This is the published version:

Ottmann, Goetz and Crosbie, Jenny 2012, *What are the most important issues in the lives of people with intellectual disabilities? A comparative methods study*, Uniting Care Community Options: Deakin University, [Melbourne, Vic.].

Available from Deakin Research Online:

http://hdl.handle.net/10536/DRO/DU:30049324

Reproduced with the kind permission of the copyright owner.

**Copyright**: 2012, Uniting Care Community Options/Deakin University
What are the most important issues in the lives of people with intellectual disabilities?

A comparative methods study

Goetz Ottmann (PhD)
Jenny Crosbie
Uniting Care Community Options
Deakin University
Aims of the Study

People with learning disabilities and their families are increasingly asked to provide input regarding what is important to them in their lives and what services and supports they require to achieve their goals. There are many ways for people to contribute their ideas, but which of these provides the most accurate reflection of their views?

This research project sought to:

(1) Compare the views of people with disabilities with those of carers and service providers to highlight what these groups consider the most important issues in the lives of people with a learning disability.

(2) Compare the outcomes of a range of qualitative methodologies to identify a combination of methods that allows researchers to obtain the input of people with disabilities in an effective, safe and non-burdensome manner.

Suggested citation:

Ottmann, G & Crosbie, J 2012, What are the most important issues in the lives of people with a learning disability? A comparative methods study. UCCO/Deakin University QPS, Melbourne.
Table of Contents

List of Tables ........................................................................................................................................... v

Declaration of Originality .......................................................................................................................... 1

Project Partners and Acknowledgements ................................................................................................. 1

Executive Summary and Recommendations .............................................................................................. 2
  Key Findings ........................................................................................................................................... 3
  Key Recommendations ............................................................................................................................ 4

Introduction ............................................................................................................................................... 6
  Aims of the Research ............................................................................................................................... 6
  Research Questions ................................................................................................................................ 7

Review of the Literature ............................................................................................................................ 8
  Interviews ................................................................................................................................................ 8
  Questionnaires and Surveys ................................................................................................................... 10
  Focus Groups ......................................................................................................................................... 11
  Observation Studies ............................................................................................................................... 11
  Participatory Photographic Methods ..................................................................................................... 11

Methodology ........................................................................................................................................... 13
  Part One ................................................................................................................................................ 13
    Recruitment .......................................................................................................................................... 14
    Inclusion Criteria ................................................................................................................................... 14
    Exclusion Criteria .................................................................................................................................. 15
    Procedures ............................................................................................................................................ 15
    A: People with an Intellectual Disability ............................................................................................... 15
      Step 1: Survey Questionnaire ............................................................................................................ 15
      Step 2: Semi-Structured Interviews ................................................................................................ 16
      Step 3: Case in Point Observation .................................................................................................... 16
      Step 4: Photographic Intervention .................................................................................................... 16
      Step 5: Focus Group ........................................................................................................................... 16
    B: Parents and Carers ............................................................................................................................ 16
      Step 1: Survey Questionnaire ............................................................................................................ 16
      Step 2: Semi-Structured Interviews ................................................................................................ 17
      Step 3: Focus Group ........................................................................................................................... 17
      Step 4: Proxy Response ...................................................................................................................... 17
  Part Two: Delphi....................................................................................................................................... 17

Results and Discussion ............................................................................................................................. 18
  General Observations .............................................................................................................................. 18
  Recruitment ............................................................................................................................................. 18
  Process .................................................................................................................................................... 18
  Results of Methods: People with an Intellectual Disability .................................................................... 18
  Survey ..................................................................................................................................................... 21
  Semi-Structured Interviews .................................................................................................................... 21
Photographic Interventions ............................................................................................................ 22
Case in Point Observation .............................................................................................................. 23
Focus Group .................................................................................................................................... 23
Parents and Carers ............................................................................................................................ 24
Survey ................................................................................................................................................ 24
Semi-Structured Interview ............................................................................................................. 25
Proxy Response .................................................................................................................................. 25
Focus Group ....................................................................................................................................... 26
Outcomes of Method: Service Providers .......................................................................................... 27
General Comments ........................................................................................................................... 27
Methodological Considerations ......................................................................................................... 27
Discussion of Methods ...................................................................................................................... 27
Limitations .......................................................................................................................................... 31
Identified Issues ............................................................................................................................... 31
People with an Intellectual Disability .............................................................................................. 31
Parents and Carers ............................................................................................................................. 33
Comparison of Important Issues by Group ....................................................................................... 34
Service Providers ............................................................................................................................... 36
Implications for Practice ................................................................................................................. 39
References .......................................................................................................................................... 42
Appendix 1: Delphi Methodology .................................................................................................... 46
List of Tables

Table 1: Participants’ Information ........................................................................................................ 14
Table 2: Data Collection Methods ....................................................................................................... 15
Table 3: Results—People with an Intellectual Disability ..................................................................... 18
Table 4: Main Issues Raised by People with Intellectual Disabilities and their Carers.................... 32
Table 5: Top Issues Raised by each Group by Frequency .................................................................... 35
Table 6: Delphi Responses—Unranked and Ranked ......................................................................... 37
Project Partners and Acknowledgements

Project Partners:

- National Disability Services Victoria (NDS)
- Heatherwood School
- Uniting Care Community Options
- Deakin University

Acknowledgements:

We would like to acknowledge the people who made their time available for this study. Without them, this project could not have occurred. We would also like to thank our partner organisations, NDS Victoria and Heatherwood School, for their support. We are thankful for the seeding grant made available by the Strategic Research Centre of Quality and Patient Safety (QPS), affiliated with Deakin University’s School of Nursing and Midwifery. Without this support, this research would not have been possible.

Financial Support:

Deakin University, Strategic Research Centre of Quality and Patient Safety (QPS), School of Nursing and Midwifery.
Executive Summary and Recommendations

People with intellectual disabilities and the families of these people are increasingly asked to provide input in order to create optimal services and supports to achieve their personal goals. With an increasing emphasis on individualised planning, particularly in the context of a National Disability Insurance Scheme, it is more important than ever that the needs of people with an intellectual disability are well understood and catered for. A range of methods have been developed to capture the views of people with a disability. For researchers and practitioners, this raises the question of which combination of methods provides the best representation of their voices.

This study examines a suite of qualitative methodologies to obtain input from people with mild to moderate intellectual and learning disabilities and their families and carers to determine which mix of methodologies generates a good representation of their views. The methodologies examined included surveys and questionnaires, semi-structured interviews, focus groups, ‘case in point’ ethnographic observations, and photographic interventions. Family members were also asked to provide proxy responses to answer for the person for whom they care.

This study also sought to document the most important issues in the lives of people with intellectual disabilities from the perspectives of carers or family members and service provider staff. A Delphi-inspired survey was used to obtain responses from service provider staff about the most important issues in the lives of people with an intellectual disability.

The most important issues identified by people with an intellectual disability were those of contact with family and friends, attaining study and employment, ensuring access to technology and social networking, and attending community-based activities. Family members of people with intellectual disabilities identified employment, recreation and leisure activities, independent travel and having a valued role as the most important issues. Service providers identified relationships, health, accommodation, financial issues and high quality support staff as the most important issues.
Key Findings

- People with mild or moderate intellectual disabilities can offer valid accounts that are stable over time of those things that are important to them, provided appropriate research methods are used.
- Different methodologies generated different insights. Whereas more formal methods, such as semi-structured interviews, produced a number of issues that appeared to be frequently discussed with parents and carers (‘big ticket’ items), informal methods raised a number of equally important issues that were more related to everyday life. When asking carers to discuss issues, it is important to distinguish between complex issues and everyday issues, and to consider the short term, medium term and long term implications of each.
- In this study, semi-structured interviews (with a person with a disability) in conjunction with a photographic intervention method produced good outcomes that consistently covered most of the issues that were important to participants. It is likely that the ideal mix of methods will depend on the type of the research (whether it is evaluative, exploratory or another type).
- Additional methods, such as proxy interviews or ‘case in point’ ethnographic observations, can be used to validate the responses.
- Questionnaires and surveys represent a poor choice of method for carers, family members and principal participants. Focus groups can be difficult to organise and can produce information that is not as rich as semi-structured interviews.
- Methodological issues, such as recency effects, positive response bias and communication challenges, affected all methods. Positive response bias was not a major issue, principally because the study did not employ any evaluative questions. Recency effects can be easily overcome by carefully validating responses with reverse questioning or prompting. Communication challenges can be overcome by engaging an experienced interviewer.
- Methodologies such as participatory observation and photographic intervention provide people with communication difficulties with an opportunity to make meaningful contributions.
- The use of a photographic method was facilitated by the fact that many participants had a mobile telephone. If given enough lead time, a discussion focusing on photographs could occur concurrently with the semi-structured interview. Thus, only one face-to-face visit would be required.
- Proxy responses provided by service provider staff conveyed that disability services professionals have a good understanding of the issues affecting people with an intellectual disability. However, a simple survey, followed by an aggregation of responses, generated a picture that accentuated the agenda of service providers. A Delphi-type rating procedure was required to produce an outcome that reflected more closely the concerns of people with a disability.

**Key Recommendations**

A mix of methodologies should be used when seeking input from people with mild to moderate intellectual or learning disabilities to ensure a good representation of the issues that are most important in their lives.

When conducting an exploratory study that addresses an open-ended research question, the following mix of methods may achieve good results:

- Semi-structured interviews in conjunction with a photographic intervention with the principal participants; and
- Proxy responses and/or ‘case in point’ ethnographic observation to validate responses.

When relying on proxy responses from service provider staff, a Delphi-type rating process should be employed.
When seeking input from people with disabilities and their carers, researchers should consider the effect of the setting used. For example, a focus group held in a school setting will reproduce some of the cultural connotations of that context.

The findings of this study can be used by service providers to plan effective consultations with people with intellectual disabilities.
Introduction

Stakeholder consultations play an important role in the way Australian government agencies and industry service providers include people with disabilities in programme and policy design. Indeed, government departments have published guidelines that outline how people with a disability are to be involved ‘at every stage of the consultation’ (Commonwealth of Australia 2011). However, stakeholder consultations focusing on people with disabilities and their carers are often marred by a lack of clarity regarding the effectiveness of the research methods to be employed. While numerous research publications outline the benefits and disadvantages of different research approaches and highlight the need for multi-method research (Boland et al. 2008; Conyers et al. 2002; Preece & Jordan 2009; Raphael et al. 1993; Stoneman 2007), when seeking to capture the voices of people with disabilities and their carers, there is no research evidence available regarding the kind of methodological mix that is the most appropriate and effective.

This study employed a range of qualitative methods in a serial manner to determine how each research method contributes to capturing the voice of the participant in a complete and efficient manner. As the aim was to generate recommendations for government and service provider consultations, only methods that were less resource intensive were trialled. Methods such as narrative and life story approaches that require significant time and resources were excluded from this study.

The research yielded pilot data of the issues that stakeholders regard as significantly affecting the lives of people with disabilities and these people’s carers. It is expected that the research model will inform future stakeholder consultation research with people with disabilities.

Aims of the Research

The aims of this study were twofold:
1. To develop and test a mix of methods to involve people with intellectual disabilities in research and stakeholder consultations; and
2. To identify the most important issues facing people with disabilities, and their carers.

**Research Questions**

1. Which methodological mix produces the most complete representation of the voices of people with learning and intellectual disabilities?

2. Which methodological mix produces an adequate representation of the voices of people with learning and intellectual disabilities, with the greatest efficacy?

3. What are the issues identified by people with intellectual disabilities and their carers as the most significant issues affecting their lives?
Review of the Literature

Research evidence suggests that people with mild or moderate intellectual disabilities can provide valid accounts of their previous experiences, provided appropriate interview methodologies are used (Stenfert Kroese et al. 1998; Young 2006; Nind 2008; Moonen et al. 2010; Atkinson 1988). This leaves researchers and practitioners with the task of determining which methodologies are appropriate for different forms of enquiry. A number of methods recommend themselves when conducting a stakeholder consultation: structured, semi-structured, and open-ended interviews; questionnaires and surveys; focus groups; ethnographic observations; and photographic interventions. The following section discusses each of these methods in turn.

Interviews

Interviews are a widely used methodology to obtain the views of people with mild and moderate intellectual disabilities. However, interviews can produce a number of challenges, ranging from positive response bias (the reluctance to say something critical about a particular topic, particularly the provision of services) to recency effects (the increased likelihood of recalling those words said most recently) and the problem of acquiescence (a tendency to agree with the viewpoint of the interviewer). These challenges are not specific to people with learning difficulties, and can be observed when conducting interviews with the wider population.

Research conducted in the 1980s and 1990s sought to develop strategies to overcome these issues. In their seminal work, Glanzer and Cunitz (1966) pointed out that acquiescence and recency effects tend to be associated with a more structured line of questioning (Glanzer & Cunitz 1966). Hence, researchers have highlighted the benefits of using open-ended questioning and avoiding forced and categorical response formats (Wyngaarden 1981; Voelker et al. 1990). Forced choice scenarios and categorical response formats can be interpreted by research participants as being a formal test with a ‘right’ and ‘wrong’ answer (Chapman & Oakes 1995; Rapley 1995). A number of researchers have highlighted the
benefits of a carefully validated (Ramcharan & Grant 2001), less formal approach, instead of structured questioning (Atkinson 1988; Redworth & Redworth 1998; Jurowski & Paul-Ward 2007).

Another way to address the issue is to incorporate a variety of response formats that generate more options for research participants to express their views and introduce validation points, such as multiple-choice questions followed by open-ended questions. This appears to increase responsiveness and the validity of responses (Sigelman et al. 1982). A number of researchers experimented with the use of a simple analogue scale with pictorial anchors and questionnaires, with some using a three-point Likert scale (Degnan et al. 1994; Jurowski & Paul-Ward 2007). While the use of this tool resulted in more detailed information, it did not overcome positive response bias (Jurowski & Paul-Ward 2007). Moreover, the use of faces depicting emotions as the basis of the Likert scales was found useful only when accompanied by specific instructions or a preliminary test (McVilly 1995; Cummins 1993). Some researchers have argued against the use of preliminary tests, as this introduces a degree of formality that tends to inhibit research participants’ responses (Jurowski & Paul-Ward 2007).

Another approach employed by researchers to overcome methodological problems has been the use of a combination of methods, such as the use of triangulation to obtain additional data from independent sources—such as carers—to supplement interviews (Lovett & Harris 1987; Kabzerns 1985; Groove et al. 1999; Young 2006). This approach has yielded highly consistent data sets in a number of studies (Lovett & Harris 1987; Voelker et al. 1990). However, it has been found that some proxy respondents can find it difficult to separate their own views from those of the person for whom they respond (Cummins 2002). One possible way to mediate this is to give interview proxy respondents the opportunity to express themselves separately (Clegg 2003).

Interviews may also create a range of communication challenges, such as unresponsiveness (particularly in open questioning), difficulty generalising from experience, and thinking in abstract terms (Booth & Booth 1996; Clarke et al. 2005). To address these issues, authors advocate for a questioning style that contains a minimum of abstract concepts or questions
that rely on a temporal dimension. Others found that a question and answer format was more constraining than a statement or narrative approach (Lewis 2004). While this may be the case, some participants may require highly structured support to enable them to voice their opinions. However, this support may be regarded as distorting their voice (Lewis et al. 2008). Moreover, some participants may only have a limited vocabulary, which raises issues regarding the correct interpretation of their statements. Some researchers have recommended collaborations with speech and language specialists to ensure a better comprehension of participants’ statements (Cambridge & Forrester-Jones 2003).

Other approaches have been found to help to overcome communication issues, such as the use of visual communication support tools—including cue cards, talking mats or photographs—and the use of peer informants (Lewis et al. 2008; Brewster 2004). There is a growing consensus that the use of visual representations (such as life story books, visual game techniques, talking mats and cue or flash cards) and photographic images may increase the frequency and intelligibility of responses of people with communication difficulties and those with communication difficulties and/or more severe intellectual disabilities (Heal & Sigelman 1995; Booth et al. 1989; Frost & Taylor 1986; March 1992; Young 2006; Folkestad 2009).

**Questionnaires and Surveys**

Questionnaires are rarely used in research involving people with learning disabilities, as lower literacy levels among this population group tend to prevent their usage. Research attempting to overcome these limitations tends to either exclude those with lower literacy skills or reduce the authenticity of the voice of the research participants by using a proxy to complete the questionnaire (Townsley 1995; McConkey & Mezza 2001). A small number of studies have used a face-to-face interview-style, administering the questionnaire by using visual supports, such as cue cards (Nind 2008). Arguably, this type of augmented survey/questionnaire becomes indistinguishable from a visual tool–assisted structured interview, and should be treated as such.
Focus Groups

Focus groups are regarded as an alternative to interviews that provide research participants with a secure and supportive environment that can assist them to express themselves (Cambridge & McCarthy 2001). Focus groups have been used successfully in a number of studies (Barr et al. 2003). The challenges of conducting focus groups are associated with the combination of different behavioural needs, communication difficulties, sensory impairments and life histories (Nind 2008). Focus groups may be convenient in bringing together people who work or reside in the same location. However, a focus group setting may also exclude participants with significant communication difficulties (Nind 2008). In addition, even when conducted within the context of a photographic intervention, focus groups have been found to yield less information than one-on-one interviews (Jurowski & Paul-Ward 2007). Some researchers have argued that the use of skilled focus group facilitators and groups containing less than six participants may overcome these issues (Fraser & Fraser 2001).

Observation Studies

A number of ethnographic observation studies have been conducted to explore a range of issues in the lives of research participants. Ethnographic observation tends to generate methodological challenges regarding the interpretation of actions and utterances, and has also raised ethical issues for the researchers involved (Nind 2008). The current study’s researchers were unable to locate studies describing the efficacy of short case in point observations—observations that typically last no longer than two or three hours that can provide a context to interviews.

Participatory Photographic Methods

Photographic interventions have emerged relatively recently in the field of disability studies. Photographic interventions are thought to generate better responsiveness and a sense of ownership when engaging research participants in research. They are regarded as
particularly suitable for people with communication difficulties and have been recommended as a means to supplement other methods (Jurowski & Paul-Ward 2007). The use of photographs focuses more on research participants’ capacities and allows them to better steer and control the data generation and interpretation process. However, photographic interventions that request participants to take the photographs may exclude people with physical disabilities, unless carers are included in the process.

A number of photographic intervention approaches have been developed, ranging from the use of photo albums in open-ended interviews (Swain et al. 1998) to Photovoice—an approach that uses the photographs of participants to represent their individual lives (Booth & Booth 2003). There is some evidence that, compared to focus groups, Photovoice appears to highlight different, but no less important, issues in the life of a person (Jurowski & Paul-Ward 2007). Some researchers argue that it might be advantageous to enlist the assistance of caregivers in photographic interventions (Jurowski & Paul-Ward 2007). A number of more recent publications have highlighted ethical issues that researchers may encounter in an increasingly restrictive research environment. The key recommendations of these studies include the need to clearly articulate how privacy and anonymity concerns are being addressed (Boxall & Ralph 2009; Clark et al. 2010). The current study’s researchers were unable to locate research that systematically compared different methodologies. This study addresses this gap in the literature.
Methodology

There were two parts to this research project. The first part consisted of a comparison of the results of five qualitative methods involving people with intellectual disabilities and their families or carers. The second part of the study consisted of a comparison of qualitative methods results involving a survey and a Delphi-inspired ranking process that obtained data from service providers. To facilitate the methodological comparison, both parts focused on one question:

*In your opinion, what are the most important issues that affect the lives of people with intellectual disabilities?*

This question was rephrased appropriately for the research functions involving people with intellectual disabilities.

**Part One**

The participants of the study were young people with intellectual disabilities. All participants, except two, lived at home with their family. Four participants were in their late twenties. Six participants were in their late teenage years. The participants ranged from having high support needs, to functioning very independently. Disability types included cerebral palsy, autism, Down’s syndrome and generalised intellectual disabilities. None of the participants had complex communication difficulties that required augmentative or alternative communication. Part one was conducted between March 2011 and February 2012.
<table>
<thead>
<tr>
<th>Code</th>
<th>Gender</th>
<th>Age Range</th>
<th>Disability (Mild, Moderate or Severe)</th>
<th>Data Collection Point</th>
<th>Principal Known Disability</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>F</td>
<td>20–30</td>
<td>Moderate</td>
<td>Home and day programme</td>
<td>Moderate intellectual disability</td>
</tr>
<tr>
<td>B</td>
<td>M</td>
<td>15–19</td>
<td>Mild</td>
<td>School and work placement</td>
<td>Mild intellectual disability</td>
</tr>
<tr>
<td>C</td>
<td>F</td>
<td>20–30</td>
<td>Moderate</td>
<td>Home and day programme</td>
<td>Moderate intellectual disability</td>
</tr>
<tr>
<td>D</td>
<td>F</td>
<td>20–30</td>
<td>Mild</td>
<td>Home</td>
<td>Mild intellectual disability</td>
</tr>
<tr>
<td>E</td>
<td>M</td>
<td>20–30</td>
<td>Severe</td>
<td>Home</td>
<td>Intellectual disability with high support needs</td>
</tr>
<tr>
<td>F</td>
<td>M</td>
<td>15–19</td>
<td>Mild</td>
<td>School and home</td>
<td>Autism</td>
</tr>
<tr>
<td>G</td>
<td>M</td>
<td>15–19</td>
<td>Mild</td>
<td>School</td>
<td>Autism</td>
</tr>
<tr>
<td>H</td>
<td>F</td>
<td>15–19</td>
<td>Mild</td>
<td>School</td>
<td>Mild intellectual disability</td>
</tr>
<tr>
<td>I</td>
<td>M</td>
<td>15–19</td>
<td>Mild</td>
<td>School</td>
<td>Autism</td>
</tr>
<tr>
<td>J</td>
<td>M</td>
<td>15–19</td>
<td>Mild</td>
<td>School</td>
<td>Autism</td>
</tr>
<tr>
<td>K</td>
<td>F</td>
<td>15–19</td>
<td>Mild</td>
<td>School</td>
<td>Autism</td>
</tr>
</tbody>
</table>

**Recruitment**

Participants were recruited via case managers at a large service provider in the south eastern suburbs of Melbourne, and from a special school in the eastern suburbs of Melbourne.

**Inclusion Criteria**

Each participant was required to have a parent or carer who was also willing to participate in the study. The researcher met with each person to explain the study and gain informed consent.
Exclusion Criteria

Those excluded were people with an intellectual disability who wanted to participate in the study, but did not have a parent or carer who was willing to partake. People under the age of 16 were also excluded.

Procedures

Participants were asked to participate in five distinct qualitative methodological approaches. Participants were asked to complete a survey questionnaire, a semi-structured interview, a case in point ethnographic participant observation study, a photographic intervention, and a focus group. Carers were asked to complete a survey questionnaire, semi-structured interview and focus group.

<table>
<thead>
<tr>
<th>Table 2: Data Collection Methods</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>People with an Intellectual Disability</strong></td>
</tr>
<tr>
<td>Structured Questionnaire</td>
</tr>
<tr>
<td>X</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Parents/Carers of People with an Intellectual Disability</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Structured Questionnaire</td>
</tr>
<tr>
<td>X</td>
</tr>
</tbody>
</table>

A: People with an Intellectual Disability

Step 1: Survey Questionnaire

Participants were asked to complete a written questionnaire. If necessary, they were assisted by the researchers or a carer. The participant had the opportunity to provide up to five responses to the question, ‘In your opinion, what are the most important issues that affect the lives of people with intellectual disabilities?’ The question was rephrased in a number of ways to assist comprehension.
Step 2: Semi-Structured Interviews

Each participant undertook a semi-structured interview. These were either undertaken in the participants’ homes or at an education or training facility.

Step 3: Case in Point Observation

Each participant spent time with a researcher undertaking an ethnographic observation/interview process. This method sought to highlight issues associated with everyday contexts, such as those of work or training environments.

Step 4: Photographic Intervention

Each participant was asked to take 10 photographs that represented things that were important in their life. Two participants required carer assistance to take the photographs, due to physical or vision impairments. Participants then met with the researcher to describe the photographs.

Step 5: Focus Group

Participants were invited to attend a focus group session. The session was conducted at an education facility in Melbourne’s eastern suburbs.

B: Parents and Carers

Step 1: Survey Questionnaire

Participants were asked to complete a questionnaire. They had the opportunity to provide up to five responses.
Step 2: Semi-Structured Interviews

Each participant took part in a semi-structured interview.

Step 3: Focus Group

Participants were invited to attend a focus group session.

Step 4: Proxy Response

Parents and carers were asked to provide up to five responses on behalf of the person for whom they were caring.

Part Two: Delphi

The Victorian branch of a disability peak body contacted service providers via email to invite them to be involved in the study. Service providers were asked to reply to the email and list what they believed to be the most important issues affecting the lives of people with intellectual disabilities. They could provide up to five responses.

All the responses received were compiled into a list of the 20 most frequently mentioned issues. This list was then returned to all the service providers who had responded, with a request to rank the responses from one to 20, based on their perceived importance of each issue.
Results and Discussion

General Observations

Recruitment

There was considerable difficulty involved in recruiting participants for the study. This may have been because of the time involved and the need to have the commitment of both the person with an intellectual disability and their parent or carer. There was also concern regarding the capacity of some potential participants to complete the required tasks.

Process

The researcher went to the homes of four respondents to explain the study and gain their consent. All of the participants commenced providing information during this process. The researcher did not formally collect the data provided during these visits, as the intent of the visit was only to gain consent. In future, obtaining informed consent and data collection could commence concurrently.

Results of Methods: People with an Intellectual Disability

The following section provides an overview of the results achieved by each of the methods employed. An overview of the outcomes is presented in Table 3.

<table>
<thead>
<tr>
<th>Important Issues</th>
<th>Respondent Dyads</th>
<th>Questionnaire</th>
<th>Focus Group</th>
<th>Interviews</th>
<th>Observation</th>
<th>Photographic Intervention</th>
<th>Care Proxy</th>
<th>Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family</td>
<td>A</td>
<td>N/A</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>B</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>C</td>
<td></td>
<td>x</td>
<td>x</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>D</td>
<td></td>
<td></td>
<td>x</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Important Issues</td>
<td>Respondent Dyads</td>
<td>Questionnaire</td>
<td>Focus Group</td>
<td>Interviews</td>
<td>Observation</td>
<td>Photographic Intervention</td>
<td>Carer Proxy Response</td>
<td></td>
</tr>
<tr>
<td>-----------------</td>
<td>------------------</td>
<td>---------------</td>
<td>-------------</td>
<td>------------</td>
<td>-------------</td>
<td>--------------------------</td>
<td>---------------------</td>
<td></td>
</tr>
<tr>
<td>Gaining Employment/Volunteer Work</td>
<td>E</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Further Education (TAFE, Day Programmes, Activities)</td>
<td>A</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Computers, Mobile Telephones, IT Assisted Communication, Television</td>
<td>B</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Friends/Boyfriend/Girlfriend</td>
<td>C</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

19
<table>
<thead>
<tr>
<th>Important Issues</th>
<th>Respondent Dyads</th>
<th>Questionnaire</th>
<th>Focus Group</th>
<th>Interviews</th>
<th>Observation</th>
<th>Photographic Intervention</th>
<th>Carer Proxy Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hobbies and Interests</td>
<td>A</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>B</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>C</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>D</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>E</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>F</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>G</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>H</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>I</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>J</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Being Independent in the Community</td>
<td>A</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>B</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>C</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>D</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>E</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>F</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>G</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>H</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>I</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>J</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other, Including Access to Equipment</td>
<td>A</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>B</td>
<td></td>
<td></td>
<td></td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>C</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>D</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>E</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>F</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>G</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>H</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>I</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>J</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Church</td>
<td>A</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>B</td>
<td></td>
<td></td>
<td></td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>C</td>
<td></td>
<td></td>
<td></td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>D</td>
<td></td>
<td></td>
<td></td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>E</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>F</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>G</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Accommodation/Home</td>
<td>A</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>B</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>C</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>D</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>E</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>F</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>G</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Survey

The survey proved to be an ineffective method for this group of participants. As anticipated, only two of the participants with intellectual disabilities completed the written questionnaire. Even those participants who were competently able to read and write declined the opportunity to complete the written questionnaire. Some participants did not have the skills, while others lacked the confidence to complete the questionnaire. Those participants that did respond tended to provide one-word answers. Responses to the structured questionnaire tended to focus on issues that would be regarded as important lifestyle concerns, such as employment, accommodation, family and social life.

Semi-Structured Interviews

Six of the semi-structured interviews were conducted in a school environment. The remaining four semi-structured interviews were conducted in a home environment.

The semi-structured interview provided the opportunity for the researcher to develop rapport with the participant and probe for more detailed answers. Responses to the semi-structured interview questions tended to be ‘big ticket’ items—the issues that are
significant for most people, including accommodation, employment, further education, income, socialisation and so on. These issues form part of a ‘family/carer discourse’ and are the topics that are regularly raised, such as during discussions at the dinner table. They included future living arrangements, day programme activities, employment and leisure activities. Other methods added depth to this data by highlighting everyday issues that were equally important to the respondents. However, these supplementary methods overall failed to generate ‘big ticket’ items.

**Photographic Interventions**

The photographic intervention provided a more informal opportunity for participants to provide input. Half of the participants had their own camera or mobile telephone that they used to take the photographs. Others borrowed a camera provided by the researcher. The responses provided through the photographic intervention were less likely to be ‘big ticket’ items and more likely to be concrete objects that were grounded in everyday life and easy to photograph, such as iPods, computers and mobile telephones. The complementary nature of photographic interventions was also observed by Jurowski and Paul-Ward (2007). The participants enjoyed the photographic intervention. Photographic observation was particularly useful for people who were not outgoing in nature or confident in providing their ideas verbally (see Jurowski & Paul-Ward 2007).

As most people with a mild or moderate disability have access to a digital camera, photographic interventions are an effective and potentially low-cost way to supplement interviews. Research participants require sufficient lead time to take their photographs before the date of the semi-structured interview. The photograph discussion, analysis session and semi-structured interviews could be held during one face-to-face encounter.

In retrospect, it may have also been useful to ask people if there was anything else they would have photographed, if given the opportunity. This would have provided participants the option to comment on items more difficult to photograph or items they may not have been able to access at the time of the study.
**Case in Point Observation**

The ethnographic observation/interview responses were context specific. For example, observations that took place in a work setting tended to focus on work and employment. The participatory observation was also informal in nature, which allowed for expanded discussions of the issues raised. In many cases, observation sessions incorporated elements reminiscent of open-ended interviews. Many of the participants enjoyed the participatory observation as they were able to showcase aspects of their life that were important to them. Moreover, participants were able to visually demonstrate the issues they raised. This facilitated the contextualisation and, subsequently, the interpretation of statements.

Case in point observations tend to highlight one specific area of a person’s life. They can be used as a validation tool to indicate the degree to which issues have been covered by other methodologies. However, to obtain a clear representation of the issues that are important to people with intellectual disabilities, there would need to be a number of observations across a number of contexts, such as school, work, leisure and family. Hence, information obtained through the case in point observation interviews tended to confirm responses, rather than generating new insights.

It was found that the methodological challenges regarding data interpretation—such as those mentioned by Nind (2008)—can be relatively easily overcome if the observation forms part of a multi-pronged methodological approach.

**Focus Group**

It was very difficult to organise the focus group, as the potential participants had very different schedules and many were reliant on transportation provided by their parents. The one focus group that was eventually conducted comprised of three participants. This took place at an education facility in Melbourne’s eastern suburbs and was attended by the three participants who found the location convenient. The focus group generated a set of very limited responses that were strongly affected by the context (the focus group was held in a classroom) and the presence of peers. The participants required prompting and used the
information acquired by the other methods in order to participate fully. The focus group worked better once more structured questions were introduced (such as, ‘What do think is missing from your life at the moment?’).

The researchers made a list of the issues raised by the participants. The participants were then asked to rank these issues on a 10-point Likert scale. No graphical representation of the scale was provided, as participants did not require this. Participants easily managed this task; however, they responded by ranking the issues on what appeared to be a three-point Likert scale (high/medium/low importance). In retrospect, this would have been a more natural way to request them to rank the issues.

The process-oriented methodological issues associated with focus groups mentioned by Nind (2008) were not encountered, principally because the three participants had similar communication capacities. However, it is clear that the focus group session would have excluded participants with greater communication difficulties. The results of the focus group session in this study resonate with the findings of Jurowski and Paul-Ward (2007), who found that focus groups yield a more limited range of information. The small size of the focus group—suggested Fraser and Fraser (2001) as a possible way to avoid this problem—did not provide a resolution.

Parents and Carers

The following section provides an overview of the results of the methods employed with the parents and carers. An overview of these results is provided in Table 4 on page 32.

Survey

Not all of the parents and carers were able to complete the survey. Parents and carers who spoke English as their first language were able to respond more competently. However, participants from a non-English speaking background often lacked the confidence to complete the written questionnaire, while all except one completed the survey. The sample also included a number of respondents who had difficulty reading and writing. As a result,
they were unable to complete the survey. This suggests that surveys and questionnaires are not a suitable method for carers and family members because they potentially exclude a significant segment of this group.

The structured questionnaire provided a basis of discussion for those parents and carers who were able to complete it. Many of the parents and carers completed the questionnaire just prior to the semi-structured interview. These responses then formed the basis of the discussion during the semi-structured interview. The semi-structured interview provided the opportunity for the responses to be expanded with further information and anecdotes.

**Semi-Structured Interview**

The semi-structured interview provided the opportunity for parents and carers to ensure that the issues they regarded as important were adequately recorded. It also provided the opportunity for parents and carers to expand their responses with anecdotes and examples. Many of the responses focused on major decisions in life, such as accommodation, employment, day programme activities, recreation, friends and family.

For the parents and carers, the questionnaire and semi-structured interview were conducted within a short timeframe. The responses provided during the semi-structured interview gave depth to the responses provided in the questionnaire.

The semi-structured interview was the most effective method for parents and carers of people with disabilities, as it allowed all parents and carers to participate, and provided them with the opportunity to explore issues with the level of detail they considered necessary.

**Proxy Response**

Each parent and carer was asked to respond to the research question on behalf of the person for whom they cared. The parent or carer was encouraged to respond as if they were the other person. It is important to note that the issues that were raised during the proxy
interviews were significantly different to those raised during the semi-structured interviews. Overall, the parents and carers were able to undertake the exercise in good faith and demonstrated that they had a clear understanding of the issues that were important to the person for whom they cared.

**Focus Group**

It was difficult to organise the focus group for the parents and carers. Most of the parents and carers had competing demands, including work (sometimes shift work), caring for other family members and transport issues. These issues were overcome by holding the focus group via telephone. Again, many of the issues raised tended to be focused on important life choices, such as accommodation and employment—as was already raised during the semi-structured interviews. However, the accounts did not provide the same level of intimate detail as the semi-structured interviews. The focus group gave parents and carers the opportunity to share information and ideas about the issues that were important to people with intellectual disabilities. Indeed, at times, the focus group had connotations of a peer support group. Other issues that were raised tended to focus on parents’ concerns about safety and friendships. At the end of the session, participants commented on the fact that they found the session very useful.
Outcomes of Method: Service Providers

General Comments

Using a large peak body to distribute information about the study ensured that a large number and wide variety of service providers were contacted. Using email as the distribution and response format meant that it was relatively easy for service providers to respond. The response rate decreased by more than 50 per cent when service providers were asked to rank the responses.

Methodological Considerations

When asked for the five most significant issues affecting the lives of people with intellectual disabilities, service provider staff tended to focus on services—particularly the services provided by their agency. It was only when asked to rank the responses that service provider staff seemed to take the opportunity to distance themselves from their work context and provide a holistic proxy response. The ranking process enabled service provider staff to look beyond their own priorities and consider the needs of people with an intellectual disability. A single survey and an aggregation of the responses would have not generated this result.

Discussion of Methods

The methods employed generated two distinct discourses. More formal interview-based methods produced a discourse that focused on ‘big ticket’ issues central to the future of the person with a disability. On the other hand, the photographic intervention and ethnographic observation generated insights about everyday issues encountered by the person.

‘Big ticket’ items surfaced during the semi-structured interviews with people with a disability and their parents and carers. The issues that surfaced during the proxy interviews were noticeably different from the issues raised by carers and parents during the semi-
structured interviews and focus group. The parents’ and carers’ semi-structured interviews generated responses outlining their concerns about the future of the person in their care, the wider support system with which they dealt, and the stressful situations they faced. Similar issues were raised during the carer focus group, albeit not to the same level of intimacy. Hence, the parents and carers in this study were capable of differentiating between issues that were important to them, but not important to the person for whom they cared.

Thus, the outcomes of this study do not necessarily support Cummins’s (2002) claim that carers find it difficult to considers issues from the perspective of the person for whom they care. Indeed the current study found—as have other researchers (Groove et al. 1999; Kabzerns 1985; Lovett & Harris 1987; Young 2006)—that the proxy responses tended to match those provided by people with a disability during the semi-structured interview sessions. However, it is also true that some of the participants with a disability raised some ‘big ticket’ issues that were probably more important to their carers than to them. For example, most of the young people interviewed were happy to continue living at home with their parents, but spoke of moving out ‘one day’. However, parents saw future living arrangements as a very important issue and one that would not be easily resolved.

More informal methods, such as the photographic intervention and the ethnographic intervention, raised issues that were equally important to people with disabilities, but were probably discussed less with family members and carers. These typically related to hobbies and interests, specific socialisation activities, friendships, computer-games, social media, media streaming and home-based leisure activities. If these methods had not been employed, many of these issues would have been missed. Hence, to obtain an adequate representation of the voice of people with a mild to moderate intellectual disability, a mix of formal and informal research methods is required (see Groove et al. 1999; Kabzerns 1985; Lovett & Harris 1987; Young 2006). Moreover, the use of more informal methods allows participants with communication difficulties to meaningfully participate in the research.

In this study, it was found that the use of semi-structured interviews with people with a disability in conjunction with a photographic intervention produced an adequate
representation of issues (see Booth et al. 1989; Folkestad 2009; Frost & Taylor 1986; Heal & Sigelman 1995; March 1992; Young 2006). Given the availability of digital photography in the form of widely available mobile telephones, photographic interventions can be implemented with minimal extra resources and without increasing the burden on participants. In addition, proxy responses or ethnographic observation can be used to validate outcomes. However, it is likely that the ideal mix of methods will depend on the type of research being conducted.

The survey questionnaire produced poor outcomes when offered to people with a disability and to their carers and family members, as the survey format excluded participants with lower literacy skills and confidence, and those who were from a non-English speaking background.

Responses provided by participants were stable over time. The data collection period for each individual was three to six months. This timeframe gave the researchers the opportunity to test responses at different time points, several months apart. The results lead to the conclusion that people with mild or moderate intellectual disabilities can give valid accounts of their previous experiences that are stable over time, provided appropriate methodologies are used.

The focus group with people with a disability generated less insightful information. Moreover, both focus groups were very difficult to organise. Many of the participants with intellectual disabilities were reliant on their parent or carer to transport them to the focus group. Parents and carers had many varied responsibilities and it was difficult to find a timeslot that suited everyone. It was found that the only way to enable carers and family members to participate in the focus group was to organise a telephone conference.

Methodological challenges involving minor recency effects and acquiescence were encountered during the formal and informal methods that relied on verbal communication. These effects were more pronounced when involving participants with a moderate intellectual disability. Hence, this study did not support other research in which recency effects and acquiescence were observed particularly in the context of formal interview-
based methods (Atkinson 1988; Jurowski & Paul-Ward 2007; Redworth & Redworth 1998) featuring a more structured line of questioning (for example, Glanzer & Cunitz 1966; Voelker et al. 1990; Wyngaarden 1981). However, it is important to state that most of these studies focused on interviews within an evaluation context. It is possible that this different context shapes the way methodological challenges present themselves. Positive response bias did not play a major role, as the line of questioning was exploratory and open-ended and did not primarily involve a rating scale (Jurowski & Paul-Ward 2007). Both recency effects and acquiescence could be easily overcome by careful validation, probing and reverse questioning (see Ramcharan & Grant 2001).

Similarly, communication and interpretation challenges associated with some individuals were encountered during each of the methods employed. As anticipated, it was found that an experienced interviewer using visual representations of issues obtained through photos can relatively easily overcome communication issues. This outcome resonates with a growing body of research (Booth et al. 1989; Folkestad 2009; Frost & Taylor 1986; Heal & Sigelman 1995; Jurowski & Paul-Ward 2007; March 1992; Young 2006). Moreover, the input of carers or family members obtained in a separate proxy interview facilitated the interpretation of statements.

Proxy responses provided by service provider staff conveyed that disability services professionals have a good understanding of the issues affecting people with an intellectual disability. However, a simple survey, followed by an aggregation of responses, generated a picture that accentuated the agenda of service providers. A Delphi-type rating procedure was required to produce an outcome that reflected more closely the concerns of people with a disability.
Limitations

In the more formal methodologies—except the photographic intervention—participants were limited to five responses. In some cases, participants may have provided more responses if they had the opportunity.

In future studies, researchers should consider asking people to rate or rank (depending on what the research aims to achieve) their responses according to the effect it has had on their lives. This is particularly the case when people are asked for input regarding planning services and programmes that will support them. With limited funding, people will often not be able to have everything financially supported and will be forced to prioritise.

Researchers should also consider asking participants to think short term, medium term and long term when considering their responses. For example, young people living at home with their parents do not consider future accommodation as an important concern. However, once their parents are older, accommodation will become very important to them. Accommodation is a complex issue that often requires a longer lead time in terms of planning than other services require, such as recreation and day services.

Identified Issues

This section outlines the responses provided by people with an intellectual disability, their carers and their service provider staff. An overview of the issues raised can be found in Table 4 (on page 32) and Table 5 (on page 35).

People with an Intellectual Disability

Overwhelmingly, young people with an intellectual disability in this study had similar aspirations to their non-disabled peers (McDonald et al. 2011; Burchardt 2005). Their goals tended to focus around study, future work identities, relationships, friends and family. Many of the responses were commensurate with the thoughts and concerns of non-disabled
people of the same age. They were short-term issues that focused on here and now. They were not thinking too far into the future—rather, they were focusing on what is required to transition from childhood to adult life.

Six of the participants were in transition from school to TAFE or work at the time of the study. The research was able to identify some of the supports that they and their parents required to move forward, including support to access employment and further education courses.

![Table 4: Main Issues Raised by People with Intellectual Disabilities and their Carers](image)

Young people with intellectual disabilities use social networking sites to maintain contact with friends and to download information. Many of the participants had smart telephones and laptops that they used to access Facebook, YouTube and other social network and media streaming internet sites.

Employment is a goal for many young people with an intellectual disability. Others spoke of doing something they enjoy or consider important. Community-based activities are very important for young people with an intellectual disability. Many use funded services, such as Interchange, to assist them to socialise in the community. Living away from their parents...
more independently at some point in the future is also a goal for many young people with an intellectual disability.

Parents and Carers

Responses from carers and family members varied depending on the age and support needs of their child. Family members of young people with mild intellectual disabilities had high expectations for their children. Most parents expected that their child would obtain paid employment, live independently and move around the community independently. Parents who had children with higher support needs were more concerned about establishing an individualised support model for their child to meet both the child’s and family’s needs. Supported accommodation, stimulating activities, day programmes, respite, and reliable and skilled support workers were all important issues.

All parents reported concerns about the safety of their child in the community. In particular, parents were concerned about independent travel, exploitation and people taking advantage of their child.

A number of parents of school-leavers expressed concern about navigating the service system when their children left school. While at school, young people often receive a package of services. Post-school, the young adults have to take on a much greater advocacy role to gain the services they require.

The parent and carer questionnaire tended to raise issues central to independent life, such as employment, accommodation and valued roles.

Parent and carers universally wanted similar life outcomes for their child with an intellectual disability as they wanted for their other children. Parents and carers had very high expectations of what their child could achieve, and these were often similar to the expectations they had for their other children. For example, ‘It is very important for X to go to TAFE and get a qualification. Both the other children are at university’. 
Carers’ and family members’ responses were short and medium term in their focus. For example:

We are happy that X is living at home with us for now. Her sister is moving out at the moment and it has made us think a bit more about where she will live in the future. We haven’t really planned for her moving out at this stage.

Many of the parents of children finishing school expressed concern about how to navigate the service system now that their children had left school. A number believed that a case manager would be beneficial in assisting them.

Parent and carer proxy responses were often well matched with participant responses (see Table 4). This demonstrates that the parents and carers had a good understanding of what was important to their child with a disability, even if they did not necessarily agree with them.

Comparison of Important Issues by Group

Many of the people with disabilities who were involved in this study were under 25. Like their peers, they tended to focus more on concrete issues and issues relating to friendship and enjoying life. They were interested in study and work, spending time with friends and family and enjoying leisure activities.

Parents and carers focused on larger, medium to long term views of their child’s needs. They were more concerned about their child’s continuing life (finishing school, attaining employment, moving out of home, creating friendships, finding a partner) and were planning for the transition required.

There were a number of issues that were common to all three groups, including accommodation, jobs, meaningful activities and friendships. Relationships rated very highly for people with disabilities and service providers, but were not in the 10 most important issues stated by carers and family members.
Table 5: Top Issues Raised by each Group by Frequency

<table>
<thead>
<tr>
<th>Participants</th>
<th>Carers (Proxy)</th>
<th>Service Providers</th>
</tr>
</thead>
</table>
| 1. Family and Friends  
Spending time with friends (going to the movies, debutant ball), having a girlfriend/boyfriend | 1. Interests/Hobbies  
Singing, theatre, basketball, cooking, special Olympics | 1. Relationships  
Maintaining friendships and social networks, limited social networks outside family and paid support networks, sex and relationships/marriage, lack of strong and ongoing natural support networks, social isolation |
| 2. Obtaining Employment  
Earning money, working with computers, working with animals | 2. Friends  
Spending time with friends, social networking | 2. Health—Physical and Mental Health  
Poor health, access to health care, maintaining good health, obesity and healthy diet |
| 3. Day Programme/School/TAFE  
Attending an appropriate programme and gaining skills for the future | 3. Family  
Living with family, spending time together | 3. Accommodation  
Lack of accommodation options, living independently, lack of respite and supported accommodation, lack of choice about where to live and who to live with, availability of accommodation that caters for individual support needs |
| 4. Computers/Technology/  
Mobile Telephones  
Staying in touch with friends, playing games | 4. TAFE/Study  
Going to TAFE or further education to improve work opportunities | 4. Financial  
Poverty, wealth, having access to money/resources, income security, hidden additional costs to meet the needs of people with a disability |
| 5. Community-Based Activities  
Attending formally organised and not formally organised activities, such as outings, recreation and camps | 5. Ranked Equally  
- Work  
- Technology  
- Driver's licence  
- Transport/getting around  
- Day programme/volunteer work  
- Independence | 5. Support Staff  
A sustainable, well paid, trained and high quality workforce that can provide people with the support they need and desire |

Taking the approach that people with a disability are the experts regarding the issues that are most important in their lives, this study compared the top five responses of people with a disability with the top five responses of their family members and service providers.

Relationships, family and friends were identified by all three groups as very important issues. Hobbies and interests and community-based activities were important to people with disabilities and their family members.
Accommodation was only raised as an important issue by service providers. This might be explained by the age of the people with disabilities in the study (young people) and the fact that accommodation is one of the service types that is the least well provided.

Computers and technology are very important to people with disabilities. They use computers for entertainment, to communicate with others and to socialise. Neither the family members nor the service providers identified computer-based devices as an important issue in the lives of people with an intellectual disability.

Health was identified as an important issue by service providers, but not by people with disabilities or their family members. Service providers were also the only group to have ‘support staff’ in their top five issues. This might be because many agencies are having difficulty recruiting and retaining high quality staff.

Many of the family members’ responses focused around the transition from school to adult life. These issues included further study, creating friendships, attaining employment, travelling independently and obtaining a driver’s licence.

Family was important to people with disabilities and their family members. In this study, much of the daily support for people was provided by their family. Service providers did not identify family in their top five issues, which perhaps indicates that there is a lack of understanding in the sector of the important role that families play.

Service Providers

The ranked Delphi responses demonstrated that service providers generally do have a good understanding of the needs of people with an intellectual disability and are often in agreement with parents, carers and people with disabilities. The ranking of responses by service providers was:

1. Relationships;
2. Health—physical and mental;
3. Accommodation;
4. Financial concerns;
5. Support staff;
6. Self-direction/empowerment/valued roles; and
7. Support models.

A limitation of this Delphi study was the small number of ranked responses (n = 18). This may be because responses were only received from organisations or staff members that were very committed to service delivery for people with an intellectual disability.

The data shown in Table 6 indicates that service providers have a ‘service provision’ perspective regarding the issues of importance to people with disabilities, while family members are focused on a mix of what is important to them and to their family member.

Table 6: Delphi Responses—Unranked and Ranked

<table>
<thead>
<tr>
<th>Ranked Responses by Frequency</th>
<th>Unranked Responses by Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Relationships</strong></td>
<td></td>
</tr>
<tr>
<td>Maintaining friendships and social networks, limited social networks outside family and paid support networks, sex and relationships/marriage, lack of strong and ongoing natural support networks, social isolation</td>
<td><strong>Accommodation</strong></td>
</tr>
<tr>
<td><strong>Health—Physical and Mental Health</strong></td>
<td>Lack of accommodation options, living independently, lack of respite and supported accommodation, lack of choice about where to live and who to live with, availability of accommodation that caters for individual support needs</td>
</tr>
<tr>
<td><strong>Accommodation</strong></td>
<td><strong>Self-Direction/Empowerment/Valued Roles</strong></td>
</tr>
<tr>
<td>For description, see above cell</td>
<td>Valued roles—such as work, education and social roles—support people to achieve socially valued roles. Concerns included lack of input into decisions that affect their lives, the need for ongoing skill development to suit the learning needs of a person with an intellectual disability, opportunities to have quality of life and wellbeing that is meaningful to each individual, having their opinions heard/communication</td>
</tr>
<tr>
<td><strong>Financial</strong></td>
<td><strong>Social Inclusion/Public Perception</strong></td>
</tr>
<tr>
<td>Poverty, wealth, having access to money/resources, income security, hidden additional costs to meet the needs of people with a disability</td>
<td>Authentic community integration, opportunities to participate on a social level in communities, sustainable connection to community, acceptance and respect in the community, being able to join meaningful recreation activities, being a real part of a community, general community attitudes towards people with different abilities</td>
</tr>
<tr>
<td><strong>Support Staff</strong></td>
<td><strong>Employment</strong></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>A sustainable, well paid, trained and high quality workforce that can provide people with the support they need and desire</th>
<th>Employment opportunities, real wages, the lack of opportunities for appropriate employment, supported places are limited particularly in rural areas, lack of support to participate in the workforce and earn a living, valued work—either paid or voluntary</th>
</tr>
</thead>
</table>
| **Self-Direction/Empowerment/Valued Roles**
For description, see above cell | **Funding**
Lack of adequate funding to support people to fully participate in the community, inadequate funding to support people with complex needs, a system that is offering ‘thinking big’ with goal setting and not being able to provide the support to follow through with this |
| **Support Models**
Access to flexible and tailored supports, having a support system that is adequately funded and that maximises the use of those funds to address the level of unmet needs that currently exists, access to and creation of specialist and mainstream services in the community, linkage of services, cohesion among service providers | **Transport**
Access to affordable, easy to use and reliable transportation; assistance in purchasing and identifying appropriate motor vehicles to transport people with intellectual disabilities; financial assistance to pay for the modification of an appropriate motor vehicle; lack of frequent accessible public transport in rural areas; accessible transport |
| **Social Inclusion/Public Perception**
For description, see above cell | **Training and Education**
Limited day placement funding, lack of real inclusion in education and good educational outcomes, skills development (e.g. literacy, numeracy, living skills—such as use of money, cooking, etc.) |
| **Funding**
For description, see above cell | **Support Models**
For description, see above cell |
| **Access**
Having someone available to help whenever they have problems, accessing a case worker from the Department of Human Services or support networks | **Financial**
For description, see above cell |
Implications for Practice

- People with mild or moderate intellectual disabilities can give valid accounts that are stable over time of what is important to them, provided appropriate research methods are used.

- In order to produce the most complete representation of the opinions of people with learning and intellectual disabilities, a combination of methods is required that is beyond the scope of this study. The methods employed in this study, while producing an adequate representation, did not suffice to generate a picture that comes close to a complete representation.

- Different methodologies generate different insights. Whereas more formal methods, such as semi-structured interviews, produce a number of issues that appear to be frequently discussed with parents and carers (‘big ticket’ items), informal methods raise a number of equally important issues that are more related to everyday life. When asking carers to discuss issues, it is important to distinguish between complex issues and everyday issues, and to consider the short term, medium term and long term implications of each.

- A mix of methods producing an adequate representation of the voices of people with disabilities can be generated by combining one formal method with one informal method. In this study, semi-structured interviews (with a person with a disability) in conjunction with a photographic intervention method produced good outcomes that consistently covered most of the issues that were important to participants. It is likely that the ideal mix of methods will depend on the type of the research (whether it is evaluative, exploratory or another type).

- Additional methods, such as proxy interviews or case in point ethnographic observations, can be used to validate the responses.

- Questionnaires and surveys represent a poor choice of method for carers, family members and principal participants. Focus groups can be very difficult to organise and they produce information that is not as rich as semi-structured interviews.

- Methodological issues, such as recency effects, positive response bias and communication challenges, affected all methods. Positive response bias was not a
major issue, principally because the study did not employ any evaluative questions. Recency effects issues could be easily overcome by carefully validating responses with reverse questioning or prompting. Communication challenges can be overcome by an experienced interviewer.

- Methodologies such as participatory observation and photographic intervention provide people with communication difficulties with the opportunity to make meaningful contributions.
- The use of a photographic method was facilitated by the fact that many participants had a mobile telephone. If given enough lead time, a discussion focusing on the photographs could occur concurrently with the semi-structured interview. Thus, only one face-to-face visit would be required.
- Proxy responses provided by service provider staff conveyed that disability services professionals have a good understanding of the issues affecting people with an intellectual disability. However, a simple survey, followed by an aggregation of responses, generated a picture that accentuated the agenda of service providers. A Delphi-type rating procedure was required to produce an outcome that reflected more closely the concerns of people with a disability.

A combination of methodologies should be used when seeking input from people with mild to moderate intellectual or learning disabilities in order to ensure a good representation of the issues that are most important in their lives.

When conducting an exploratory study that addresses an open-ended research question, the following mix of methods may achieve good results:

- Semi-structured interviews in conjunction with a photographic intervention with the principal participants; and
- Proxy responses and/or case in point ethnographic observation to validate responses.

When relying on proxy responses from service provider staff, a Delphi-type rating process should be employed. In addition, when seeking input from people with disabilities and these people’s carers, researchers should consider the effect of the setting used. For example, a
focus group held in a school setting will reproduce some of the cultural connotations of that context.
References


Booth, T & Booth, W 2003, 'In the frame: photovoice and mothers with learning difficulties', Disability & Society, vol. 18, pp. 43-442.


Commonwealth of Australia 2011, National Disability Strategy 2010-2020, FaHCSIA, Canberra, ACT.


Fraser, M & Fraser, A 2001, 'Are people with learning disabilities able to contribute to focus groups on health promotion?', Methodological Issues in Nursing Research, vol. 33, pp. 225–233.

Frost, D & Taylor, K 1986, 'This is my life', Community Care, vol. 7, pp. 28–29.


Lovett, DL & Harris, MB 1987, 'Important skills for adults with mental retardation: the client’s point of view', *Mental Retardation*, vol. 25(6), pp. 351-356.


McDonald, P, Pini, B, Bailey, J & Price, R 2011, 'Young people’s aspirations for education, work, family and leisure', *Work, Employment and Society*, vol. 25, no. 1, pp. 68–84


Nind, M 2008, *Conducting qualitative research with people with learning, communication and other disabilities: methodological challenges*, ESRC National Centre for Research Methods, University of Southampton, Southampton.


Appendix 1: Delphi Methodology

Research guidelines for the Delphi survey technique

Consensus methods, such as the Delphi survey technique, are currently being employed to enhance effective decision making in health and social care. The Delphi survey is a group facilitation technique, which is an iterative multistage process that is designed to transform opinion into group consensus. It is a flexible approach that is used commonly within the health and social sciences. When used systematically and rigorously, the Delphi survey can contribute significantly to broadening knowledge.

The Delphi method originated in a series of studies that RAND Corporation conducted in the 1950s. The objective was to develop a technique to obtain the most reliable consensus of a group of experts (Dalke & Helmer, cited in Okoli and Pawlowski 2003).

Methodology

Step 1

National Disability Services sent an email to their members asking them to be involved in the study. Members were asked to reply via email to answer the following question:

In your opinion, what are the most important issues that affect the lives of people with intellectual disabilities?

Respondents were requested to provide five responses. All responses received by the closing date were included. Responses that were similar were grouped under appropriate headings.

Total number of responses N = 42.

Step 2: Ranked Responses

All service providers who submitted a response were included in the second part of the study. Service providers were sent a list of the 20 issues that were the most frequent responses and were asked to rank them in order of importance from one to 20.

Total number of responses N = 17.