

Let's Talk Health - Disability and Access to Health

ACTCOSS – 2pm, 8 December 2017 (You can watch a video of the event on [Facebook Live](#))

Celebrating International Day of People with Disability

Made possible by I-Day grant from the Office for Disability of the ACT Government

Introduction by Susan Helyar

Opened by Minister for Health and Wellbeing Meegan Fitzharris MLA

Panel chaired by Craig Wallace

Panel participants: Alicia Flack-Kone, Cara Matthews, Dwayne Cranfield, Jan Kruger, Louise Bannister and Simon Viereck.

This ACTCOSS 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.

Playing “[Medicopoly](#)” - the game format was chosen to represent the randomness affecting the health care experiences of people with disability– the loss of control and feeling locked out of basic choices.

Launch of the Canberra Disability Review edition focused on the experiences of people with disabilities accessing health care – this publication is available for download, along with previous Volumes of the Canberra Disability Review, from [this page](#) on the People With Disabilities ACT website.

This edition largely features the direct personal experiences of people with disabilities, with contributions via social media and the disability and health project work.

In conjunction with this event, ACTCOSS has also published a collated data [Snapshot: Disability and access to health services](#).

Barriers to Access/Navigation

Real difficulties in terms of accessing services, which can be complicated by drug and alcohol addictions, mental illness, language barriers, cultural understandings and taboos.

“..how do you find your way around the health system, through translation...if English isn't your first language?”

Experiences of

- patients from Non-English Speaking Backgrounds relying on family members to translate at medical appointments, because some ethnic communities are small and translators are not trusted to keep information private because “everybody knows everybody's business”. e.g. a young boy having to tell his mother she had ovarian cancer.

- services in silos, rather than holistically addressing an individual's problems: "People get stuck and can't get in any door because they have multiple health issues."
- food and nutrition concerns of people with disabilities are not well-known – and not good access to services like dietitians.

Attitudes

Still a long way to go to shift negative attitudes towards disability:

"We're still fighting attitudes and cultural expectations... It's even worse when you get into the medical scenario because specialists have this belief that they're the experts and you have no knowledge of your own body - you've got to do what they say and you have no knowledge of what you're talking about... they're often arrogant, disrespectful".

"It's often not attitudes that people consciously have – it's ignorance."

A lack of understanding:

"a chicken and egg thing... they'll go *"you need to be healthy in order to feel well"* but to be healthy I need to feel well enough in order to do it."

Being told after a brain injury – *"You'll never work again."*

"I had doctors and medicos and lawyers and everyone who basically thought *"Pack up and go home"*."

Lack of patience and extra time or support to accommodate a patient's disability:

Response to needle phobia and panic attack (in the context severe anxiety) - "The nurse looked at me and said *"Well, you're just going to have to get over that"* and walked out and sent me home"

Flippancy in delivering news of possible diseases:

"It's either MS or a tumor on your spine" Said very blasé and matter-of-factly, as if to say *Why would it affect me to have another disability?*

Stigma around having mental illness can affect how seriously other health issues are taken in the patient.

Experiences of:

- people presenting to Emergency with Asthma attack, but if staff see history of mental illness in file: *"Oh, are you sure you're not just having a panic attack?"*
- difficulties with getting good treatment for multiple disabilities and health conditions – e.g. attributing all symptoms to the already diagnosed condition and not taking patient concerns seriously.
- people not receiving good medical care because everything is seen through the lens of their disability: "Instead of seeing a person they see a disability."

Medical Model

Significance of shifting away from "Medical Model" to "Social Model" of disability.

This shift includes reducing preoccupation with health problems or diagnosis, which can stifle dreams of individual and their family. (Encouraging people to have aspirations and follow their dreams is a focus of Jan Kruger's organisation [Imagine More.](#))

It's important for medical professionals to not let disability define a person, and allow new parents, or individuals who have acquired a disability, to hold high expectations for education, employment, contributing to the community etc.

Minister's introduction mentioned the new Territory-wide health services framework - intended to put people at the centre - the patient should be the focus of all their health professionals and not the other way round.

ACT Health is aiming for individualised, wrap-around services that meet patient needs – “no wrong door” approach.

Affordability

Experiences of

- people cannot afford dental work, access yearly check ups, or go to the gym
- people “will go without medications because they can't afford it for that particular fortnight, and that has ongoing repercussions”.

“...people are having to make choices that they shouldn't have to make, about how do I live? What do I need? And am I going to be in pain today because I can't afford that...?” (medication/test/ procedure.)

People are often prescribed a range of medications, including medications that are not on the PBS (Pharmaceutical Benefits Scheme).

Some tests are either very expensive to have done in Canberra or people need to travel to Sydney.

Some dentists will not see people with Down Syndrome, so need to wait longer for appointments.

Rebates may be available for services, but will not provide access for people who do not have the required fee in your account.

“Private Health Insurance seems to be covering less and less...”

Cost of tests can vary according to who prescribes them:

e.g. twice as much if ordered by mobile physiotherapist rather than GP

Infrastructure

Experiences of

- poor infrastructure and
- not being able to take disability supports into health system with them
- having to go interstate to access services
- people have difficulty accessing medical procedures that would make their lives better
- under-resourcing places stress on all health professionals – so under pressure to deal with patients quickly, which often doesn't work for people with disabilities
- inadequate links between different services, especially for counselling and psychologists: “where having to build rapport, and tell your story a million times - because they need to know that information - and it gets to the point where it's actually not therapeutic to say what's happened to you over and over again.”

Choice and Decisions

Experiences of

- communication problems,
- feeling left behind in an increasingly rushed system in hospitals and superclinics
- loss of control
- no time or opportunity to build relationships of understanding and trust

Risk aversion approach – “want to insulate person from trying things or doing anything new”

Failing can still be a learning experience.

The dignity of risk – “the whole concept of people taking risks with their lives because that’s how we grow and change”

Should “allow people to grow and experience the world as they choose to experience it” [and learn through making mistakes].

Control over diet is often something tipping people over into substitute decision making.
(See ADACAS [forum](#) on Supported Decision Making and health care).

In relation to making choices about food and health, need to build people’s knowledge and literacy.

Easy Read resources needed around whole process – shopping, preparing and cooking food.
(See resource: Advocacy for Inclusion [DVD](#) “Pete & Annie’s Dinner Party – Nutrition and Self-advocacy”)

Final reflections:

In a busy system, “people who communicate differently – how can we really take the time to actually understand? Especially if they’re in pain, that might then lead to assumption that the person has challenging behaviour, when actually they’re probably just really trying to tell you something.”

“In the health system, that’s struggling to meet the general population’s needs, let alone the needs of people with disability...at some point, doctors are going to have to start being trained about how to deal with people with disability, how to have those conversations, how to work with them, how to truly engage with people with disability, not just on a surface level...”

“Having people with disability actually working in the health system, in positions of authority to make the change and deliver the training... having people with that depth of understanding actually creating environments where that can grow...”

Quotes from people with Down syndrome:

“I don’t know where I’m in pain, I can’t tell you where it is, but it’s all the time.”

“Talk to me.”

“Who is this person wanting me to lift my shirt? I don’t know you - who are you?”

“I want to be seen as a whole person and not just as my disability... I really don’t think I should be saying that in 2017.”

“We’ve got an opportunity here in Canberra because we have a teaching hospital, to get in at ground level and possibly influence...we need really good disability awareness for doctors.”

“We should acknowledge that there actually a lot of really good people working in the health system.”

Idea of “turning hospitals into welcoming systems – it’s the culture change...so that when someone comes to the door, their first response is “*Welcome, thanks for coming today - let’s see if we can work out what’s happening for you and if we can fix it – and if can’t, we’ll see if we can find someone who can help you.*” And that’s the attitude you start with.”

Wrap Up:

There is good practice, and there are good people doing good work.

Good practice guidance:

- See me as a whole person
- Ensure people get access to translation and interpreting services that are confidential
- Stop diagnostic overshadowing
- Take time understanding people who communicate differently
- Put in some proper workforce training on health needs, engagement methods and disability awareness
- Create settings that are welcoming and problem-solving focused
- Employ people with disabilities in health settings
- Build relationships and ensure mutual understanding
- Have better pain assessment and responses
- Think about both affordability and continuity of service
- Recognise and appreciate good practice where you see it