to achieve the health outcomes promised to all by Article 25 of CRPD and other National and international Laws.



What the World Organisation says

The World Health Organization has made findings and recommendations on meeting obligations under Article 25 of the UN Convention on the Rights of People with Disability

How are the lives of people with disabilities affected?

People with disabilities are particularly vulnerable to deficiencies in health care services. Depending on the group and setting, persons with disabilities may experience greater vulnerability to secondary conditions, co-morbid conditions, age-related conditions, engaging in health risk behaviors and higher rates of premature death.

related to) a primary health condition associated with disability. For example the prevalence of diabetes in people with schizophrenia is around 15% compared to a rate of 2-3% for the general population.

Age-related conditions

The ageing process for some groups of people with disabilities begins earlier than usual. For example some people with developmental disabilities show signs of premature ageing in their 40s and 50s.

pending on the health condition. However an investigation in the United Kingdom found that people with mental health disorders and intellectual impairments had a lower life expectancy.

Barriers to health care

People with disabilities encounter a range of barriers when they attempt to access health care including the following.

Prohibitive costs

Affordability of health services and transportation are two main reasons why people with disabilities do not receive needed health care in low-income countries – 32-33% of non-disabled people are unable to afford health care compared to 51-53% of people with disabilities.

Limited availability of services

The lack of appropriate services for people with disabilities is a significant barrier to health care. For example, research in Uttar Pradesh and Tamil Nadu states of India found that after the cost, the lack of services in the area was the second most significant barrier to using health facilities.

Physical barriers

Uneven access to buildings (hospitals, health centres), inaccessible medical equipment, poor signage, narrow doorways, internal steps, inadequate bathroom facilities, and inaccessible parking areas create barriers to health care facilities. For example, women with mobility difficulties are often unable to access breast and cervical cancer screening because examination tables are not height-adjustable and mammography equipment only accommodates women who are able to stand.

Inadequate skills and knowledge of health workers

People with disabilities were more than twice as likely to report finding health care provider skills inadequate to meet their needs, four times more likely to report being treated badly and nearly three times more likely to report being denied care.

Addressing barriers to health care

According to WHO, Governments can improve health outcomes for people with disabilities by improving access to quality, affordable health care services, which make the

After the cost, the lack of services in the area was the second most significant barrier to using health facilities

Secondary conditions

Secondary conditions occur in addition to (and are related to) a primary health condition, and are both predictable and therefore preventable. Examples include pressure ulcers, urinary tract infections, osteoporosis and pain.

Co-morbid conditions

Co-morbid conditions occur in addition to (and are un-

Engaging in health risk behaviours

Some studies have indicated that people with disabilities have higher rates of risky behaviours such as smoking, poor diet and physical inactivity.

Higher rates of premature death

Mortality rates for people with disabilities vary de-

best use of available resources. As several factors interact to inhibit access to health care, reforms in all the interacting components of the health care system are required.

Policy and legislation

Assess existing policies and services, identify priorities to reduce health inequalities and plan improvements for access and inclusion. Make changes to comply with the CRPD. Establish health care standards related to care of persons with disabilities with enforcement mechanisms.

Financing

Where private health insurance dominates health care financing, ensure that people with disabilities are covered and consider measures to make the premiums affordable. Ensure that people with disabilities benefit equally from public health care programmes. Use financial incentives to encourage health-

care providers to make services accessible and provide comprehensive assessments, treatment, and follow-ups. Consider options for reducing or removing out-of-pocket payments for people with disabilities who do not have other means of financing health care services.

Service delivery

Provide a broad range of modifications and adjustments (reasonable accommodation) to facilitate access to health care services. For example changing the physical layout of clinics to provide access for people with mobility difficulties or communicating health information in accessible formats such as Braille. Empower people with disabilities to maximize their health by providing information, training, and peer support. Promote community-based rehabilitation (CBR) to facilitate access for disabled people to existing ser-

vices. Identify groups that require alternative service delivery models, for example, targeted services or care co-ordination to improve access to health care.

Human resources

Integrate disability education into undergraduate and continuing education for all health-care professionals. Train community work-

ers so that they can play a role in preventive health care services. Provide evidence-based guidelines for assessment and treatment.

Data and research

Include people with disabilities in health care surveillance. Conduct more research on the needs, barriers, and health outcomes for people with disabilities.

SHUT OUT REPORT SOLUTIONS

Most proposed solutions focused on the need for greater funding of health care for people with disabilities to ensure all their health needs are met, including expansion of the health care card system to improve access and affordability and increased subsidies for essential medications.

Most submissions also advocated for improved training of health and allied health professionals.

Submissions also called for greater funding of early intervention for children with disabilities, and more extensive research into effective methods and practices.





Supported Decision Making in Healthcare: Part of the change

Everyone has the right to make decisions about their own health. Further to the UNCRPD articulation of rights the National Disability Forum was held by the Australian Human Rights Commission in 2014.

A need was reported for “increased access and support for persons with disabilities, including access to information, services and support in decision making” at that time.

In 2016, in a report by the QLD Public advocate, Jodie Griffiths-Cook, it was noted, “risk factors and vulnerabilities for people with disabilities are often poorly understood, even among health professionals”.

Coming to the end of 2017, people with disability continue to report limits on active participation in their health care decisions sometimes resulting in informal or formal substitute decision making.

On occasion this reflects assumptions about ability, misunderstanding about rights or limited resources for offering the support required.

In response, the project team at ADACAS has designed an action research project called Respect Know Act (RKA) to explore how supported decision making can be implemented as a tool to enable better access to health services in the ACT.

RKA is funded by an ILC jurisdictional grant to build on the work in supported decision making already done through ADACAS. It aims to encourage Respecting rights, Knowing how to enable rights and taking Action to support rights for PWD to access health services.

Supported decision making rests on the understanding that decision making capacity is decision specific, time specific and dependent

on the support we receive. We aim to model supported decision making as an access tool as necessary as a ramp, hearing loop or interpreter for those with impairment to decision making ability.

We acknowledge impairment to decision making ability can exist for all of us but for those with intellectual disability, brain injury, dementia or illness that affects cognition or mental health it can prove a barrier to exercising many rights.

We recognise a role for us all in supported decision making and seek advice from the community about experiences in health care interactions. We are working with PWD, ACTOSS, the NDIA, Public Guardian and Trustee, ACT Health, Capital Health Network, Human Rights Commission, Public Advocate, Privacy Commissioner, Health Care Consumers Assoc, Men-

tal Health Community Coalition, Mental Health Community Network and others.

We want to hear and learn from those experiences.

We want to work with those confronting health care decisions who might be interested in trialling SDM as a tool, carers and families, support staff and health care professionals.

We would like to build capacity in a collaborative way to address the issues identified and be part of the change.

Our vision is for decision support to be available when and where it is needed to progress equitable access to health care.

*Helen Connolly
and Isabella Toole*

*RKA Project, ADACAS
02 6242 5060*

supportmydecisions@adacas.org.au

Enough to make you sick?

Put me in the hospital for nerves
 And then they had to commit me
 You told them all I was crazy
 They cut off my legs now I'm an amputee, goddamn you
 I'm not sick but I'm not well
 And I'm so hot cause I'm in hell

– Lyrics from the 1997 grunge song by Lit

In this edition of *The Canberra Disability Review* we shine a light on how the health system is not meeting human rights, expectations and community standards for people with disability.

Disability doesn't have to be experienced as a sickness, but an awful lot of us don't feel well. Instead, as the song goes, some of us feel like we're in hell.

People told us that their daily interactions with the health system were years away from article 25 of the UN Convention on the Rights of People with Disability as well as the actions agreed by the ACT when it signed the National Disability Strategy.

Last months #pwdhealth social media forum heard that people felt that hospitals were dangerous places where supports and equipment melted away and some nursing staff seemed to make assumptions that disabled lives were not worth living.

As Wilma puts in "If my mother or myself had not been able to stay at the hospital, sleeping on a camp bed in my brothers room, we dare not think how it would have ended. We feel he wouldn't have survived..."

Tom, a wheelchair user with Spina Bifida, told us he has trouble transferring to a GP exam bed. Peter was 147th in line for a diagnosis which affected his support access. Jean said no one understood her mums disability and gave her unsafe equipment. Gavin said he couldn't take NDIS supports into a hospital. And on it goes.

For everyone health takes unwelcome twists and turns. A diagnosis at the cardiologist or the oncologist can transform our lives in an instant.

Yet most Canberrans strive for *some* control by maintaining our general health, diet, fitness and an age appropriate prevention regime. We try to impose order on the chaos of our ageing bodies even if that is ultimately in vain.

But people with disabilities tell us they can't access a yearly check-up; see hospitals as a nightmare; can't afford dental maintenance; and that the social infrastructure and services needed to maintain general health are caught up in a maze of transport, communication, digital and physical barriers. Some services

aren't in Canberra and when they are travel is difficult.

An underpinning is affordability – the chronic low incomes of people with disability locked out of the labour market compounded by poor general health and spiralling costs. Even if you can afford health insurance, it covers less and less.

the last edition. It seems too many of us are playing "Medicopoly" and losing.

Evidence across time is compelling. In 2010 the Shut Out report was scathing about healthcare with a call for cross-jurisdictional action. Women With Disabilities ACT in 2015 highlighted flawed assumptions;

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Some of us lose control due to decisions being taken away – often due to a health event. Too often this is the experience of people with intellectual, cognitive or psychosocial disability.

We *literally* don't know what's around the corner and for that reason this edition revisits the Choice and Control Game published in

a lack of access to health and wellbeing services; issues accessing specialists care and allied health professionals; inadequate supports to maintain mental health and wellbeing; issues at the aged care interface; challenges with the skills of support workers; poor information access; waiting times and interactions with NDIS.

Work by the Australian Institute of Health and Welfare in 2015 found people experience poor access to dental and GP services, are more likely to experience diabetes, heart disease and mental illness as well as being more likely to attempt suicide.

More recently a new study in NSW finds more deaths amongst people with intellectual disability including significant signs of overshadowing. After recoding deaths previously attributed to disability, 38% of deaths amongst people with intel-

lectual disability were potentially avoidable. The Gallop Report is a reminder that this has also happened here.

An obvious question is why? And when are we going to get on and fix it?

The irony is we should be premium health “customers”. GP clinics, dentists and hospitals should be falling over themselves to meet the disability standards and actively seek to engage disabled people as partners in delivery and design of health infrastructure and services.

One answer is to consider health as part of the same market failure that sees poor taxi services when we are high users; low take up of universal design in an ageing population; and a refusal by the tourism industry to step up to access despite ageing disabled grey nomads wanting service.

When the writer of Taking Me Seriously (page 7) decided to write his piece in Comic Sans font he made an effective point that no-one took his complaints about a lack of care and responsiveness in

the health system seriously.

The same might equally be said for much said in this area – we might as well *all* start writing in comic sans.

As with the NDIS we need to move from passive recipients of care to those driving change within a human right framework and we invite you to consider some prescriptions for the health system on the back page.

But above all it's time health access and human rights of people with disabilities moved from prescription to action.

ARE YOU A PERSON WITH A DISABILITY OR A CARER?

We want to hear YOUR experiences of healthcare in Canberra.

ACTCOSS is looking to identify a mix of people with disability and carers willing to share their experiences as users or potential users of preventative, primary and/or tertiary healthcare in Canberra.

The project is part of work under the National Disability Strategy to improve access to healthcare for people with disability and is being supported with funding from the Office for Disability in the ACT Government.

If selected, you may be asked to provide feedback about your experiences via a personal interview (1-2 hours) or a focus group (2-3 hours).

People involved will receive remuneration for their time and expertise. Putting in an expression of interest does not oblige you to take part or mean that you will be selected.

**Interested? Find out more,
contact Craig Wallace via craig.wallace@actcoss.org.au**

**DISABILITY IS NOT
A BARRIER.**



DISCRIMINATION IS.

**DO YOU HAVE A QUESTION OR CONCERN
ABOUT DISABILITY DISCRIMINATION?**

contact us on (02) 6205 2222

or email HRCIntake@act.gov.au



**ACT HUMAN RIGHTS
COMMISSION**

Rx PRESCRIPTION

<p>AUTHORISING PRACTITIONER</p> <p>The ACT Disability Community</p>	<p>PATIENT</p> <p>ACT Health Services, the ACT and Federal Governments along with public, private and allied as well as wellbeing services</p>
<p>AILMENT</p> <p>Chronic access, affordability and cultural issues</p>	<p>DATE</p> <p>Urgent action required</p>

PATIENT INSTRUCTIONS:

- Audit, stocktake and invest in improvements to all public and allied health infrastructure in the ACT to meet **modern standards of accessibility in physical, digital and communications infrastructure**
- Institute **compulsory disability confidence and human rights training** for Doctors, Nurses and Allied health professionals in the ACT using the social model of disability
- Identify **gaps in specialist health services in the ACT and region** and initiate strategies to fill these gaps while providing interim financial and logistical support for people who need to travel
- **Maintain contingency** for mentoring, peer support, self help and other emerging gaps in the NDIS transition
- Provide **financial assistance to low income people with disabilities** to access extended yearly check-ups and dental services
- Undertake work to **identify groups of people with diagnostic disabilities most at risk of poor health outcomes**, especially people with intellectual and cognitive disability and dual disability, and meet their needs with **fit for purpose assistance** across systems needed to retain health and wellbeing
- **Require all wellness and lifestyle services** including gyms, pharmacies, wholistic health providers, dieticians, clinics, dentists and community health centres to meet disability access requirements prior to being given planning approval
- Provide **funding and training in the access and use of communication** boards, facilitated communication, learning of Auslan and easy English within all publicly funded and regulated health settings
- Require **all examination and treatment beds to provide disability access** by the completion of the current National Disability Strategy in 2020
- Support, fund and mandate **continued work on Supported Decision Making at the health interface in the ACT**
- Allow people with disabilities to **take NDIS supports into clinical settings** where these relate to natural supports and disability supports
- **Employ people with disability within the ACT Health system in authorised positions** to enable, communicate and spread cultural change
- **Consult with people with disability and chronic health conditions** about strategies to change culture and practice

Dosage: Generous
Repeat: As long as needed
Contraindications: Patronising medical model of disability
Take with: Human Rights Compliance

