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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


• Found custom built (ie bespoke) on line survey meets highest number of accessibility standards
Assessment of online survey tools against 16 accessibility standards

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

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

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

Circles indicate survey responses.
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

1st 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
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

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

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: Example content selection

Think about the past three months. How well were your needs met in these areas?

<table>
<thead>
<tr>
<th></th>
<th>Not at all</th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th>Fully</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Having social contact with other people</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Doesn’t apply to me</td>
<td></td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td></td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>10</td>
</tr>
<tr>
<td><strong>Having a social life</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Doesn’t apply to me</td>
<td></td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
<td>O</td>
</tr>
<tr>
<td></td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>10</td>
</tr>
</tbody>
</table>
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
### Improving Social Inclusion

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

<table>
<thead>
<tr>
<th></th>
<th>Attitudes of others</th>
<th></th>
<th>Feeling safer</th>
</tr>
</thead>
<tbody>
<tr>
<td>O</td>
<td>Physical access to places</td>
<td>O</td>
<td>Services and supports</td>
</tr>
<tr>
<td>O</td>
<td>Others being able to understand the way I communicate</td>
<td>O</td>
<td>Money</td>
</tr>
<tr>
<td>O</td>
<td>Transport</td>
<td>O</td>
<td>Better health</td>
</tr>
<tr>
<td>O</td>
<td>Less rules and red-tape</td>
<td>O</td>
<td>Housing</td>
</tr>
<tr>
<td>O</td>
<td>Being listened to</td>
<td>O</td>
<td>Aids &amp; equipment</td>
</tr>
<tr>
<td>O</td>
<td>Options to do what I want</td>
<td>O</td>
<td>People to do things with</td>
</tr>
<tr>
<td>O</td>
<td>The way I feel about myself</td>
<td>O</td>
<td>Employment</td>
</tr>
<tr>
<td>O</td>
<td>Information that I can understand</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
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
Contact

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• Dr Rob Campain
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References


Indicators references:


Indicators references continued:


