

# Measuring the social inclusion of people with a disability in Australia: the first national 1-in-4 poll

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# Background to 1 in 4 poll

## Project Rationale

- People with disabilities and their carers constitute 1 in 4 of all Australians
- People with disabilities have been largely excluded from participative democratic processes
- ‘deliberative inequality’ (Bohman 2000)
  - Power differences between groups/people
  - Communicative inequalities – not everyone able to communicate with those in power
  - Lack of developed capacities to do activity of participation and influencing of those in power
- ‘one size fits all’ democracy does NOT enable everyone to participate equally

# Purpose of project

## Purpose

- To provide a way for people with disabilities to have their voice heard (ie new mechanisms for democratic participation)
- To increase understanding of the views of people with a disability
- To influence government policy based on the opinions of people with disabilities

# Project overview

- Led by Scope and Deakin University
- National accessible survey (poll) of Australians with a disability
  - Periodic surveys on different topics (eg 1-2 per year)
- Engage wide range of agencies to promote
  - All States and Territories
- Use data to influence government policy and social attitudes
  - Led by Scope in partnership with other agencies
- Idea based on UK poll by Capability Scotland

To achieve the project goals, need  
a method that is:

- accessible
- ethical
- relevant

# Accessible

- Purpose: to enable the widest diversity of people with disability to provide their information
  - Self report focus
    - [Online survey](#)
    - [Easy English](#) and Standard English versions
    - Can be completed by a person with a disability with assistance from another person
  - Proxy report option
    - Where person is unable to communicate their views (eg profound ID), a carer can complete survey
    - From the person with a disability's view point if possible (ie reflect the person's experience and preferences)

# Accessible

## On line survey

- Range of existing ‘off the shelf’ on line survey tools
- Evaluated these against national and international standards, & ease of use with Assistive Technology
  - Gottliebsen, D., Layton, N., & Wilson, E. (2010). Comparative Effectiveness Report - online surveys. *Disability & Rehabilitation: Assistive Technology*, in press.  
<http://informahealthcare.com/doi/abs/10.3109/17483101003793404>
- Found custom built (ie bespoke) on line survey meets highest number of accessibility standards

# Assessment of online survey tools against 16 accessibility standards

Name	Passed	Partial	Failed
Bespoke <small>custom built survey</small>	16	0	0
Only a Survey	15	1	0
Survey Monkey	12	2	2
Our Web Survey	11	1	4
Lime Survey	9	3	4
eSurveys Pro	9	2	5
Opinio	9	1	6
Survey Gizmo	7	6	3
Checkbox Survey	7	2	7
Sigma Survey Suite	7	2	7
QuestionPro	7	1	8
Zoomerang	5	1	10






From Gottliebsen et al (2010)

# Accessible

## Easy English versions

- Of both survey tool and Plain Language Statement
- Developed in conjunction with the Communication Resource Centre (Scope) – speech therapy and communication experts
- Easy English survey trialled with people with range of disabilities
- Aim of Easy English – as a resource to be used alongside other supports, aid in comprehension

# Accessible: Example from Easy English survey

 How happy are you about											
		 I feel unhappy					 I feel happy				
 Joining in social groups	0	1	<del>2</del>	3	4	5	6	7	8	9	10
 Feeling people are ok about who you are	0	1	2	3	4	5	6	<del>7</del>	8	9	10

# Ethical

## Design includes:

- Surveys are anonymous
  - Clear identification of ‘type’ of respondent: person with a disability, or proxy report (carer)
- Individuals can register on a ‘Mailing list’ to be sent information about up-coming surveys – no way to link mailing list to survey responses
- Two sets of ethics approval: Scope & Deakin University

# Relevant

## 1<sup>st</sup> poll on Social Inclusion

- Reflect an area of current government policy

## Structure of survey:

- Demographic questions
- Social Wellbeing Index (Cummins, 2008)
- Questions on main topic: social inclusion
- Nominate a topic for next survey
- Evaluation of accessibility of survey

# Relevant: Development of content

## Overview

- Literature review relating to the social inclusion of people with a disability
  - Few studies on social inclusion in Australia purposefully include people with disabilities
  - Summarise and compare key statistical findings across studies THEN compare with general community statistics
  - Identify question items used on surveys, select and adapt these

# Existing research on social, service and economic exclusion

Item	% People with disability	% General population
No regular contact with others	33.9	18.6
No access to family support	51.4	24.6
Nobody to give them important advice	40.8	21.2
No access to a local doctor	8.7	4.5
No access to dental services	46	14.5
No access to disability services	56	
Do not have a decent and secure home	40.5	29.5
Unable to afford prescription medication	42.5	24.5
Do not have a substantial meal every day	22.8	13.7

Saunders, Naidoo & Griffiths (2007)

# Relevant: Content selection

- Use domains of Social Inclusion Framework (Saunders et al 2007 & 2008) and add sub domains to these
  - Social exclusion (Disengagement) e.g. feel part of the community
    - Social contact
    - Participation
    - Group membership
    - Support
    - Feeling valued and belonging
    - Outlook (for the future)
  - Service exclusion e.g. access to medical services
    - Medical
    - Disability
    - Public facilities
  - Economic exclusion e.g. having enough money to get by on
    - Assets
    - Essential elements
- Select and adapt from items in range of published sources (over 80 items identified in multiple studies – see ‘Indicators references’ in reference list)



# Relevant: Content Selection

Also added new question areas:

- Future outlook
- Barriers to inclusion (3 things to change)
  - Based on literature review of identified barriers to social inclusion

## Relevant: Example of new question area

### Improving Social Inclusion

Consider ALL the things below. Tick the **3 things** that would most improve your social inclusion if they were changed.

<input type="radio"/>	Attitudes of others	<input type="radio"/>	Feeling safer
<input type="radio"/>	Physical access to places	<input type="radio"/>	Services and supports
<input type="radio"/>	Others being able to understand the way I communicate	<input type="radio"/>	Money
<input type="radio"/>	Transport	<input type="radio"/>	Better health
<input type="radio"/>	Less rules and red-tape	<input type="radio"/>	Housing
<input type="radio"/>	Being listened to	<input type="radio"/>	Aids & equipment
<input type="radio"/>	Options to do what I want	<input type="radio"/>	People to do things with
<input type="radio"/>	The way I feel about myself	<input type="radio"/>	Employment
<input type="radio"/>	Information that I can understand		

# Reflections on method so far...

- Utilise wide range of expertise:
  - IT software designer with experience in disability accessibility
  - Communication Resource Centre (Scope) and speech pathologists
  - Two Schools (Psychology, and Health and Social Development) at Deakin University
  - Disability service provider - Scope
- Time
  - 18 months of development to get to live online survey
- Based on significant research in range of areas:
  - literature reviews and critical appraisals in
    - Accessible data collection methods for people with disabilities
    - Levels of social exclusion of people with disabilities in Australia
    - Methods for measuring social exclusion
    - Accessible online surveying
- Build-in evaluation of accessibility method
  - Ask all respondents to rate accessibility and suggest improvements

# Next steps

- Organisations around Australia will be mailed information
- The online survey will go 'live' this month  
<http://www.1in4pollaustralia.com/>
- Data collated and analysed, reports made public to all interested parties
- Media and influencing activities
- Preparation for next survey

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