



Council for
Intellectual Disability



From rights to results!

Systemic advocacy and leadership by people with intellectual disability

Shu Hua Chan and Jim Simpson

Who we are

Council for Intellectual Disability (CID) is a disability rights organisation led by people with intellectual disability.

- Systemic advocacy
- Information
- Capacity building



Where we came from

- 1956 A peak for service providers
- 1980 The parent advocates take over
- 2004 People with intellectual disability rule



How our advocacy has changed

- From lobbying for education and disability support for people with intellectual disability.
- To multistrategy advocacy for full inclusion with people with intellectual disability



What systemic advocacy means at CID

Acting with strength and determination

and minimum conflict of interests

with people with intellectual disability

to change the community so it:

- protects the rights of people with intellectual disability,
- includes everyone, and
- supports people well.

The Our Health Counts campaign shows how we do it.....

Our Health Counts – what’s the problem?

- The experience of people and their families
 - Research evidence
 - The views of key allies
- Definition of the problem
- Doctors and nurses not trained and supported
 - Health problems not picked up or treated
 - People not getting normal preventative health
 - Twice the hospital costs
 - 38% preventable deaths

Open Access

Research

BMJ Open Cause of death and potentially avoidable deaths in Australian adults with intellectual disability using retrospective linked data

Julian Trollor, Preeyapom Srasuebku, Han Xu, Sophie Howlett

To cite: Trollor J, Srasuebku P, Xu H, *et al*. Cause of death and potentially avoidable deaths in Australian adults with intellectual disability using retrospective linked data. *BMJ Open* 2017;7:e013489. doi:10.1136/bmjopen-2016-013489

► Prepublication history and additional material is available. To view please visit the journal (<http://dx.doi.org/10.1136/bmjopen-2016-013489>).

Received 15 July 2016
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ABSTRACT

Objectives: To investigate mortality and its causes in adults over the age of 20 years with intellectual disability (ID).

Design, setting and participants: Retrospective population-based standardised mortality of the ID and Comparison cohorts. The ID cohort comprised 42 204 individuals who registered for disability services with ID as a primary or secondary diagnosis from 2005 to 2011 in New South Wales (NSW). The Comparison cohort was obtained from published deaths in NSW from the Australian Bureau of Statistics (ABS) from 2005 to 2011.

Main outcome measures: We measured and compared Age Standardised Mortality Rate (ASMR), Comparative Mortality Figure (CMF), years of productive life lost (YPLL) and proportion of deaths with potentially avoidable causes in an ID cohort with an NSW general population cohort.

Strengths and limitations of this study

- This study provides death statistics and details of potentially avoidable deaths in adults with intellectual disability (ID) who received disability services in New South Wales.
- The study provides evidence of mortality gaps in people with ID compared with the general population.
- The high proportion of potentially avoidable deaths for people with ID indicates an opportunity for the development of possible preventative strategies.
- Since the ID cohort is derived from registered users of disability services, people with mild ID may be under-represented
- These findings are not generalisable to everyone with ID.

Our Health Counts

Is the time right? YES

Led by CID in partnership with Inclusion Australia



And in collaboration with

- Australian Association for Developmental Disability Medicine
- Down Syndrome Australia
- Department of Developmental Disability Neuropsychiatry UNSW



Deciding the ask?

What will?

- Make a big difference, and
- Make sense to decisionmakers, and
- Get lots of support in the disability community and beyond

We went for

- Fix university training
- ID teams in Primary Health Networks
- An expert inquiry

Design the campaign

Putting the problem and the ask into messages that will grab

- Our supporters
- The allies we want

Challenge government but encourage them to be part of the solution.

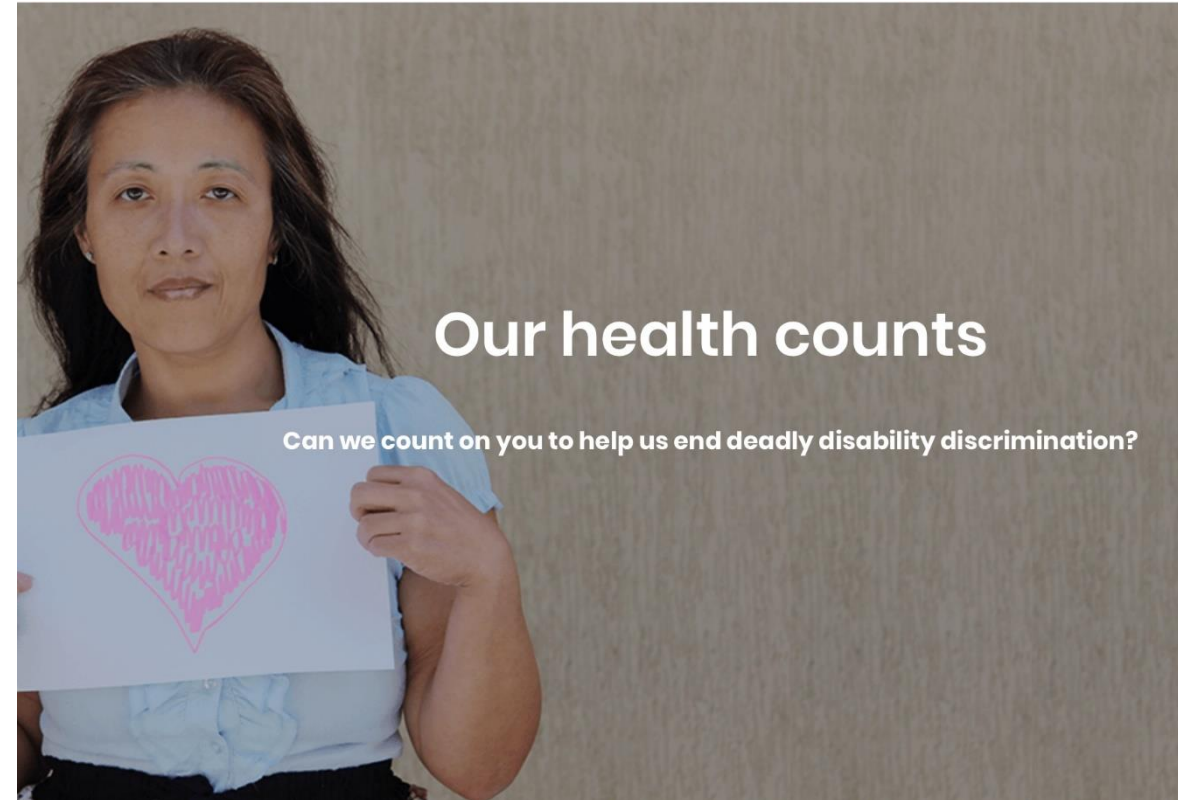
We went for

- Fix university training
- Training and support for GPs
- An expert inquiry

Design the campaign

Use

- Strong imagery and stories
- Social media



And mainstream media

Intellectual disability advocates' \$50m push to improve medical care

Carers say health procedures are made more difficult because of doctors' lack of understanding



Helen Davidson

04:00 Monday, 01 April 2019

[Follow Helen Davidson](#)

Seven-year-old Ryan has Down's syndrome and was born with a multitude of other medical conditions, including three holes in his heart and a diagnosis of leukaemia at the age of 13 months.

"It's amazing how tough he is, how resilient he is," Ryan's mother, Rebecca Kelly, said.

"No one looking at him today would think he's ever been through anything let alone the number of things he went through."

More on this topic
National Disability Agreement 'outdated', Productivity Commission says

Kelly said Ryan has been through many "incredibly traumatic" medical procedures, made more difficult because of a lack of understanding about his different needs by some

doctors.

Their experiences have formed a case study for a push by the New South Wales Council for Intellectual Disabilities for \$50m of federal measures to improve the medical care of patients with intellectual disabilities.

It's supported by more than 120 current and former heads of medical and health



Some key strategies

- Alliances
- Eminent support
- Petitions

Seek to neutralise potential opponents.

ORGANISATIONS WHO HAVE ENDORSED THE CAMPAIGN



The Royal Australasian
College of Physicians

Royal Australasian College of Physicians



The Royal
Australian &
New Zealand
College of
Psychiatrists

Royal Australian and New Zealand
College of Psychiatrists



Academy of Child and Adolescent Health



the Australian College
of Mental Health Nurses Inc.

Australian College of Mental Health Nurses



Every Australian Counts



Australian Federation of
Disability Organisations

Australian Federation of Disability Organisations

**End
Deadly
Disability
Discrimination**

Professor Fiona Stanley AC, Australian of the Year 2003 is one of 120 signatories to our Open Letter to address health inequalities for people with intellectual disability.



Some key strategies

- Target the key decision maker(s)
 - Talk to the department and advisers first
 - That meeting with the minister
- Lobby other polities
- Think interests
- Be nimble

You want everyone saying, “Yes, do it minister!”

Seek to neutralise potential opponents.



Never, never give up

Systemic advocacy sometimes gets quick wins.

Often NOT

- Review and modify strategy
- Bide your time
- But be relentless

Keep calm and carry on!



YES, Our Health Counts!

Labor promised \$10m
Liberals promised a roundtable...

Roundtable happened in August:

- PHN program underway
- Minister wrote to the universities
- Draft roadmap
- 2nd roundtable to be in February

Plus we have the Royal Commission



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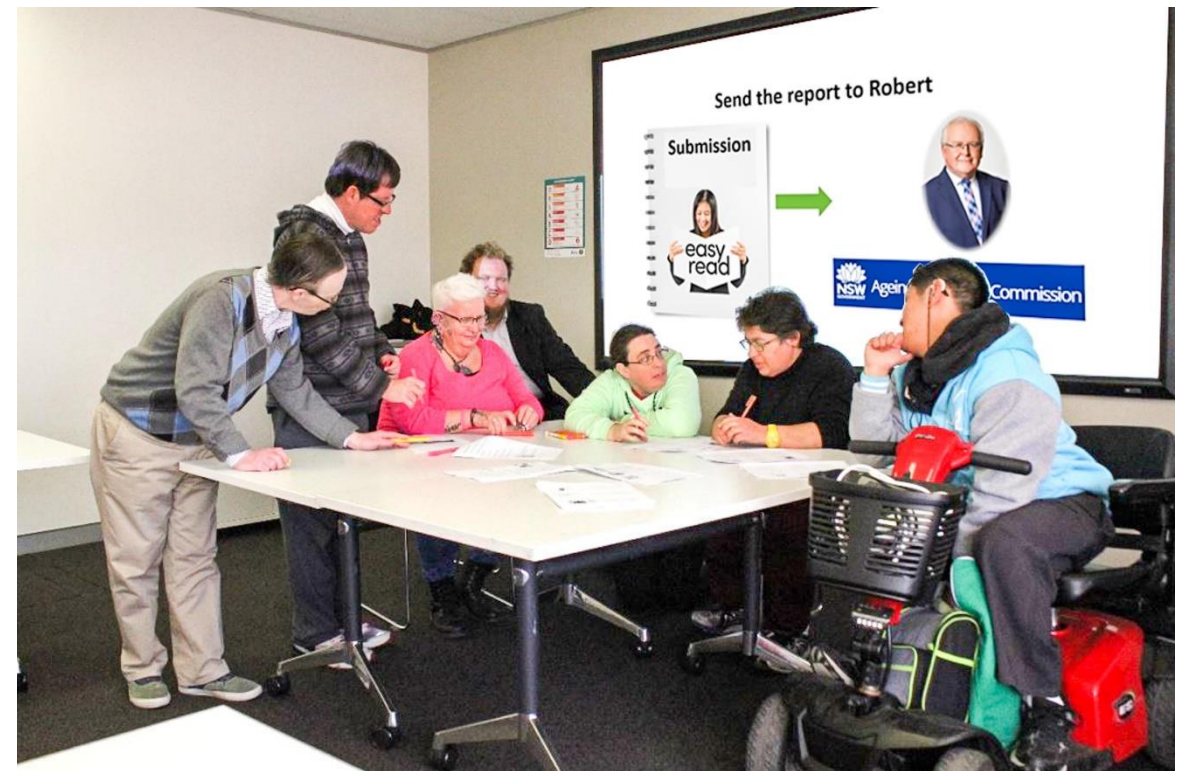
National roadmap for improving the health of Australians with intellectual disability

The Australian Government will develop a national roadmap for improving the health of Australians with intellectual disability. The roadmap will be implemented from 2020 as part of the 10 Year Primary Health Care Plan.

Page last updated: 04 October 2019

Supporting the central role of people

- Our board
- Our advocacy group
- Face of the campaign
- Meetings with politicians
- Roundtables and forums



Our advocacy needs multiple skills

- People and families
- Advocacy
- Campaigning
- Communications

That combination has led
to multiple wins in recent years.



And finally, YOU too can be an advocate

Our workshop will cover
some basic advocacy skills ...

And thanks to
for sponsoring
our keynote.





Contact and follow us



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