



## **Where we are in the 21<sup>st</sup> century: Bringing out the voices of people with intellectual disabilities**

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### **Abstract**

Recent changes in the field of special education have led to a greater focus on agency, self-advocacy and rights of persons with intellectual disability (ID). It is increasingly acknowledged that the views and experiences of people with ID are important, and need attention (Claes, et. al., 2012; Petry & Maes, 2008; Ramcharan & Grant, 2001; Tangen, 2008; Young & Cheeson, 2006). A number of researchers, conducting both qualitative and quantitative studies, started collecting data directly from people with ID (e.g., Claes et al., 2012; Cooney, Jahoda & Knott, 2006; Faragher & Brown, 2005). We now know more about the challenges that have surfaced, as well as the strategies that have been put in place to address them.

This paper first introduces challenges and strategies found in the literature, using Tourangeau's model of survey response process as a working framework (Tourangeau, Rips & Rasinski, 2000). We argue that what can be found in the literature is still limited and needs further adaption for research on people with ID, most particularly when collecting self-reported data. As Fujiura (2012) pointed out, "a more nuanced portrait of self-report may yield new opportunities" (p. 354). We share an account of a worked example through our study, and propose a more inclusive adaptation of Tourangeau's model. It is our hope that by making visible the challenges as well as the inclusive strategies involved in our study we are able to provide researchers and practitioners with some useful insight and practical suggestions for their field work.

**Key Words:** Intellectual disabilities, research methodology, Tourangeau's model

## Introduction

Research aimed at people with intellectual disabilities (ID) has traditionally faced a conundrum related to the issue of voice. Voice is important, particularly when investigating subjective issues, as it is thought that people have “privileged access” to their own minds (Alston, 1971, p.223). However, research involving people with an intellectual disability has most often relied on proxy accounts, instead of tapping on the direct voice. For example, in their quality of life study of 94 people with ID and autism, Beadle-Brown and colleagues (2009) collected direct data from 12 persons and proxy data for the other 72 persons, either from a parent or a caregiver. Alverson and colleagues (2010) conducted a literature review of post-school outcomes data collection methods among those studies. They found that in more than half of the 100 studies reviewed, the respondents were either proxies, or not reported at all. Researchers have also noted that the evaluative method of using proxy responses does not offer a compelling theoretical credibility (Rapley, Ridgeway, & Beyer, 1998). On the other hand, the overwhelming focus on proxy data is perhaps understandable, given the particular challenges of research with persons with ID. It is increasingly acknowledged that the views and experiences of people with ID are important, and need attention (Claes, et. al., 2012; Petry & Maes, 2008). As a result of their work, we now know more about the challenges that have surfaced, as well as the strategies that have been put in place to address them.

Tourangeau’s model of survey response (Tourangeau, 1984) has been adopted among many studies to investigate how people answer and respond to questions (Ryan, Gannon-Slater, & Culbertson, 2012; Schwarz, 2007; Tourangeau & Bradburn, 2010; Tourangeau, Rips, & Rasinski, 2000). Comprising four major components, the foundational component is *comprehension*, which entails correctly understanding and interpreting questions by being able to attend to questions and instructions, identifying right focus of questions and link relevant concepts to key terms of questions (Tourangeau, Rips, & Rasinski, 2000). The second component of the model is *retrieval*, which involves a series of recalling tasks by adopting strategies and cues to retrieve specific events, and making inferences to fill in gaps in partial recollections (Ryan, Gannon-Slater, & Culbertson, 2012). The third component of responding is *judgment*, which can be seen as the process of using information from the stages of comprehension and retrieval to formulate answers to questions. The fourth component of the model is the production of *response*, in which process respondents actively map their judgment onto response options and edit their answers (Tourangeau, Rips, & Rasinski, 2000). Note that the components should not be treated as linear, although they are represented as such (see Table 1). That is, in the actual survey response process, these components may come into play at any stage.

| Component     | Specific Processes  |
|---------------|---|
| Comprehension | <ul style="list-style-type: none"> <li>• Attend to questions and instructions</li> <li>• Represent logical form of question</li> <li>• Identify question focus (information sought)</li> <li>• Link key terms to relevant concepts</li> </ul>   |
| Retrieval     | <ul style="list-style-type: none"> <li>• Generate retrieval strategy and cues</li> <li>• Retrieve specific, generic memories</li> <li>• Fill in missing details</li> </ul>  |
| Judgment      | <ul style="list-style-type: none"> <li>• Assess completeness and relevance of memories</li> <li>• Draw inferences based on accessibility</li> <li>• Integrate material retrieved</li> <li>• Make estimate based on partial retrieval</li> </ul> |
| Response      | <ul style="list-style-type: none"> <li>• Map judgment onto response category</li> <li>• Edit response</li> </ul>  |

Table 1: Tourangeau’s Model (Adapted from Tourangeau, Rips, & Rasinski, 2000, p.8)

### Strategies and challenges in research with people with ID

Studies involving persons with ID often screen potential participants for severe language and communication difficulties (Booth & Booth, 1996; Finlay & Lyons, 2001; Fujiura, 2012). However, even among selected (and therefore “capable”) participants, difficulties may exist. Thus, a finer analysis employing Tourangeau’s model seems productive. In terms of the component of Comprehension, people with ID usually ‘mis-interpret’ question content and intent. Fujiura (2012) gives the example of the use of the seemingly simple word “friends”, which can carry widely variable meanings for persons with ID, depending on their social histories. In terms of Retrieval, researchers have reported the problem of ‘recency bias’, or the tendency of persons with ID to select the last option from multiple-choice type questions (Perkins, 2007; Stancliffe, 2000). Recency bias can hinder their process of retrieving memories and cues to answer questions. Most challenges seem to relate to Judgment. Participants may have problems making ‘time-based judgments’ or with making ‘direct comparisons’ (Finlay & Lyons, 2001). For example, participants, when being asked about a specific event, may report inaccurate dates and times. Direct comparison in questions, such as “Do you feel closer to your parents or to your friends?” can also be difficult. From the perspective of Response, people with ID may have ‘limited verbal language’, which can affect their responses to questions (Booth & Booth, 1996; Finlay & Lyons, 2001). Another challenge is that of ‘acquiescence’, or saying yes, regardless of question content, which is prevalent among people with ID (Perkins, 2007; Ramirez, 2005; Sigelman, Buhd, Spanhel & Schoenrock, 1981). This tendency, which is often seen as an expression of social desirability or submissiveness, can definitely interfere with Response.

Researchers have proposed and adopted strategies to address these challenges. An essential strategy would be that of ‘simplifying language’. Shorter sentence structures and more specific vocabulary usually make questions more accessible to these participants and can mitigate the comprehension challenge. Researchers could reduce or avoid questions that involve direct comparisons (Finlay & Lyon, 2001). Due to the above mentioned challenges, it is not

uncommon to collect information by communicating with a third party other than respondents with ID, which takes the form of proxy data (e.g., Beadle-Brown et al., 2009) as opposed to direct data (e.g., Cui, Stapleton, & Suttle, 2008).

Some researchers have pointed out that ‘open-ended questions’ may work better in flexibly accommodating the retrieval and judgment behaviours of people with ID, thus reducing the occurrence of recency bias and acquiescence (Booth & Booth, 1996; Finlay & Lyon, 2001). ‘Situational marker’ is another strategy that can be used as support for time-based questions that challenge this population. A significant event can be identified in the respondent’s life (by gathering such information prior to interview), and used as a marker for questions relating to that period of time of the event happened (Finlay & Lyon, 2001).

| <b>Component</b> | <b>Challenge</b>  | <b>Strategy</b>   |
|------------------|---|---|
| Comprehension    | <ul style="list-style-type: none"> <li>• Mis-interpretation</li> </ul>  | <ol style="list-style-type: none"> <li>1. Screening participants</li> <li>2. Simplifying language</li> <li>3. Collecting proxy data</li> </ol>  |
| Retrieval        | <ul style="list-style-type: none"> <li>• Recency bias</li> </ul>  | <ol style="list-style-type: none"> <li>1. Screening participants</li> <li>3. Collecting proxy data</li> <li>4. Using open-ended questions</li> <li>5. Using situational marker questions</li> </ol> |
| Judgment         | <ul style="list-style-type: none"> <li>• Recency bias</li> <li>• Difficulty in time-based judgment</li> <li>• Difficulty indirect comparison</li> </ul> | <ol style="list-style-type: none"> <li>1. Screening participants</li> <li>3. Collecting proxy data</li> <li>4. Using open-ended questions</li> <li>5. Using situational-marker questions</li> </ol> |
| Response         | <ul style="list-style-type: none"> <li>• Recency bias</li> <li>• Acquiescence</li> <li>• Limited verbal language</li> </ul>                             | <ol style="list-style-type: none"> <li>1. Screening participants</li> <li>3. Collecting proxy data</li> <li>4. Using open-ended questions</li> <li>5. Using situational marker questions</li> </ol> |

Table 2: Consolidation of Challenges and Strategies to Tourangeau’s Model

### **An account of a worked example**

In the following sections, we share a worked account of how we fine-tuned our strategies to become more inclusive in nature, and as such, more accessible to our participants.

This research project is a Quality of Life (QOL) study focusing on the post-school outcomes of youth with mild ID in Singapore, using a mixed methods design of qualitative and quantitative measures. The QOL framework that forms the basis of our project underscores the focus of our investigation, namely the views and experiences of our participants. As such, it is of critical importance that participants’ voices be heard directly, and not through proxies. Participants were recruited with the assistance of our collaborating organization, an adult centre that works with persons with ID. A total of 106 participants, all with mild ID and in the age range of 19 to 34, agreed to participate in our study. Parental consent was also obtained for all participants, in keeping with the protocols that we set together with our collaborator. This research project received ethical approval from the authors’ affiliated institute of higher learning.

The instrument used in the study is the Quality of Life for Persons with Intellectual/Development Disabilities questionnaire (QOLP-ID/DD) (Renwick & Myerscough, 2012), based on a Quality of Life conceptual framework by the Centre for Health Promotion in Toronto (Raphael, Brown, Renwick & Rootman, 1996). It has an open-ended interview format and the questionnaire can be presented and completed through “a series of short conversations” (Renwick & Myerscough, 2012, p.15). Basically key questions – those questions that require responses to be recorded - are accompanied by two or three optional support questions. Support questions can be used to clarify a key question, or to provide some context so as to facilitate the cognitive processing and responses of participants. This enables a more individualized and flexible fit for the study participants, and also strengthens the validity of responses.

Additionally, we carried out a small pilot study with several volunteers with ID, so as to get a sense of potential difficulties and possible solutions to these. Some visual options in the QOLP-ID/DD screening tool were found to be small and unclear. We replaced them with bigger and clearer pictures. Where possible, the new options are also culturally more appropriate in the Singapore context. For example, a picture of a strawberry was replaced with a picture of a durian, which is a common local fruit. The objective of replacing items is to ensure clarity and reduce confusion on part of our participants, thus minimising potential problems at the initial stage of our study.

### **Additional challenges and strategies identified**

In trying to administer the instrument QOLP-ID/DD, we faced most challenges documented in the literature. However, six additional challenges were identified. ‘Guardian interference’ is a unique challenge when conducting research with this special population. The term “guardian” in our context includes the parents or main caregivers of our participants. Most of our participants were accompanied by their guardians when coming for the survey interview. Guardians can be either very protective or domineering during the interview process. Their voice could overwhelm voices of participants. Also, participants were at times easily distracted and showed signs of fatigue, due perhaps to the unfamiliarity of context. Oftentimes participants’ personal contexts play a key role in to engaging them in attending to the survey questions. It is challenging for people with ID to relate their personal experience with others’. This limits their abilities to relating things and become a challenge of ‘disassociated experience responses’ and further hinders the retrieval process during the survey interview. ‘Exam syndrome’ and off-topic responses are two other challenges that our team has encountered. As our participants’ previous experiences with question-and-response situations were mostly restricted to school examinations and tests, they tended to regard our survey as a test with “right” and “wrong” answers. We also found that our participants tended to veer off-topic and sometimes gave responses that were only remotely relevant.

Our research team tackled these challenges with strategies that are presented in the following sections. Numbering of each strategy follows the sequence of previous five strategies reviewed and consolidated earlier in our paper (See Table 2).

**6. Preparing the participants.** As participants are required to use a Likert-type scale in the questionnaire, we developed a procedure based on the pre-test from ComQol (Cummins, 2005)

to familiarise participants with the use of the Likert scale, using both concrete and abstract references. This was very useful in helping participants with their responses.

**7. Re-ordering related questions.** The QOLP-ID/DD is a comprehensive questionnaire that covers a wide range of QOL domains. However, the breadth of coverage can make it time-consuming to be administered and completed. Participants with ID may have attention and memory deficits, adding further challenges to their survey response process. Our strategy was to re-order survey questions in the QOLP-ID/DD, by grouping related items together. For example, questions relating to hygiene, body care, self-care routines, neatness and personal appearance were pulled together as a group, while questions relating to socialising and interacting were placed together. These modifications were undertaken to make the interview process more efficient, as the participants can stay on a topic for a while, thus reducing going the back-and-forth present in the original format. We also wished to reduce the time spent on the interview, as long interviews can tire the participant (and often, the interviewer as well). Another concern was that lengthy interviews may affect the quality of responses. Finally, we also felt that the re-organised format simulated the flow of a natural conversation, which could enable the participants to be more relaxed and responsive while answering questions.

**8. Simplifying explanation.** Much has been written about the importance of clarity of meaning in questions. Finlay and Lyon (2001) described in detail the importance of question content, in terms of vocabulary and abstract concepts, most particularly in questionnaires that assess mental and subjective states, and that involve judgments of frequency or degree. Words in the questions that are unfamiliar, vague or that can be interpreted in different ways should be simplified; alternatively a question can be re-worded. One aspect of comprehending a question is that there are variations in personal definitions of a concept. For example, a question like “Are you okay?” can be understood by participants as a question about whether they are well or sick, or as a question about how they feel. Thus extra care should be taken during the simplification process in retaining the intention of the question (Fujiura, 2012). In sum, the purpose of simplifying questions, and making them as straightforward as possible, is to improve the respondents’ comprehension of questions. During our pilot sessions, the research team noted that one of questions in our survey, “*How much do you think of yourself as a distinct person?*” was not well understood by our volunteer participants. We examined breakdown points for responses from every volunteer participant, and also questioned several of them to get to know how they approached the question before we simplified the question. To make it simpler for participants, we split the question into two parts. The initial question was “*Do you think you are special?*” If the respondent said yes, this was followed up with “*Tell me how you are special?*” If the respondent said no, this was followed up with the support questions that were already provided in the questionnaire: *What kind of person do you think you are? How are you the same as other people? How are you different from other people?* A key aspect of the simplification process in our study is that, as far as possible, we used language at the level of a third grader because the lowest level of comprehension of the participants was about that of a third grade student, although some of them were more capable. Literature also advocates plain language for participants with ID (Cameron & Murphy, 2006; Iacono & Murray, 2003; Roberts & Roberts, 1999). Finally, we also took into account the fact that for many of our participants, English is not their first language, even if they do use it widely in an everyday context.

**9. Adding personalised context.** Researchers have noted that the reliability of a response can be enhanced if a question is modified to suit participants based on individual backgrounds or experience, without compromising the intention of that particular question. Such contextualisation can facilitate estimations of time (Finlay & Lyon, 2001), and also help with the interpretation and formulation of a response from participants (Fujiura, 2012). In other words, personalised contextualisation can aid respondents with *retrieval* of information from long-term memory, with *judging* the information they have retrieved – how it matches the question that was asked – and with coming up with a *response* (components B, C and D of Torangeau’s model, Table 1).

In the pre-interview preparation, we read each participant’s profiling documents and collected information from the collaborating institution, job coach or guardian to familiarise ourselves with participants’ backgrounds before the survey interview. Thus, we were able to use questions that refer to specific activities. As Finlay and Lyons (2001) noted, “Questions may be more successful when situated in specific contexts or events from the person’s own life (p.330)”. One question in the QOLP-ID/DD that we modified originally asks “*Is it important for you to celebrate special events? How important?*” Before asking this question, our interviewer may build some context by saying “*Let’s talk about your birthday. Do you celebrate your birthday?*” This would lead the participant to remember and talk about his or her birthday celebrations. Only after the participant has shared for a few moments, will the interviewer ask the key question. For those who do not celebrate birthdays, support questions centering on local celebrations like Chinese New Year and Hari Raya are asked. Embedding questions in personal experiences, as described above, was part of our efforts to help with the recall processes of individual participants. Differences in cultural contexts were also addressed. Some questions had to be re-phrased or even changed to suit the Singaporean context. For example, an item in the questionnaire refers to watching people play a game like baseball or hockey, neither of which is much played in Singapore. The games were changed to football and basketball, which are both popular Singapore sports. Finally, to cater to participants who are more conversant in Mandarin, QOLP-ID/DD was translated into Mandarin. Back translation was performed to ensure the evidence of validity. However, in order to establish a confidence level of frequently occurring experiences for some questions, we repeated similar questions in various domains, in which specific activities and single events were referred to. This was partially done when we re-ordered the questions as mentioned earlier and re-enacted through interview.

While literature has focused on the need to reduce response biases of individuals with ID in a research context, there is little material on improving the questioning behavior of interviewers. It is a particularly important issue when working with individuals with ID, who may, for example, perceive interviewers as persons of high status (Heal & Sigelman, 1995). This leads us to further look into the improvising interview procedures.

**10. Improvising interview procedures.** A major contributing factor in inaccuracies of response is the uncertainty of interviewers themselves. Tourangeau, Rips and Rasinski (2000) point out that interviewers should know the definitions of key terms in questions, so that they can offer consistent and appropriate clarification when respondents need them. Finlay and Lyon (2001) also recommend that interviewers use follow-up scripted questions to establish the meaning of the participants’ responses, if needed. The research team put extra effort in training and improving our questioning techniques, based on our experience during pilot sessions. In addition

to modifying key questions as described in the section above, we also selected two support questions from those provided in the questionnaire, and went through the meanings of major concepts and appropriate ways of expressing them.

The strategy of improvised procedures can also be applied to at least four aspects of the interview procedure, although it should be used with caution. One aspect is ‘flexible schedule’. We went down to the center to meet with participants who were clients of the adult center. Participants who were not clients of the adult center, on the other hand, were allowed to choose an interview site and time at their convenience. This meant that interviewers sometimes had to conduct interviews in the evenings, or during weekends. In terms of the second aspect, ‘informal style’, we realised that our participants tended to respond to questions as if they were doing a test, where no matter what options are provided, there is only one right answer. This could perhaps be due to their lack of exposure to surveys. We then adopted a more relaxed, conversational style which also fitted in well with the modified questions. For example, when meeting participants, the interviewer would ask how participants had travelled to the place of interview. Whether they came in their parents’ car, or took the train, bus or taxi, participants’ responses provided a useful point of reference for several key questions on mobility, “Is it important for you to get around? How important?” and, “Are you happy with how you get around? How happy?” Interviewers then fitted in customized support questions such that these questions suited individual participants’ situations. For example, for a participant who took a bus, the interviewer would say, “I remember you said you took a bus here this morning. Do you usually travel on buses? How about trains, do you use the MRT?” If it was a participant who came with her mother in a car, “Earlier you told me that your mother drove you here. Does she usually drive you to places? Have you taken a bus? How about trains, do you use the MRT?” In terms of the third aspect, ‘flexible time’, research on survey response indicates that in general, accuracy of responses improves when respondents are given more time (Blair & Burton, 1987). In cases where respondents have cognitive impairments, this strategy can be particularly helpful, as more time may be used to compensate for processing difficulties. The strategy here was simply to pause after a question and wait (in an encouraging manner). This strategy was applied to all questions. Initially, interviewers had to consciously think to themselves: Pause... Wait. As interviews progressed, as our participants relaxed and talked, the pausing and waiting became more natural and unconscious. Whenever we detected signs of fatigue, breaks were allowed in the process. In terms of the fourth aspect, ‘small talk’, we found that at times during our pilot sessions, our inclination was to ask support questions as soon as we saw a respondent seeming to struggle with coming up with a response to a key question. We addressed this by embedding key questions within a sequence of “small talk”, then the key question, and followed by support questions if needed. This strategy was only used for more challenging questions, such as the key question, “Do you sometimes do things to make yourself feel more peaceful inside?” However, we caution that issues of consistency and validity may be affected with this kind of flexible practice. More discussion regarding this will follow in a later section of this paper.

**11. Avoiding the voice of guardians.** An important aspect that interviewers need to attend to is that of working with the guardians of participants. The presence of a guardian can be helpful to both the interviewer and the participant - for example, the guardian can provide some background information which can help the interviewer to approach the interview process, while at the same time act as a familiar and supportive presence for the participant during the interview.

On the other hand, there may be a guardian who is over-protective, anxious, or controlling. Learning from the pilot study experience, the research team developed a guardian questionnaire that the guardians could fill on their own while participants were being interviewed. The purpose of the guardian questionnaire was two-fold. Firstly, it served an important means of obtaining another perspective of the experiences of our primary participants. Secondly, it also enabled some triangulating of the data that we obtained from our primary participants. Thirdly and most crucially, since guardians were engaged in completing the parent survey, there was less opportunity for them to overwhelm the participants' voice.

## **Conclusion**

Overall, this current study addressed methodological issues relating to research with participants with ID. As the focus on the voice of marginalised people becomes increasingly important, especially when involving service outcomes and policy making, researchers in fields such as quality of life continue to seek sound research methods to present the true voice of such persons. This study has adapted Tourangeau's original model for participants with ID and provided new observations. The new component of Participation was identified in this inclusive adaptation, arising through the emphasis of participants' voices of this current study. Challenges adaptation to the Tourangeau's original model to include participants with ID, we did face a dilemma in balancing our methodological decisions between flexible interview procedures and instrumentation issues (e.g., reliability and validity). In order to solicit authentic responses of participants with ID, a more flexible procedure to survey questions is a must. However, flexibility has to be adopted with caution. We invite researchers to address this issue in future studies.

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