

# Research Survey Analysis

NSW Agency for Clinical Innovation  
Intellectual Disability Network

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## Abbreviations

The following is a list of abbreviations that have been used in this report.

ABBREVIATION	MEANING
ABS	Australian Bureau of Statistics
ACI	Agency for Clinical Innovation
ADHC	Ageing, Disability and Homecare
AIHW	Australian Institute of Health and Welfare
ATSI	Aboriginal & Torres Strait Islander
CALD	Culturally and linguistically diverse
CBT	Cognitive behaviour therapy
DOB	Date of birth
FACS	Family and Community Services
ID	Intellectual disability
NGO	Non-government organisation
NSW	New South Wales
PBS	Pharmaceutical Benefits Scheme
R & D	Research and development
WWS	WestWood Spice



## 1. Introduction

The NSW Agency for Clinical Innovation (ACI) was established in January 2010 to promote innovation, engage clinicians and design and implement new models of care across the NSW health system. It has over 30 clinical networks. These provide a framework for clinicians and consumers to meet with a mandate to drive improvements in care through innovation in clinical practice.<sup>1</sup>

The Intellectual Disability Network is one of its networks. Within the Intellectual Disability Network, there are four subcommittees: Research & Development, Access & Equity, Workforce & capacity and Models of Care.

The Research and Development (R & D) Subcommittee of the NSW Agency for Clinical Innovation (ACI) Intellectual Disability Network has recently surveyed academics, researchers and practitioners working in the field of intellectual disability and health with a view to:

- better understanding of the research landscape in NSW;
- highlighting possible gaps in research;
- eliciting views about the development of a disability data set;
- exploring experiences around the barriers and enablers of research; and
- commencing information collection to support the development of a catalogue of current research which could be hosted and maintained by ACI on its website.<sup>2</sup>

WestWood Spice (WWS) was contracted to provide assistance with the survey analysis and the identification of gaps in the research.

An allied task of the contract was to assist the subcommittee with exploring the development of guidelines on research procedures in the area of intellectual disability. This second task is the subject of a separate discussion paper.

Throughout the project, ongoing support has been provided to WestWood Spice through a number of meetings of the subcommittee and liaison with the Manager, Intellectual Disability Network, NSW Agency for Clinical Innovation, Tracey Szanto.

In addition, separate interviews were conducted with Associate Professor Julian Troller, co-chair of the subcommittee and subcommittee members Dr Natalie Ong, Dr Bronwyn Hemsley and Joyce Man.

Where contact information had been supplied, follow-up contact by email and/or phone was made with a number of survey respondents to obtain additional details about particular research projects which they had described in their survey responses.

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<sup>1</sup> <http://www.aci.health.nsw.gov.au/networks>

<sup>2</sup> "It is anticipated the survey results would be used to develop a catalogue of research activity to inform interested professionals about current research activity" from the project brief.

## 2. Survey findings

### 2.1. Survey distribution

The survey was designed by members of the Research and Development subcommittee.

Ethics approval was received from NSW Population and Health Services Research Ethics Committee.

The survey was set up for on-line completion and it was hoped that it would reach a wide range of professional groups involved with intellectual disability issues in NSW. It was distributed by the Manager of the Intellectual Disability Network by email to known contacts with an expectation that recipients might forward the link onto others who may also be involved in research and/or interested in completing the survey. The initial distribution of the on-line survey in mid 2013 resulted in 57 responses by the nominated closing date. A decision was taken by the R & D subcommittee to redistribute the survey during July/ August 2013 and this increased the total number of completed responses to 105.

### 2.2. Survey respondents

#### 2.2.1. Main place of work

Table 1 below shows respondent distribution by single main place of work. Although respondents were drawn from a wide variety of workplaces, there was a clear health focus. As can be seen from the table, over 40% of respondents were working directly in a health setting, with almost half of these people located in a hospital setting and the remainder in a non-hospital health care setting. The next most common workplace was a university, accounting for almost 20% of respondents.

**Table 1: Main place of work of survey respondents**

Single main place of work	# of respondents	%
Hospital setting	25	23%
Health care service (non hospital)	20	18%
University	21	19%
Accommodation service	2	2%
Ageing, Disability and Homecare (ADHC)	19	17%
Non-government sector (NGO)	16	15%
Education	6	6%
TOTAL	109 <sup>3</sup>	100%
Other	10	

Amongst the other workplace settings mentioned were a correctional setting, Medicare local, General Private practice, NSW Ombudsman, FACS, a peak body and the Ministry of Health.

<sup>3</sup> There were 105 survey respondents, but four individuals gave two places on the list as their main place of work (two working in both a hospital and non hospital health care setting; one in both education and a health care service and one in a university and a non-government organisation).

### 2.2.2. Role

Information was sought about the occupations of respondents. Most individuals nominated one role but about 10% chose to select two roles as appropriate to them. Given the predominance of health-based workplace settings discussed above, it was not surprising that the largest group of respondents described their role as clinician (40%). Twenty five per cent of the sample were academics and a similar proportion (23%) worked in an intellectual disability service setting. Examples of roles given by this latter group included manager, service manager, nurse manager, support person. Ten per cent selected the advocacy category, but this included a number of people working in government policy roles that used the advocacy category as there was no separate category option for government/ policy roles.

**Table 2: Main roles of survey respondents**

My role is (can select two answers)	# of respondents	%
Student	2	2%
Academic	29	25%
Clinician	47	40%
Intellectual Disability Service Provider	27	23%
Advocate	12	10%
TOTAL	117 <sup>4</sup>	100%
Other	23	

### 2.2.3. Clients

Respondents were asked to nominate which of the following (broadly aged-based) categories described their clients – Paediatrics, adolescent and adult.

Less than 10% of respondents did not work directly with clients.

An analysis of the data was undertaken to see the patterns in client groups. This showed that adults and adolescents was the most common group (40%) followed by adults only (29%).

**Table 3: Categories of clients**

My clients fall into the following categories	# of respondents	%
All age groups	21	21%
Paediatric clients only	10	10%
Adults only	28	29%
Adolescents and adults	39	40%
TOTAL RESPONDENTS ANSWERING QUESTION	98	100%

<sup>4</sup> 12 respondents nominated two roles.



### 2.3. NSW Intellectual Disability data set

The survey sought respondent views about the importance of a comprehensive NSW Intellectual Disability data set, views about its major purposes, whether the information collected should be identified or de-identified and what should be the basic information collected. One respondent noted that if the intention was to create a data set about individuals with intellectual disability in NSW that *“the work being done by AIHW for a disability identifier for administrative data sets is already heading along this path.”*

#### 2.3.1. Importance of a minimum data set

Table 4: Minimum data set importance rating

In your opinion, how important is it to have a comprehensive NSW Intellectual Disability data set?	# of respondents	%
Unsure	3	3%
Not at all important	0	0%
Of limited importance	1	1%
Of some importance	11	10%
Very important	44	42%
Essential	46	44%
TOTAL RESPONDENTS ANSWERING QUESTION	105	100%

Eighty six per cent of respondents rated a minimum data set as very important or essential.

#### 2.3.2. Major purposes of a minimum data set

There were a number of purposes offered and respondents on average chose five purposes.

The following table lists responses in order of greatest frequency of nomination.

Table 5: Major purposes of a minimum data set

What would you consider to be the major purposes of an Intellectual Disability data set?	# of respondents	%
Identification of unmet need in service provision	78	76%
Cross agency coordinated state wide data	69	68%
Better decision making about health plans for individuals	67	66%
Identification of areas for improvement in health promotion	61	60%
Up to date medical history/ health record for population groups	54	53%
Identification of unmet need for individual client	51	50%
Other	14	14%
TOTAL RESPONDENTS ANSWERING QUESTION	102	100%

Amongst those providing comments in the “other” category was mention that population data should be complemented by use of Commonwealth e-health records for individuals, that benchmarking could be undertaken and data linked to other data sets such as Medicare, PBS, Centrelink, Education, and that the information could inform the allocation of resources and future planning.

### 2.3.3. Identification of data

The largest group of respondents (41%) thought that information collected should be de-identified. Thirty two per cent were unsure and 27% indicated that information should be identified.

### 2.3.4. Basic information types

There were twelve<sup>5</sup> categories of information from which respondents could choose. On average people chose eight of these. Feedback from one respondent indicated that there could be some learning from the experience in Western Australia where there has been a data set for many years and that consideration should be given to standardising items such as those used by Australian Bureau of Statistics (ABS) and AIHW and alignment with planned advances in administrative data sets in Australia.

The table below has ranked responses in decreasing order of frequency.

**Table 6: Basic information to be collected**

Rank	What do you consider would be the Minimum Data Set (basic information to be collected)?	# of respondents	%
1	Demographic information i.e. DOB, sex, postcode, suburb, need full patient details if clinical, ATSI, language spoken at home, interpreter required	92	88%
Equal 2	Medical and health information	88	84%
Equal 2	Functional level of disability	88	84%
3	Primary and comorbid diagnoses	83	79%
4	Current Services accessed	81	77%
5	Assessed level of disability	66	63%
6	Gaps in service	65	62%
7	Aboriginal or Torres Strait Islander	58	55%
Equal 8	Ethnic background	56	53%
Equal 8	Waiting times for services (which services and length of wait)	56	53%
9	Refugee status	39	37%
10	Funding - health care card, carer’s allowance	38	36%
	TOTAL RESPONDENTS ANSWERING QUESTION	105	

<sup>5</sup> There was some confusion with ATSI and language spoken at home listed as demographic information, but also separate categories for Aboriginal or Torres Strait islander and Ethnic background.



A number of other suggestions were made. In particular, more than one person indicated that level of support needs was more useful than level of disability.

Other suggestions included parental status, living arrangements, who is the primary carer/ contact details of consenting person, outcomes from health and lifestyle planning, communication method, case management service, transport, numbers of acute admissions, behaviour support plans, use of “restrictive practices”.

## 2.4. Research activity

Information was collected on the extent of workplace engagement in research activity, previous involvement in ID research, and current extent of inclusive research (with people with intellectual disability, family members, support workers).

### 2.4.1. Does your workplace undertake research?

As can be seen by Table 7 below, of the 90 respondents who answered this question, over half (52%) work in a setting where some research is undertaken and 21% where there is a lot of research.

Table 7: Extent of involvement in research

To what extent does your workplace or organisation engage in Intellectual Disability research?	# of respondents	%
Unsure	4	4%
Not at all	20	22%
Somewhat	47	52%
A lot	19	21%
TOTAL RESPONDENTS ANSWERING QUESTION	90	100%

### 2.4.2. Previous involvement in intellectual disability research

With respect to individual involvement in intellectual disability research, approximately one-third of respondents have never been involved in such research. However, 25% indicated that they have been active in intellectual disability research for more than five years.

### 2.4.3. Inclusive research

For both people with an intellectual disability and family members/ support workers there is some involvement in research activity as part of research teams. However, in the case of people with ID only 8% of respondents indicated that a lot of involvement has been a feature of research teams and while there was more involvement for family members/ support workers, this was only 13%.

**Table 8: Inclusive Research activity**

Active involvement in your research team	People with ID		Family members/ support workers	
Unsure	10	11%	10	11%
Not at all	44	49%	34	38%
Somewhat	29	32%	34	38%
A lot	7	8%	12	13%
TOTAL RESPONDENTS ANSWERING QUESTION	90	100%	90	100%

## 2.5. Research enablers and barriers

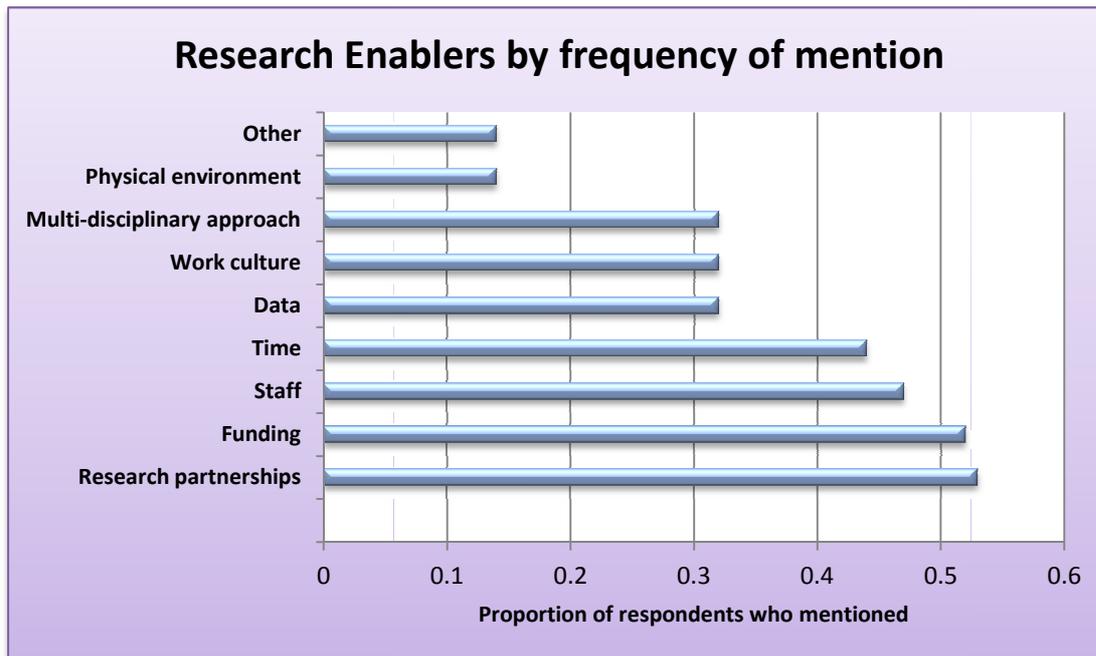
About two-thirds of respondents gave information about factors which had made a helpful contribution to their research and those which had presented barriers. As about one-third of respondents had never been involved in research, this suggests those answering this question were those involved in research. To some extent, the absence of enabling factors were the barriers. The barrier question provided more choices with respect to some of these elements. On average, respondents nominated both three enablers and three barriers. The enablers and barriers are shown in the tables which follow. Each table is presented in order of frequency and is followed by a pictorial representation in its associated figure.

The most significant enablers were research partnerships and funding, nominated by 53% and 52% of respondents respectively. The barriers which were mentioned most often were lack of time for research (64%) and lack of funding for staff (53%).

**Table 9: Factors helpful to research**

Rank	What have been the most helpful contributing factors to assist you in Intellectual Disability research?	# of respondents	%
1	Research partnerships	35	53%
2	Funding	34	52%
3	Staff	31	47%
4	Time	29	44%
Equal 5	Data	21	32%
Equal 5	Work culture	21	32%
Equal 5	Multi-disciplinary approach	21	32%
Equal 6	Physical environment	9	14%
Equal 6	Other	9	14%
	TOTAL RESPONDENTS ANSWERING QUESTION	66	100%

Figure 1: Enablers of research

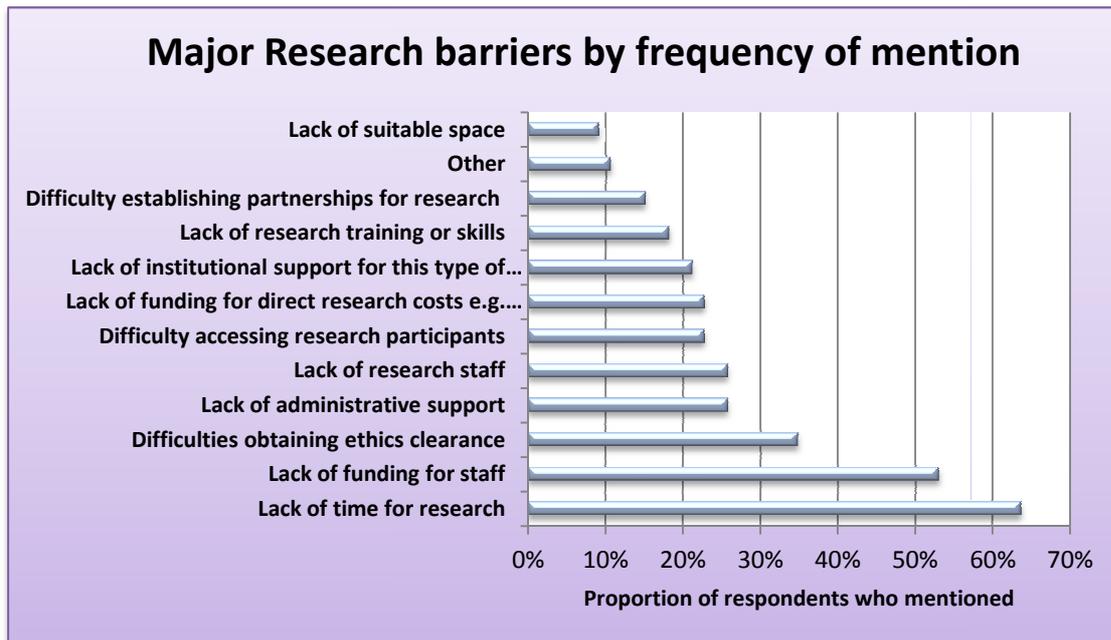


In commenting about other helpful factors, mention was made of the importance of communities of researchers and international collaborations, research being a dedicated component of employment, consultations with service providers who have direct experiences of the challenges, the use of disability networks to recruit research informants (carers) and the development of close links with people with intellectual disability and the establishment of trust.

Table 10: Major barriers to research

Rank	What major barriers have you faced in your research endeavour?	# of respondents	%
1	Lack of time for research	42	64%
2	Lack of funding for staff	35	53%
3	Difficulties obtaining ethics clearance	23	35%
Equal 4	Lack of administrative support	17	26%
Equal 4	Lack of research staff	17	26%
Equal 5	Difficulty accessing research participants	15	23%
Equal 5	Lack of funding for direct research costs e.g. equipment, materials	15	23%
6	Lack of institutional support for this type of research	14	21%
7	Lack of research training or skills	12	18%
8	Difficulty establishing partnerships for research	10	15%
9	Other	7	11%
10	Lack of suitable space	6	9%
	TOTAL RESPONDENTS ANSWERING QUESTION	66	100%

Figure 2: Major research barriers



A common comment about barriers was the unattractiveness/ lack of priority of the area of intellectual disability research to research funders. Comments were also made about the difficulty of accessing research participants, including the issues of consent, gatekeeping by service providers, problems with accessing data, both in terms of time taken to access information from government data bases and restrictions on access to data such as Medicare and PBS data and time barriers faced by carers and service providers. An important point was made by one respondent who noted:

*“A critical component of building research capacity is to engage students at undergraduate and post-graduate level in staff research projects - many of which are carried out in clinical and other facilities. This ensures developing the next generation of researchers dedicated to research with and about people with intellectual disability.”*

### 3. The research catalogue

Survey respondents were asked to provide information about their research activity. The introduction to the survey described this as current research<sup>6</sup> and went on to explain:

*“We seek to understand what is happening in research in Intellectual Disability in NSW as the first step to building a comprehensive catalogue of Intellectual Disability research activities and funding opportunities. Your permission is requested to place your research information on the ACI website in an effort to promote professional collaboration.”*

The specific question in the survey, however, asked for “information about your past of current research activity in the area.” Respondents were invited to provide:

- name of investigators;
- title of project;
- status (active, past);
- name of funding body;
- amount of funding; and
- year(s) of project.

Room was made available for any additional information which respondents chose to include.

As it transpired, a number of respondents chose to provide details of research which had been undertaken many years ago, for example in the 1990’s and also in jurisdictions beyond NSW, including overseas.

In discussion with the R & D subcommittee, including co-chairs, it was agreed that “current” would include research which has been undertaken in the past five years (i.e. from 2008). Additionally, the project would capture in a separate listing any older research which met the other criteria for listing (NSW based<sup>7</sup>, focused on health or health related issues for the population of people who have an intellectual disability or developmental delay).

Work was undertaken to develop a template for the catalogue listing and this was circulated to subcommittee members for feedback. A revised version of the template incorporating the suggestions which were made is included at Appendix A.

The process for compiling the listing was:

- review of survey responses to identify specific research projects meeting criteria for inclusion (66 projects);
- set up of an excel spreadsheet to mirror the template items;
- data entry of project information;
- where contact information was available for the researchers, transfer of project information into a template document emailed to the survey respondent with a request to provide additional details to complete the template. Key additional areas were: project aims; participants; methodology; results; and any publication details. (Follow-up was undertaken for 18 contacts; feedback was received in respect of 11 projects.)

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<sup>6</sup> “Investigating Current Research into Intellectual Disabilities in NSW”. The third section asks about you and your current research activity. (From background explanation to survey.)

<sup>7</sup> NSW based included research which might be part of a multi-site study beyond NSW.

Within the broader ACI structure there is a Research Committee (a subcommittee of the ACI Board), which was established in late 2010. One of the functions of this committee is:

*“Review and advise on the communication strategy for research activities and outcomes, including communication with government, the community, clinicians and health managers.”<sup>8</sup>*

While it is likely this is intended to relate to research activities specifically instigated by ACI, it is suggested that the research catalogue of Intellectual Disability research activities to be maintained and hosted by ACI through the efforts of the Intellectual Disability Network R & D subcommittee could also be seen as part of the broader ACI research communication strategy.

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<sup>8</sup> Section 3.1 Overarching Governance- “Responsible Governance, management and Conduct of Research; An ACI Framework” July 2013 p8.



## 4. Gaps in research

Interviews were undertaken with a range of R + D subcommittee members to seek their views on current gaps in research in the area of intellectual disability and health. Interviews were conducted with:

Associate Professor Julian Troller (co-chair of the R & D subcommittee)  
Chair, Intellectual Disability Mental Health  
Head, Department of Developmental Disability Neuropsychiatry  
School of Psychiatry UNSW Medicine

Dr Natalie Ong  
Staff Specialist Developmental Paediatrician  
Team Lead Specialist Disability Health Team  
Children's Hospital Westmead

Dr Bronwyn Hemsley, Ph.D.  
Senior Lecturer (Speech Pathology) Chief Investigator: Keeping People with Communication Disability Safe in Hospital (NHMRC 2013-16)  
University of Newcastle

Joyce Man, Ph.D. student  
Macquarie University

There were a number of discrete areas which were identified as gaps in research and these are summarised below. It should be kept in mind that this is not an exhaustive list, but is representative of the views of the interviewees.

### 1. Epidemiological research

There is a need for more information about intellectual disability and mental health, especially in NSW, and for age groups other than adolescents. It was noted that the National Mental Health Well-being Survey specifically excludes intellectual disability.

### 2. Specific sub-populations who are under-researched:

- a. Older people who have an intellectual disability;
- b. People with more severe levels of intellectual disability;
- c. People with intellectual disability and mental health and/or drug and alcohol issues at risk of offending behaviour;
- d. People with intellectual disability who have communication issues; and
- e. People from a culturally and linguistically diverse background.

3. Communicating with a person with an intellectual disability in a hospital setting:

It was noted that there is considerable literature about possible strategies, but limited research to indicate which strategies are effective, no controlled studies and no focus on health, safety and well-being outcomes. There were no examples of participant action research in this area. Research would enable decisions to be made about prioritising resources to the strategies which have the largest impact and to provide information about which areas should be researched first. This could include an exploration of the role of services before a period of hospitalisation and the provision of training to the person with the intellectual disability.

4. Mealtime safety:

Despite extensive staff training, screening, use of diet plans and the development of nutrition and swallowing checklists, the rates of malnutrition and choking in this population have remained unchanged.<sup>9</sup> There is a need for observational research to identify what factors remain and to understand why there has been no change despite this significant investment in staff training and protocols.

5. Transition from child and adolescent health services to adult health services:

Service models shift from family-centred practice to person-centred models as individuals with an intellectual disability enter adulthood. Health services are one part of the overall transition to adulthood. It was suggested that there is a need for mapping studies to explore interactions with health services and how the health system is responding to this transition. Anecdotally, considerable variation in practice around the timing of transition was reported with some health services for children and adolescents having a rigid 18 year old cut-off, while others transition individuals earlier or later, depending on individual circumstances.

Other associated research areas were:

- the changing role of family in contrast to families who do not have a child with an intellectual disability, with increased advocacy demands accompanying fewer services/ less allied health and therapy intervention in adulthood; and
- the ongoing role of family members as key informants about the health needs of a person with an intellectual disability, even though they have reached adulthood and how to harness this information in a climate of issues surrounding consent and privacy provisions.

6. Social media:

There is an increasing interest in the use of social media for accessing information about health. A helpful research area would be greater understanding of the benefits and issues associated with the use of social media in health for people with an intellectual disability, including how to harness the benefits of social media for this population and what supports are needed.

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<sup>9</sup> <http://www.ombo.nsw.gov.au/news-and-publications/publications/annual-reports/reviewable-deaths-vol-1/report-of-reviewable-deaths-in-2010-and-2011-volume-2-deaths-of-people-with-disabilities-in-care>

7. Engagement options for inclusion of people with a severe/ profound level of intellectual disability in research:

It was noted that people with more significant levels of intellectual disability are underrepresented in research activity.<sup>10</sup>

8. Issues which are specific to supporting the health needs of people with an intellectual disability who are from a culturally and linguistically diverse (CALD) background:
- Insufficient knowledge about cultural beliefs around disability and health care. This has implications for understanding the impact of this on family members and the roles which they may play and on accessing services;
  - Understanding the cultural and language barriers faced by CALD families. This can extend to problems when using interpreters, where there may not be appropriate terminology available or the concept may not exist in the primary language;
  - Research around how service providers and therapists can better engage with CALD families (beyond the development of good relationships) to deal with issues such as lack of understanding of the importance of the advice which they are receiving or the risks involved in not seeking treatment or in not accepting treatment when it is offered;
  - Mental health and behavioural issues which are compounded by CALD issues - how do these cultures view mental health and behavioural issues? There can be a lack of insight on the part of parents about the role which their own behaviour can play in impacting on the health outcomes of their child who has an intellectual disability; A related issue requiring greater understanding is the impact of child rearing beliefs and practices on the health of the person with an intellectual disability; and
  - Research about how to build trust between some culturally-based or marginalised groups and officials.
9. Sedation for young people with intellectual disability:  
What is suitable sedation? There is some work in the area of sedation for dental treatment but not for treatment of other health issues.
10. Appropriate communications and clinical pathways in order to access the hospital system:  
There could be research into how to pave the way to be smooth pathways.
11. Weight management:
- How to deal with obesity when there is an intellectual disability involved, especially when food has been used by families as the major or the only reinforcer which has worked in dealing with behavioural issues;
  - What modifications should be made to weight management plans which are commonly used so that they can be used by people with an intellectual disability?; and
  - Access to tertiary services for support with weight issues which would be used by other overweight people - the role of home visits and the role of psycho- social factors leading to obesity for people with an intellectual disability.

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<sup>10</sup> A suggestion was made that Associate Professors Michael Arthur-Kelly and Ian Dempsey at the University of Newcastle could provide some perspectives on this area.



12. Sexual health:

There is a need for research into effective strategies for young males about appropriate management of issues such as masturbation. There are some resources for young females with an intellectual disability, but not young males and none known with a CALD focus.

13. Health Promotion activities:

Another research gap is understanding how to modify broader population health campaigns about issues such as having a healthy diet, women's health issues, maintaining oral health, so that messages also target people with ID. (The Health Fact Sheets produced by NSW Council on Intellectual Disability are relevant here.)

14. Support for families when there is a diagnosis of intellectual disability:

More research is needed to better understand the experiences of families when they get a diagnosis, their needs at this point of time and how to provide better support. More information is needed about resilience and the impact of resilience factors. Better understanding of what keeps some families together given the increased level of family breakdown when there is a family member who has a disability may assist in reducing levels of family breakdown.

15. Specialised assessment and screening tools

- a. More research is needed into behavioural equivalents for identifying symptoms of health issues such as depression, especially in populations which have more severe levels of intellectual disability where traditional tools are inappropriate;
- b. Research into the efficacy of using multi-disciplinary approaches to improve confidence in mental health diagnoses for people with an intellectual disability and to develop improved treatment paths.

16. Participation in mental health treatments such as counselling and psychotherapy by people with an intellectual disability:

- a. Issues of informed consent;
- b. Effectiveness of specific therapies e.g. CBT, group participation; and
- c. How to present or modify information so that it is more accessible to people who have an intellectual disability.

17. Spirituality:

Research into the development of spirituality in people with an intellectual disability and the role spirituality can play in health outcomes and quality of life more generally.



## Appendix A: Catalogue template

<b>Clinical/ non-clinical</b>	
<b>BROAD CATEGORY</b>	
<b>Title of project:</b>	
<b>Project key words:</b>	
<b>Investigators</b>	
Chief researcher:	
Other team members:	
Organisation:	
Contact details :	
<b>Project timeframe</b>	
Completed project: (please tick)	Yes <input type="checkbox"/> No <input type="checkbox"/>
Date of commencement of project:	
Date of completion/ anticipated completion of project :	
<b>Project description</b>	
Aims and objectives:	
Participants:	
Methodology:	
Results:	
<b>Project funding</b>	
Amount:	\$
Source:	
Category of source:	Government <input type="checkbox"/> Non-Government <input type="checkbox"/> Philanthropic <input type="checkbox"/>
<b>Publication details:</b>	