



Imagining Better

**Reflections on access, choice and control
in ACT health services for
people with disability**

Report of the Appreciative Inquiry Project
supported by the ACT Office for Disability

August 2019

About ACTCOSS

ACTCOSS acknowledges Canberra has been built on the land of the Ngunnawal people. We pay respects to their Elders and recognise the strength and resilience of Aboriginal and Torres Strait Islander peoples. We celebrate Aboriginal and Torres Strait Islander cultures and ongoing contribution to the ACT community.

The ACT Council of Social Service Inc. (ACTCOSS) represents not-for-profit community organisations and advocates for social justice in the ACT.

ACTCOSS is a member of the nationwide COSS network, made up of each of the state and territory Councils and the national body, the Australian Council of Social Service (ACOSS).

ACTCOSS' vision is to live in a fair and equitable community that respects and values diversity, human rights and sustainability and promotes justice, equity, reconciliation and social inclusion.

The membership of the Council includes the majority of community based service providers in the social welfare area, a range of community associations and networks, self-help and consumer groups and interested individuals.

ACTCOSS thanks the members of the Appreciative Inquiry Group and the people with disability and families who provided personal testimony and lived experience about their health experiences.

Contact Details

Phone: 02 6202 7200
Address: Weston Community Hub, 1/6 Gritten St, Weston ACT 2611
Email: actcoss@actcoss.org.au
Web: www.actcoss.org.au
Director: Susan Helyar
Policy Officer: Craig Wallace

August 2019

ISBN 978-1-876632-58-8 (electronic version)

© Copyright ACT Council of Social Service Incorporated

This publication is copyright, apart from use by those agencies for which it has been produced. Non-profit associations and groups have permission to reproduce parts of this publication as long as the original meaning is retained and proper credit is given to the ACT Council of Social Service Inc (ACTCOSS). All other individuals and Agencies seeking to reproduce material from this publication should obtain the permission of the Director of ACTCOSS.

An ACT Government funded initiative.

Initiative of



Table of contents

Acronyms and definitions	4
Introduction.....	5
Findings relevant to policy, service reform and workforce development	7
There is a need for work and investment in this area	7
Poverty is a major barrier to good health for people with disability.....	7
The social model of disability is lacking in medical settings.....	8
Attitudes are making it worse	8
There is a lack of specialist support	9
Knowledge gaps	9
Poor infrastructure contributes to poor health	10
Tangible initiatives are needed to make a difference.....	10
Disability services should not disappear at the clinic door.....	10
Ideas for impact.....	11
What would make the <i>most</i> impact?	12
Focus areas for the health reform agenda	14
Fund, implement and resource an ACT Disability Health Strategy.....	14
Use lived experience to inform service and infrastructure improvement.....	14
Improve infrastructure.....	15
Fund an extended free annual check-up for people with disability.....	15
Encourage centres of excellence	15
Implement a two-way information strategy.....	16
Preventative health care approaches should be consumer tested	16
Purpose	17
Project outcomes and outputs.....	17
1. Stakeholder engagement and resource development	18
2. Dialogue and data collection	19
3. Reflection and problem solving	19
What we heard – focussed consultation	21
Best experiences	21
Individual reflections	22
JANINE – They Just Don’t Get It	22
TOM – I’m not sick, I’m sick of how they treat me.....	23
GARY – Waiting to be answered.....	24
RAY – Just talk to me	26
BRON – I just stopped asking	27
ANNE – Disbelieved and denied	29
JIM – Let’s get this over with	30

Acronyms and definitions

ACT	Australian Capital Territory
ACTCOSS	ACT Council of Social Service Inc.
ADACAS	ACT Disability, Aged and Carer Advocacy Service
AS	Australian Standard
CEDAW	Convention on the Elimination of All Forms of Discrimination Against Women
CRC	Convention on the Rights of the Child
CRPD	Convention on the Rights of People with Disability
disability	Disability is an interaction with manageable social and environmental factors that can either impede or facilitate social participation, including access to health services
DSP	Disability Support Pension
GP	general practitioner
ICESCR	International Covenant on Economic, Social and Cultural Rights
OT	occupational therapy
PHN	Primary Health Network Area
PWD ACT	People With Disabilities ACT
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
NDS	National Disability Strategy
WHO	World Health Organisation

Introduction

This report explores findings of a project to improve access by people with disability to health care in the Australian Capital Territory (ACT). It uses a citizen voice approach based on lived experience, qualitative information and reflections by people with systemic advocacy expertise.

Access to health care is a human right covered by the International Covenant on Economic, Social and Cultural Rights (ICESCR) Article 12; the Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW); the Convention on the Rights of the Child (CRC); and the Convention on the Rights of Persons With Disabilities (CRPD).¹

The World Health Organisation (WHO) recognises health as a human right, which creates a legal obligation on states to ensure access to timely, acceptable, and affordable health care of appropriate quality. It also establishes an obligation to provide the underlying determinants of health, such as safe and potable water, sanitation, food, housing, health-related information and education, and gender equality.²

There is a range of evidence, brought together in the evidence that informed the National Disability Strategy (NDS) and the *Shut Out* report,³ that people with disability experience poor general health and co-morbidity outcomes at a greater rate than the general population, including for reasons unrelated to a core underlying condition. Good health status underpins a decent life and poor health affects all areas of life.

Lack of access to health services can mean people become ill, are unable to participate in and contribute to the community, and are exposed to adverse experiences including restraint and abuse. It can also complicate – and be complicated by – a person’s underlying disability, for instance, through diagnostic overshadowing.

This report report shows that people with disability self-report poor health outcomes arising from a mixture of:

- Economic disadvantage
- Diagnostic overshadowing (where a person’s disability is treated as the problem rather than a person’s presenting medical condition)⁴

1 Australian Human Rights Commission, *Right to health*, Australian Human Rights Commission, nd, viewed 19 July 2018, <<https://www.humanrights.gov.au/right-health>>.

2 World Health Organisation, *Human rights and health*, World Health Organisation, 29 December 2017, viewed 19 July 2018, <<http://www.who.int/news-room/fact-sheets/detail/human-rights-and-health>>.

3 National People with Disabilities and Carers Council, *Shut Out: The Experience of People with Disabilities and their Families in Australia*, Australian Government, 2009, viewed 19 July 2018, <<https://www.dss.gov.au/our-responsibilities/disability-and-carers/publications-articles/policy-research/shut-out-the-experience-of-people-with-disabilities-and-their-families-in-australia>>.

4 Diagnostic overshadowing is the attribution of a person’s symptoms to their mental condition, when such symptoms actually suggest a comorbid condition. The term was first used to describe the underdiagnosis of mental illness in people with intellectual disability. In recent years, the term has also been used when physical illnesses are overlooked in people with mental illness. Read more at: S Jones, L Howard and G Thornicroft, “Diagnostic overshadowing”: worse physical health care for

- Poor attitudes, including a lack of a social model for responding to disability or health within clinical settings
- Inappropriate digital and physical infrastructure leading to access barriers and poor communications
- Service gaps including a lack of tailored services to help manage diagnostic conditions (i.e. to understand, treat and manage the primary and secondary health impacts of different kinds of disabilities).

This report includes extensive extracts from the firsthand feedback we heard across the project. Notes from the group discussions are included in the concluding sections of the report, as well as a ranking of their preferred options for improvements to health services for people with disability in the ACT.

ACTCOSS acknowledges the efforts of the personal witnesses, the Appreciative Inquiry Group and the people with disability and families who shared their stories and health experiences through this project. We also acknowledge partners and allied organisations who contributed to the project scoping and development at various stages including People With Disabilities ACT, the ACT Disability, Aged and Carer Advocacy Service and the Health Care Consumers Association of the ACT.

people with mental illness', *Acta Psychiatrica Scandinavica*, 2008, vol. 118, pp.169-171, <<https://onlinelibrary.wiley.com/doi/pdf/10.1111/j.1600-0447.2008.01211.x>>.

Findings relevant to policy, service reform and workforce development

There is a need for work and investment in this area

“I will end up in full time care years earlier which I will not like.” – Paul

The evidence and the personal witness gathered in this project point to serious, deep, systemic and troubling barriers, blockages and shortfalls in the health care and services being obtained by people with disability. The barriers range from inaccessible places, spaces and equipment/care tools to poor cultural practices. There is a lack of access to preventative care and exposure to critical life-threatening incidents in care settings. These are causing unnecessary pain and suffering, and increasing the risk of early entry into residential care or early death.

Poverty is a major barrier to good health for people with disability

“Many people with mental illness cannot afford to see a private psychiatrist (\$300 is one 1/3 of the DSP, or worse, for those receiving Newstart!) and fall through the cracks, while psychiatrists live comfortable lives.” – Janine

“I have had two occasions where I’ve been unwell and I think they’re going to want me to come back and I think can I budget for that? You reasonably can’t afford to be sick.” – Bron

Nearly all of the participants identified socioeconomic disadvantage as a direct personal barrier to their enjoyment of health care on an equal basis with others. This was experienced in different ways and includes the outright inability to afford certain services and the need to choose service modes which are rushed or truncated, to more subtle barriers such as the inability to afford travel or time off work to maintain health or to access lifestyle services or maintain a healthy diet.

Recent analysis by the Australian Institute of Health and Welfare⁵ provides quantitative evidence to affirm cost barriers identified by the interviewees:

- The ACT Primary Health Network Area (PHN) has the highest percentage (69.3%) of patients with any out-of-pocket costs for Medicare services outside of hospital – the national average is 50%

5 Australian Institute of Health and Welfare, *Healthy Communities: Patients' out-of-pocket spending on Medicare services, 2016-17*, Australian Government, 16 August 2018, <<https://www.myhealthycommunities.gov.au/our-reports/out-of-pocket-spending/august-2018>>.

- The ACT PHN has the highest percentage (63.7%) of patients with out-of-pocket costs per GP attendance – the national average is 33.8%
- The ACT PHN has the highest percentage (43.7%) of patients with out-of-pocket costs per diagnostic imaging service – the national average is 23.5%
- The ACT PHN has the second highest average out-of-pocket cost per patient (\$224) – the national average is \$139.

The social model of disability is lacking in medical settings

“I feel like I can’t win... I have tried to be independent but I have set backs and most of them are in the health system. I’m not sick all the time, but I am sick of how people treat me...” – Tom

The medical model of disability, which assumes that the person is the problem rather than the environment, is dominant in medical settings and is problematic for people with disabilities in these settings. Clinical settings are described as inaccessible, both in built form and culturally. People with disability perceive that there are actually fewer disability supports in hospitals than in their own homes. Hospitals are described by people with disabilities as reluctant to treat them on an equal basis with others, leading to misunderstandings, information gaps and poor clinical outcomes. The medical model contributes to a range of issues identified in this report that are relevant to diagnostic overshadowing.

Attitudes are making it worse

“I had an issue where I believed that I had had an adverse effect from a procedure and just wanted to let them know about it – I wasn’t interested in making a complaint or a case or whatever. But they just went straight into denial and I lost a valued specialist.” – Anne

A lack of understanding of disability and disability competent practices means that some practitioners lack basic skills to interact with people with disability. Sometimes people are ignored or rapport is not built. Other interactions, such as with doctors undertaking Centrelink assessments, are counterproductive, corroding people’s willingness to use and trust other supports that could maintain good health. A lack of knowledge about disability is leading to ineffective or counterproductive health care. People told us time and again that nobody listened to them and interventions were offered without full regard or understanding of a person’s disability nor its interaction with their health and treatment options. Negative attitudes also contribute to a lack of accessible and appropriate infrastructure, equipment and tools at the preventative, primary and tertiary levels.

There is a lack of specialist support

“While in Sydney we initially had access to a service that provided combined Speech Therapy, OT and Physiotherapy alongside a group (family) model which was very positive in terms of linking professionals and families, and in terms of allowing families to learn how to provide treatment by observing the professionals. However, this model was abandoned and the new model removed the opportunity for learning and independence.” – Marcia

People with disability and their families perceive specific gaps in both specialist and wrap-around support from services and practitioners who have a comprehensive and contemporary understanding of their core conditions. This reduces access to health care that could prevent comorbidity arising from conditions experienced concurrently with a disability or are made more likely through the personal or environmental experience of disability. Specialist service gaps mean people need to travel interstate to manage these conditions and/or are simply missing out on diagnostic, preventative, treatment and care services.

There is a need for centres of excellence that are collocated with hospitals to maximise access and convenience to people with disabilities. These centres of excellence would offer contemporary best practice models of care to manage core conditions, reduce unnecessary hospitalisations and length of stay, and understand and prevent comorbidities.

ACTCOSS notes the 2019-20 Budget included \$2.5 million over the next three years to co-design a program with general practitioner (GP) practices to develop better integrated care pathways and improve health outcomes and a \$1.8 million investment over the next four years to support families of paediatric patients to travel interstate to access specialist healthcare.

Knowledge gaps

“My problems in hospital... would never have happened if [the practitioner] had talked to me. All she had to do was say hello, tell me what was going to happen and I would have filled her in.” – Ray

There are gaps in knowledge about critical services and supports experienced by both practitioners and people with disability, their families and carers. People with disabilities, their families and carers lack awareness of low-cost health services and options, such as the nurse walk-in centres. Practitioners lack knowledge about disabilities and non-health system supports which could assist people experiencing those disabilities to better monitor their health status and service access. There is a confusion – a diagnostic overshadowing – which is managing people’s disabilities without due regard and/or sufficient focus on treating their medical conditions.

Poor infrastructure contributes to poor health

“I get the [bowel] testing kit however I don’t use this as a blind person. If you see the kit the objects are quite sharp and you could do some damage if you don’t use them. As a matter of fact I’m getting the message but I’m not able to do anything about it.” – Gary

There is poor and absent physical, digital and communications infrastructure in and around health and wellness settings which is contributing to people with disability missing out on health care; receiving less care than other people; and in some instances actually causing people to become sick who would not otherwise (e.g. preventable falls and accidents). Poor infrastructure around health and wellness settings, such as inaccessible transport, means that people miss out on services that they need and are eligible to use.

Tangible initiatives are needed to make a difference

“...what on earth is the colonoscopy service having an attitude to disability that says – we couldn’t have you in overnight because you’re obese?” – Anne

Tangible, specific initiatives with adequate investments are needed to improve access to health services. People who contributed to this project nominated the following initiatives that would have the most impact: free extended annual check-ups; diagnostic centres of excellence; improved physical, digital and communications infrastructure; competence in the care workforce; awareness of the social model of disability in medical spaces; and addressing training gaps.

Disability services should not disappear at the clinic door

“There are problems with the NDIS and taking your own carers into hospital – the key is I never told them. Disability ACT said as soon as you go into hospital you cease using carers and start using hospital staff. The NDIS is exactly the same...” – Ray

Disability services, whether advocacy, equipment, carer supports or communications assistance, should not disappear at the doors of health and wellness settings. People with disability should be able to confidently access their equipment in a hospital while disability services should avoid the assumption that a health setting will pick up disability supports the moment a person enters that system. The strong experience of witnesses is they don’t.

To address this, a package of work and measures is needed to ensure more supports and cohesion at the NDIS and health interface, including ensuring disability supports continue beyond the clinic door, addressing gaps and allowing people to take more NDIS supports into health care settings. The package could also include resourcing for health system-specific individual and systemic disability advocacy.

Ideas for impact

The Appreciative Inquiry Group comprised of people with disabilities and family members considered a menu of ideas which responded to issues raised by consumers and also included some of their own suggestions for improvements that could be made to policy, services and workforce development.

These improvements were to:

Policy:

- Provide a free once a year extended consultation to all people with disability
- Publish and maintain a list of disability friendly bulk billing clinics in Canberra
- 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
- 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
- Ensure that all screening kits and preventative health information and devices are reviewed by people with disabilities prior to being issued
- Allow people with disabilities to take more NDIS supports into clinical settings
- Provide plain-English medical and systems documentation
- Appoint a Deputy Health Ombudsman focussed on the NDIS.

Workforce development:

- Institute disability confidence and human rights training for doctors, nurses and allied health professionals in the ACT using the social model of disability delivered by people with a disability
- Provide focussed training and disability lived experience feedback to doctors doing Centrelink assessments
- 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.

Services:

- Support wellness and lifestyle services including gyms, pharmacies, holistic health providers, dieticians, clinics, dentists and community health centres to meet disability access requirements
- Require examination and treatment beds to provide disability access by the completion of the current National Disability Strategy in 2020
- Employ people with disability within the ACT health system in authorised positions to enable, communicate and spread cultural change
- Establish a specialist centre/centre of excellence for specific conditions and complex care needs, based on some US hospitals that have developed expertise in specific disability care. This would be a place you could visit once a year that has deep knowledge of your diagnostic condition and wrap-around supports to look at your disability and other conditions, which may travel with your disability or occur with increased prevalence because of your disability⁶
- Reduce waiting times for the pain and sleep clinics
- Strengthen disability advocacy with a health lens
- Maintain and strengthen alternatives that cater to people with barriers to accessing digital devices and technology (i.e. people who cannot access online health information or who need to communicate by phone to access health information).

What would make the *most* impact?

The Appreciative Inquiry Group was invited to collectively rank and prioritise these priorities using an online deliberative polling app called Poll Everywhere.

The highest ranked outcomes are listed below:

- Policy: addressing cost issues through dedicated low-cost services, including a once a year free extended consultation, and information access; and auditing and improving health infrastructure to make it more fit for purpose for people with disability
- Workforce development: providing a range of training, disability confidence and skills development work lead by people with disability to a range of people including practitioners, health and wellness services outside the formal system and, specifically, to doctors doing Centrelink assessments
- Services: establishing specialist centres of excellence for diagnostic disabilities with wrapped around services.

There were also a number of recommendations to ensure more supports and cohesion at the NDIS and health interface, including addressing gaps and allowing people to take more NDIS supports into health care settings.

⁶ An example would be Shriners Hospital in the US, which has a [designated spina bifida clinic](#).

Which ideas might have the most impact to address the issues we've discussed today?

28th June 2018

Provide a once a year free consultation to people with disability

Specialist centres of excellence

Publish/maintain a list of disability friendly bulk billing clinics

Examination/treatment beds to provide disability access by completion of NDIS, 2020

Support wellness and lifestyle services ... to meet disability access requirements

Training/disability lived experience' feedback to doctors doing Centrelink assessments

Audit, stocktake/invest in improvements to all health infrastructure

Disability confidence/human rights training for Doctors, Nurses, Allied health professionals

Contingency for mentoring, peer support, self help/other gaps in the NDIS transition

Financial assistance to low income PWD to access extended yearly check-ups and dental services

Interim financial and logistical support for people who need to travel

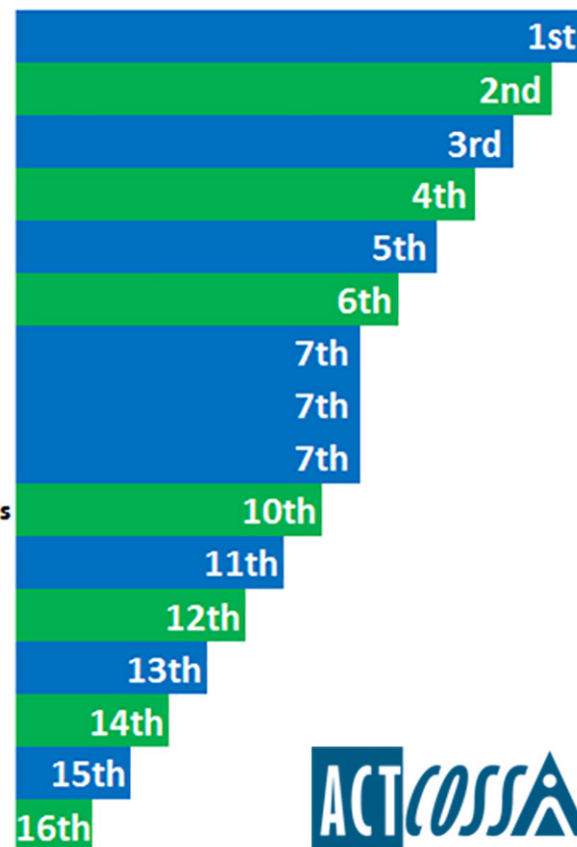
Employ PWD within the health system it to enable, communicate and spread cultural change

Allow people with disabilities to take more NDIS supports into clinical settings

Funding/training in the access/use of communication boards within all public health settings

Disability advocate with health lens

All screening kits/preventative health info and devices reviewed by PWD prior to being issued



Focus areas for the health reform agenda

Based on the themes and ideas drawn out through the appreciative inquiry process, ACTCOSS has drawn together a number of issues requiring policy work and potential investments arising from this project which warrant consideration in the broader health reform agenda.

Fund, implement and resource an ACT Disability Health Strategy

The focus areas in this report and the infrastructure, workforce and specialist service gaps could be incorporated into the Health System Reform underway under the banner of a disability health strategy focussed on:

- Addressing cost issues through dedicated low-cost services, including a once a year free extended consultation, and information access
- Establishing specialist centres of excellence for diagnostic disabilities with wrap around services
- Auditing and improving health infrastructure to make it more fit for purpose for people with disability
- Improving workforce readiness by providing training, disability confidence and skills development work led by people with disability to the health workforce including practitioners, health and wellness services outside the formal system and, specifically, to doctors doing Centrelink assessments⁷
- Strengthening the employment of people with disability in ACT Health and resourcing people with disability to develop and deliver training to doctors, nurses, ancillary staff and other wellness practitioners in the social model of disability
- Training to increase knowledge about diagnostic overshadowing and reduce its incidence.

Use lived experience to inform service and infrastructure improvement

This project has only touched the surface of a rich, detailed and too often harrowing lived experience of the ACT health system by people with disability.

Work to improve the health experience of people with disability should be integrated into the health infrastructure and service improvement agenda. Health policy should continue to be informed by direct, personal lived experience of people with disability. Opportunities should be developed to

⁷ This could include use of the “Medicopoly” device developed by ACTCOSS and PWD ACT as an awareness raising and service development tool.

expose practitioners to this feedback in a way that builds understanding of disability in a rights context. People with disability should be involved in the delivery, construction and design of new health infrastructure.

Improve infrastructure

Targeted investments should be made to improve the physical, digital and communications infrastructure of health care in Canberra:

- All GP clinics need to have height adjustable exam beds. It will be important to do detailed mapping of how many GP practices will need to invest in new infrastructure. This would inform timeframes within which all GPs would implement this
- Every person with a disability in this city should be within reach of a fitness centre that is able to accommodate people with a range of physical and/or sensory disabilities
- Hospital access should be improved to the Standards Australia AS 1428.1 or above in all of the public and private hospitals in the city
- The new University of Canberra Hospital should be a showcase of completely accessible design, equipment, care tools and disability competent practice⁸
- Some early quick wins should be considered, such as ensuring that every ward and every community health centre in Canberra has a communication board and knows how to use it.

Fund an extended free annual check-up for people with disability

People with disability in Canberra on low incomes and income support should be able to access an extended free annual health assessment focussed on prevention, early intervention and mitigating the impacts of comorbidities.

Encourage centres of excellence

Local and national work should be undertaken to establish centres of excellence for different diagnostic disabilities.⁹ The centres of excellence would provide wrapped around expertise and advice for people as they manage their disabilities across their lives (not just as children). They should be located in regions and cities and people with disabilities should be provided with

8 ACTCOSS notes that the hospital has opened since the project began with good feedback from consumers and organisations about its access and design for patients and visitors.

9 i.e. different types of disabilities – such as Down syndrome, spina bifida and other groups of conditions with similar presentations and attending issues.

assistance to travel to and to access them. Provision of mobile centres of excellence should be considered.

For instance, every person with Down syndrome should reasonably be able to sit down once a year with a specialist team that knows their disability, the common health issues associated with this disability, and the most effective interventions and self-management advice – if that is what they wish.

Implement a two-way information strategy

Every person with a disability should have access to an information resource that lists all of the bulk billing clinics in the city, ancillary services such as the walk-in centres, and provides joined up contacts for health and disability advocacy as well as illness-specific self-help services and resources. Every doctor and health practitioner should have electronic and hard copy information about ways to support, interact with and provide accommodations to people with disability. This should include information on non-health-based disability supports and service.

Preventative health care approaches should be consumer tested

New preventative health care information and kit, such as the bowel screening kits for over-50s, should be reviewed and critiqued at draft stage by a panel of people with physical, sensory and cognitive disability who might be expected to access it.

Purpose

In 2017, ACTCOSS was asked by the ACT Government's Office for Disability to help identify ways to ensure the ACT health system becomes more responsive to people with disability who need to use it. The project is part of the ACT's response to the National Disability Strategy.

The project has asked:

- What is happening to different groups of Canberrans with disability as they attempt to access health services and build good health?
- What are the barriers, attitudes and issues which effect access and how do these stack against key frameworks for rights and inclusion such as CRPD?
- What do people perceive, and in particular, are there people with disability who are under-represented in conversations about improving access to health care and what do they have to say? How do their experiences match received views?
- What changes in attitudes, practice or resourcing would facilitate them to make use of preventative and primary health?
- When at-risk groups have gained access, what has enabled this? What do people believe might improve access?

The project gathered evidence about barriers and outcomes for people with disability in the preventative and primary health care system.

The methodology for the project evolved as we gained an understanding of parallel work being undertaken by groups like ADACAS and People With Disabilities ACT, as well as an understanding of the systemic barriers and issues facing participants.

In the end, we used a mixture of evidence, community engagement and depth interviews followed by an appreciative inquiry element with a group of people unconnected to advocacy. This enabled us to get rich feedback from knowledgeable people and sources and then to provide a layer of testing with lived experience from people not in contact with formal services to add a fresh dimension to our understanding. Appreciative inquiry is a model that seeks to engage stakeholders in self-determined change by seeking out what is good and working well, in addition to critical feedback. The appreciative inquiry groups questions were framed to enable us to reach positive ideas for change and also to draw out "best experiences" which are featured at the conclusion of this report.

Project outcomes and outputs

Drawing on lived experience, we sought to understand what can be learned about barriers to, and enablers of, better access for people with disabilities to

health care in the ACT and region – improving outcomes for them and reducing unnecessary costs in service systems.

The three phases of the work included:

1. Stakeholder engagement and resource development

Project inception workshop

Identified a range of issues and considerations in disability and health and defined the scope of the project.

A health focussed edition of the Canberra Disability Review

This was produced in partnership with PWD ACT to help start a community conversation and catalyse engagement from the disability rights community in the ACT. This edition of the *Canberra Disability Review* is at Attachment A and online.¹⁰

Developing an infographic illustrating choice and control issues relevant to health status and access to care

The “Medicopoly” infographic is at Attachment B. Presentation of issues within a game of chance illustrated the unplanned and random way that health events can occur, as well as the lack of choice and control that people with disability experience in their health histories – including the ability to foresee and manage events that other people would take for granted. Key performance indicators against the United Nations Convention on the Rights of People with Disability (CRPD), especially Article 25, provides a way of interpreting health within a human rights framework and illuminated the gap between social and medical models of disability.

Hosting an interactive panel

An interactive panel of people with disability used this game-based methodology to inform practitioners and policy makers about what they can do to better serve people with disability. The session, held in conjunction with the United Nations International Day of People with Disability, invited preventative health providers (everyone from pharmacists to dentists) to hear directly from a panel of people with disabilities about the barriers that they experience accessing primary, natural and preventative health care. It used the “Medicopoly” game to spark that discussion, highlight a range of issues and prompt a lively, interactive and non-threatening sharing of perspectives.

ACTCOSS captured the event via Facebook live¹¹ and notes from the interactive panel appear at Attachment C.

10 People With Disabilities ACT, *Canberra Disability Review*, People With Disabilities ACT, 2017, vol. 4, <<https://www.pwdact.org.au/index.php/articles>>.

11 ACTCOSS, *Let's Talk Health – ACTCOSS Forum 8 Dec 2017*, Facebook Live video, ACTCOSS, 8 December 2017, <<https://www.facebook.com/actcoss/videos/954990897982795/>>.

2. Dialogue and data collection

Disability and health data factsheet

ACTCOSS produced a data factsheet on disability and access to health services.

This factsheet notes that disability is not the inevitable result of an individual's impairment or health. It presented data which demonstrated that people with disability use health services more frequently but also face greater barriers to accessing these services. The data highlighted a need to address barriers around affordability, accessibility, waiting times, transport, discrimination and coordination among health services in the ACT. The factsheet can be found online¹² and at Attachment D.

In-depth interviews and curated stories

ACTCOSS conducted a series of in-depth interviews and story curations with seven people with disability. The interviews and stories covered people with different diagnostic disabilities and experiences of various parts of the health system. These were mostly people with established connections and/or contacts with advocacy services involved in disability or health or chronic illness organisations.

Stories were solicited by open invitation and directly from people with different diagnostic disabilities. This includes, but is not limited to, people with psychosocial disabilities and chronic illness, sensory disability, intellectual and cognitive disability and physical disability. Some people spoke to dual disabilities and disability with chronic illness.

People were invited to submit stories in their own words or to be interviewed and have their stories recorded and written up.

The seven stories are accounts from real people, but some names and locations have been changed and other details omitted to respect people's privacy.

Lightly curated stories from these interviews were provided in the evidence pack to the panel and we have included some highlights and quotes in this report.

3. Reflection and problem solving

Appreciative Inquiry Group

An appreciative inquiry focus group on health access for Canberra people with disability was held on Thursday 28 June 2018. This brought together,

¹² ACTCOSS, *Factsheet: Disability and access to health services*, ACTCOSS, December 2017, <<https://www.actcoss.org.au/publications/advocacy-publications/factsheet-disability-and-access-health-services>>.

considered and articulated recommendations for change arising out of all the project elements.

This group was drawn from an open expression of interest process to identify people who do not have significant existing contact with disability advocacy and health systems but have deep contact with health care and disability intersections in their own lives.

The session included people with disability and family members – including people with cognitive disability. There were five participants and one participant who could not attend in person but provided written feedback.

This stage was designed to provide a reality check and a fresh, lateral perspective on the information brought forward by thought leaders in the discussion paper, the interactive panel and the review.

It provided an opportunity for everyday Canberrans to reflect on the extensive feedback gathered across the project and to identify positive approaches for the future.

An evidence handbook was collated that provided background information for focus group discussions.

The group was invited to reflect on the stories of Canberra people with three questions:

- Which stories most resemble your own or strike a chord with your experiences or knowledge?
- Were you surprised or did you find differences between these stories and your own experiences?
- Having regard to both the stories and your own experiences, what kinds of responses might make a positive difference to the choice, control and access experienced by people with disability in maintaining health?

The focus group was facilitated by Max Hardy who is a consultant in achieving results through different kinds of collaborative process. Max worked on two internationally recognised deliberative processes in the disability area – the Disability ACT Challenge 2014 Citizens Jury process and the Citizens Jury into the National Disability Insurance Scheme convened in early 2014.

What we heard – focussed consultation

During late 2017 and early 2018, we talked to people with disabilities about their experiences with accessing preventative, primary and tertiary health care in the ACT.

Most but not all of the people we spoke to had knowledge or experience of disability or health advocacy and specialist services systems.

As far as possible, we have left the stories in people's own words or speaking styles to retain the project focus on citizen voice and speaking truth to power.

We asked people to tell us about the times they went to hospital or accessed primary health, to talk about the experiences that have defined their opinions about the quality of health care in the ACT, to talk about positive experiences, to discuss the issues or options they exercised to maintain health, and lastly, what they would do if they were in a position to influence change.

We then invited the Appreciative Inquiry Group to reflect on each of the stories in turn – what did they hear in the stories? What was held in common with their own experiences and lives, and what was different?

Best experiences

Members of the group shared some of their best experiences of the health system and the features, attitudes and ideas which made for good experiences:

- Instances where health professionals showed an ability to see a person with disability as a whole person
- Instances where health professionals gained an understanding of people's experience and empathy
- Intensive care specialists with the ability to communicate effectively and appropriately – good bedside manner, respectful, calm, non-technical language, no jargon, not rushed. For one person the best experience was when specialist took their time, showed care and was caring
- Instances where plain English was used so that people could understand complex information
- Awareness of patient's history that enables proper preparation and treatment
- Valuing and acting on patient feedback
- For one person the most crucial intervention had come from a person's own mother who identified both the problem and a means of solving it
- Finding people able to tell you what your options are, e.g. discovering that it was possible to see any specialist in a timely manner and at a low/no cost (e.g. bulk billed) – knowing the flexibility that exists within the system

- Examples where people had found good knowledge about what questions to ask, especially to overcome the lack of understanding of bulk billing options and entitlements.

The group wished to convey two fundamental messages for the ACT Government in creating best experiences: Respect. Listen.

Individual reflections

JANINE – They Just Don't Get It

“Many people with mental illness cannot afford to see a private psychiatrist (\$300 is one 1/3 of the DSP, or worse, for those receiving Newstart!) and fall through the cracks, while psychiatrists live comfortable lives.” — Janine

Janine mentions the cost of medications and private psychiatrists. She uses a lot of physiotherapy and talks about the challenges she has had locating suitable treatment as well as find a physio that matches her need for quiet during the sessions.

She says there is a lack of suitable psychiatrists in Canberra and that the rate of attrition is increasing. Janine also speaks about the impact that the cost of transport has on her health care.

Asked what might make a difference, Janine said:

“My suggestions for improvement to the ACT health system, in particular the mental health system, is to invite and draw competent psychiatrists to the ACT and make a great leap forward, by changing the payment system so that they bulk-bill their patients! Many people with mental illness cannot afford to see a private psychiatrist (\$300 is one 1/3 of the DSP, or worse, for those receiving Newstart!) and fall through the cracks, while psychiatrists live comfortable lives! Staffing and increasing the number of mental health professionals in the public sector is also something sorely needed by the system. An adolescent mental health inpatient facility is mandatory and the ACT Health System should provide one pronto, as it has long been required!

“I also think that the ACT and Federal Governments, should improve the community aspect of mental health care. Not all people with mental illness need to go to hospital. They can have their chronic illnesses treated in the community. This means that more funding needs to swing that way instead of into hospitals. By far the numbers of people who could be treated in the community outweigh those who have acute illness and need to be hospitalised.”

What the Appreciative Inquiry Group heard in Janine's story ▼

- The cost of psychiatry is prohibitive, even when in a private health fund
- Experience of cost of living pressures while living on the DSP
- There is a lack of information sharing when seeing multiple doctors and therapists
- Reliance on public transport means that travel time to appointments is significant and challenging
- It can take a long time to find an affordable psychiatrist
- Bulk billing is hugely important in terms of affordability
- Individuals need to be in the driver's seat of their condition
- There is a risk that providing honest answers to health professionals' questions can lead to penalties, which means that people censor themselves.

TOM – I'm not sick, I'm sick of how they treat me

"I feel like I can't win... I have tried to be independent but I have set backs and most of them are in the health system. I'm not sick all the time, but I am sick of how people treat me ..." – Tom

For some people with disability, it's not about being sick all of the time, it's about being treated with a lack of sensitivity when you're unwell, facing assumptions with friends, families and co-workers, dealing with anxiety and not getting the social support you need to disclose and manage the combination of disability and an illness.

Tom has spina bifida and uses a wheelchair. He told us about the lack of access to doctors' exam rooms and also to hospitals. He says that his doctor doesn't have an exam table that is adjustable.

He writes about being anxious in hospital and one time where they didn't know how to support him having an X-ray, and also provided him with medication that lead to a bowel accident on the way home.

He talks about the compounding pressures of being on a low income, feeling lonely and under pressure at work and isolated in Canberra, and not being able to access activities which help him feel fit and well.

Tom speaks to how many issues can accumulate to reduce your overall wellbeing.

Asked what might make a difference, Tom said:

“If I could change one thing it would be to make doctors more aware of the extra consequences of being disabled. You can’t just give me a dose of laxative and expect me to get home without ‘consequences’. I’d also make access better and training. I wish that people in hospitals understood how you can be really frightened there. I’d like the people I work with to understand that actually sometimes I’m not ok. I feel better for telling this to someone who is the same and I hope it gets something changed. I’m not sick all the time, but I am sick of how everyone treats me.

“I also wish I could do more of the things I’m good at – like wheelchair sport but the [team] can’t make the numbers we did in [the other state] and I miss it. I’d also like a gym that’s not upstairs in [my suburb]. I’m strong and used of keeping fit and setting goals and I feel better mentally when I do that but the opportunities are limited.”

What the Appreciative Inquiry Group heard in Tom’s story ▼

- Highlights a failure to address the most basic access issues for people with disability in relation to the lack of accessibility of basic medical equipment, e.g. an adjustable examination table
- Lack of accessibility points to neglect
- Lack of sleep is a significant issue as it is central to living and coping
- Experiences of work pressures and bullying in the workplace in response to disability and health issues
- For specialists it can seem as though “because they are trained to be hammers so all they can see/treat are nails”.

GARY – Waiting to be answered

“I get the (bowel) testing kit however I don’t use this as a blind person. ...the objects are quite sharp and you could do some damage. I’m getting the message but I’m not able to do anything about it.” – Gary

People with sensory disability can face multiple barriers to access including online platforms which are inaccessible and physical kit which is inappropriate. People with disabilities can also be family carers and encounter barriers in supporting a significant other.

Gary is blind and speaks about the problems he has had accessing rehab for his partner who has had an amputation. He talks about a rushed and inadequate rehab experience and problems with residential rehab.

He told us about the challenges of accessing the phone services for health advice. He also talks about issues with assuming older people can access information online and the issues people who aren't obviously blind can have accessing pharmacy.

He mentions the bowel screening kit not being fit for purpose for blind people and a lack of preventative health. Gary also has a lot to say about the difficulties blind people can have in accessing healthy food and fitness as well as podiatry, moving in and out of the NDIS.

Asked what might make a difference, Gary said:

"I think rehab is important and needs urgent attention. We need a lot of education for people in the health profession particularly specialists and doctors. We need attitudinal education particularly of senior doctors and medical people and we need a generally better approach on issues of access to information in various formats including braille.

"They should start when you go into hospital – not in the preventative space. There is a fair bit of accessible information out there on prevention but there is no accessible information in the actual hospital setting. That's where the real gaps are – that goes for both hospital depending on the staff and the ward. Much depends on the ward staff and it also depends on the night and how busy it is. The second night I was in hospital I was actually left alone for about 10 hours.

"Podiatry is also a grey area. First I was told that there was podiatry and I'd be better off under NDIS. Then I access NDIS and it was good and then months into my third plan I was suddenly told that there was no podiatry because it's in the health system.

"We've really got to educate the doctors at one end and the nurses at the other end. I think that some of the cultural issues need attention where people have different attitudes to disability."

What the Appreciative Inquiry Group heard in Gary's story ▼

- Access via digital technology and via phone can be extra challenging for people with visual impairment
- Useful to have script and medicine information in Braille
- Experience of being misinformed about an eye test being bulk billed and then being informed that this was not the case and being charged \$1500, while this fee was later dropped following complaint
- How do people respond effectively to situations where they may be given bad information or information that they feel needs to be questioned/disputed?

RAY – Just talk to me

“My problems in hospital ... would never have happened if she had talked to me. All she had to do was say hello, tell me what was going to happen and I would have filled her in.” – Ray

Many people with disabilities know their own underlying conditions well and are familiar with the signs of trouble. Serious problems can arise when a medical model of disability and misaligned communications combine at the worst possible time.

Ray is a man who is a high-level quadriplegic. He's well educated and an informed patient and has done a lot to find the right people and treatments. He is a very active participant in his own health care and he talks about what that looks like, especially the presence of trusted physicians who have provided ongoing care, listening and/or gaining good knowledge.

However, that only works when professionals talk to him, and he discusses a really critical incident where they simply didn't talk to him during a colonoscopy, which caused unnecessary pain, trauma and cost to both Ray and the health system.

Asked what might make a difference, Ray said:

“If I was Minister for Health I would have disability awareness as part of the program for nurses and for all doctors, students, registrars, learning as students and becoming really, really good at what they do. 20% of the population has a disability of one form or another and about 10% have a serious disability. We also tend to use health services more. They really should be up to speed with all the different types of disability.

“I think disability awareness presented by people with a disability would be a quite good thing to do. Simply skill the people with disability and pay them – nothing says we appreciate you more than a pay check. Put the people through a workplace training course at CIT and train them. Once you take that course you become an authority – there is a lady that is doing that at work at ADACAS called ‘Moving on with Health’.

“I think protocols around training people to advocate for themselves in a health care setting and how things work and what people can expect when getting admitted and how to approach medico's and to come with a crash course on my disability on a piece of paper plus your medications.

“It's the kind of thing everyone should be doing.”

What the Appreciative Inquiry Group heard in Ray's story ▼

- Highlights communication problems
- Experience of having problems with a DSP application due to incorrect computer records
- Arrogance of some medical professionals
- People often lack the time, energy and/or money to take on a dispute or legal battle
- There is an important question about being able to hold medical professionals and the health system to account
- Advocacy organisations do not have funding to support in certain circumstances
- The dissemination of information is important – so much information is found out by accident
- Need to be given information about what you are entitled to, including how to access affordable services.

BRON – I just stopped asking

“I have had two occasions where I've been unwell and I think they're going to want me to come back and I think can I budget for that? You reasonably can't afford to be sick.” – Bron

Being on a low income as a person with a disability can mean you can't afford to be sick. In addition, it can mean rushed consultations in bulk billing clinics that barely have the time to work with disability accommodations, let alone offer a space to be heard about preventative health issues.

Bron is a person who is deaf and spoke about the consequences of being on a low income and having to access a time-rationed bulk billing system. She speaks about how that rushed and impersonal system makes her less likely to have longer conversations about her health and access preventative health care.

She talks about doctors misunderstanding her and talking in front of her, and the risks of misdiagnosis. She also talks about the limitations of hearing assistance in the NDIS.

Lastly, she compares the ACT to places she has lived in other states and talks about gaps and not knowing about things like nurse walk-in centres and where to access mental health counselling.

Asked what might make a difference, Bron said:

“I would compare the ACT to how well other states and territories are going in Australia in terms of GP usage. I think there is a fear of using GP’s.

“I think that improving the conditions of health. Improving the knowledge of where things can be found. Not everyone has access to a website. Having more reasonably available information about where things can be found like the co-op health services. There is too much that is only available through word of mouth. I think a lot more written content and advertising of what is good. I feel like Canberra has too many private clinics and private health care and private expectations – that goes for private counselling as well you have to go for a bare minimal arrangement even with [large provider].

“The type of freely available health care and well-being you can actually get is not known unless it’s through word of mouth. I wouldn’t know where to go if I was stuck and a member of my family needed free mental health or free counselling services. I would not have a clue. Mental health is still a stigma where you are told ring Lifeline if you have some issues but it’s not immediately clear where you can go. It’s more the problematic areas like drugs and alcohol that are known. But the ones where you just need a debrief or a mental health check-up – that’s not there. And I think that’s the same where you look at the mental health check-up plans to be able to referred to a psych you need to go to a GP. So here we are back in a noisy, crowded place or do you pay to get a health check. You wind up weighing up and saying am I well enough – do I really need this now?

“I came from a state where you could just walk in and get the highest bulk billing. You do tend to get used of that system after a long, long time. When you come to a system that’s more pay based you do get real shock and ask – am I sick enough? What do I need? What’s my priority?

“If there was a list of bulk billing GPs and mental health practices that were known to be deaf friendly and understood how to work with people I’d also use that. I’d also use something similar to My Schools website with a rating system with reviews and accessibility to say – is this accessible? Can you get in? What are the staff like? What are the GP’s like? If I was able to see that it would be good – but I dunno what’s around unless I ring them all manually. It’s about having the information where you need it.”

What the Appreciative Inquiry Group heard in Bron's story ▼

- Public and private psychiatrists are scarce in the ACT and there is also a low ratio of GPs to population
- People are treated like a number in the public system
- Even if you can afford a consultation, you may not be able to afford the actual treatment
- Useful to have free annual health and dental checks as a means to preventative health
- People end up making decisions about whether to seek medical assistance on a financial basis – can I afford it? And will I survive without it?
- Experiences of a lack of appropriate response (three-hour wait with a heart condition) and a lack of appropriate supplies (bandages) at walk-in centres with long waiting times and unclear triaging process.

ANNE – Disbelieved and denied

“I had an issue where I believed that I had had an adverse effect from a procedure and just wanted to let them know about it – I wasn't interested in making a complaint or a case or whatever. But they just went straight into denial and I lost a valued specialist.” – Anne

Sometimes having a disability and ongoing contacts with the health system can be a process of mounting frustration from being disbelieved, misunderstood and then feeling misinformed. A risk averse system with rationed supports can also close conversations and leave patients with disability limited opportunities to even start a dialogue.

Anne is a person with multiple chronic illnesses and a disability who struggles to be believed and understood by the medical profession, as well as experiences frustrations when trying to give feedback and dealing with complaints.

She has found it is important to have a doctor that understands you and builds rapport. She has had trouble obtaining some aids and equipment that skirt health and disability functions under the NDIS. Anne found the tertiary system unfriendly to people needing mobility equipment. She feels that communication needs to be improved, especially after procedures.

Asked what might make a difference, Anne said:

“I believe there ought to be a really deep, detailed set of agreements between the NDIA and the health systems about which bit fits where and what each bit will do about various health issues.”

What the Appreciative Inquiry Group heard in Anne's story ▼

- Highlights issues around feedback mechanisms – responses to feedback are often defensive rather than being constructive or responsive
- Knowledge gaps around complex issues and conditions
- Challenges in finding NDIS providers and the cutting back of NDIS packages.

JIM – Let's get this over with

“The Centrelink Doctor was the first medical person I disclosed to and he was angry with me... that meeting with the doctor about my pension has stuck with me for a very long time.” – Jim

Centrelink requirements can bring patients with disabilities and doctors together in a first contact that has lasting effects in areas like disclosure. Having a support network to maintain health and fitness is part of the picture, as is accessible information and understanding for people with an intellectual or cognitive disability.

Jim has a mild intellectual disability. His experience with doctors has been coloured by his negative experience during a Centrelink assessment where he found that person to be brusque. He is reluctant to disclose his disability to other practitioners because he doesn't know what their reaction would be. He worries about his personal fitness and preventative health but lacks the social network needed to sustain it. Cost is a major issue for him, especially with dentistry.

Asked what might make a difference, Jim said:

“Why don't dentists sign up to the NDIS? I know it's not covered but it's confusing. Dentists should have some sort of concession at least...”

“On disclosure... I'm always advocating for people with intellectual disability but when it comes to my own health it's almost reversed. I don't tell my doctors and I'm conservative. I'd want to hear that I'm not going to treat you differently - I'm not going to belittle you.

“Centrelink assessments ... need to be professional and detached. Plus I've got my advocate – let him in!”

What the Appreciative Inquiry Group heard in Jim's story ▼

- Patchy nature of care and knowledge
- Lasting impacts of negative interactions
- You can't isolate interactions – they are experienced by people as medical interactions whether or not they are about an income support payment. Respect needs to be consistent
- Importance of understanding the relationship between medication with diet, obesity/being overweight, and fitness.