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ORIGINAL ARTICLE

## Fumblings and faux pas: Reflections on attempting to engage in participatory research with people with an intellectual disability

Kate P. Dorozenko , Brian J. Bishop and Lynne D. Roberts 

School of Psychology and Speech Pathology, Curtin University, Perth, Australia

### ABSTRACT

*Background* Reflexivity is fundamental to developing methodologically and ethically sound research and is particularly important for researchers exploring experiences of oppression.

*Method* We offer reflections on the process of engaging in participatory research with people with an intellectual disability (ID). A reflexive journal was maintained throughout the duration of a research project that used photovoice and conversational interviewing to explore the identities and social roles of 18 members of an advocacy agency for people with ID.

*Results* Challenges and tensions arose throughout the research process, including difficulties reproducing “ideal” participatory research, issues of informed consent, and tensions surrounding the beneficiaries of the research. Broader social processes were mirrored in interactions with the members, and damaging stereotyped identities were unknowingly imposed.

*Conclusions* Self-awareness and critical reflection is necessary to ensure that the existing power relations in traditional disability research (and wider society) are not replicated during the research process.

### KEYWORDS

intellectual disability;  
participatory research;  
reflection; reflexivity;  
empowerment

Those who create new settings always want to do something new, usually unaware that they are armed with, and will subsequently be disarmed by, categories of thought which help produce the conditions the new setting hopes to remedy. (Sarason, 1974, p. xii)

### Introduction

Reflexivity is the process of critically reflecting on the kind of knowledge produced and how that knowledge is generated (Guillemin & Gillam, 2004). Researchers bring with them their own orientations and values, shaped by a range of social and historical factors, that inevitability enter into and shape their work (Northway, 2000). Rather than attempting to conceal those values that govern research or maintain a detached, objective role, the reflexive researcher acknowledges that objectivity is impossible. Instead, subjectivity is considered a strength or resource of the research that should be acknowledged and revealed (Henwood & Pidgeon, 1992; Schön, 1983). Reflexivity is an active, ongoing process that saturates every stage of the research (Guillemin & Gillam, 2004). The process of scrutinising one’s own values, motivations, actions, and characteristics in the research process is personally revealing, and at times

leads to uncomfortable conclusions (Oliver, 1997). However uncomfortable, recognising the limitations of the knowledge produced ultimately enhances the overall quality of the research (Guillemin & Gillam, 2004).

Vernon (1997) argued that reflexive practice is especially critical for researchers exploring experiences of oppression. Disability researchers must be self-critical of their own values, assumptions, and practices to ensure that they do not collude with the established hegemony (Northway, 1998; Vernon, 1997). A high level of self-awareness and critical reflection is required to ensure that the existing power relations in traditional disability research (and wider society) are not replicated or reinforced during the research process. Without critical self-reflection disability researchers can (often unknowingly) become accomplices or accessories to the oppression of people with an intellectual disability (ID; Oliver, 1997). Failure to critically reflect on the research process and the role of the researcher not only raises questions of the genuineness and inclusivity of participatory research projects, but also the role of the research in the maintenance and perpetuation of the oppression of people with ID (Bigby & Frawley, 2010; Vernon, 1997). Honest accounts of practice enable issues and dilemmas to be considered and thereby contribute to theory. Further,

reflecting on the process of doing participatory research with people with ID can assist future researchers to create research projects that are both methodologically rigorous and ethically sound (Walmsley, 2004).

Although there is an extensive body of participatory research projects with people with ID, until recently few published papers have offered reflections of the process of doing such research or provided descriptions of the role of people with ID in the research process (Bigby & Frawley, 2010). In early studies, the role of the participatory researcher was rarely canvassed (Walmsley, 2004; Walmsley & Johnson, 2003). Academic researchers have a crucial role in supporting people with ID to be involved in research (Walmsley, 2004). Despite this, researchers rarely specify their involvement or clarify their role and often dismiss or discount the skills and experience they bring to the research project. Walmsley (2004) argued that this is often done with the best of intentions, suggesting that participatory researchers in the field of disability are driven by the desire to erase difference. Diminishing their role in the research process also elevates and enhances the role of the co-researchers with ID (Walmsley, 2004).

Recent research (e.g., Bigby, Frawley, & Ramcharan, 2014; García Iriarte, O'Brien, & Chadwick, 2014; Strnadová, Walmsley, Johnson, & Cumming, 2016) has identified a number of challenges and tensions related to engaging in participatory research with people with ID. Bigby and Frawley (2010) reflected on their experiences supporting a co-researcher with ID, initially treating him the same as a “new, relatively inexperienced research assistant” (p. 56). The co-researcher experienced difficulties in sustaining interest and understanding the complexities of the research, and Bigby and Frawley conceded that they were so fixated on the prerequisites of “being a researcher” and expecting the co-researcher to “pass” (Goffman, 1963) as a researcher, that they completely disempowered and alienated him. They concluded that it is important to recognise the strengths of co-researchers with ID as “experts by experience.” Williams, Simons, and Swindon People First Research (2005) reflected on the difficulties in juggling two processes: ensuring that the researchers with ID were in control and ensuring that the research progressed. Other challenges may be systemic, such as a lack of understanding of the underlying tenets of participatory research by funding sources and ethics committees, and ensuring research is inclusive while complying with standards of academic rigor (Strnadová et al., 2016).

Despite these challenges, a number of advantages of participatory approaches to research have been identified. Bell and Mortimer (2013) reflected on their experiences of creating a research group with people with ID

who took part in a structured training program designed to improve their understanding of the research process prior to engaging in an inclusive research project. Some benefits noted included the opportunity to form new friendships and acquire new skills in research. The participants with ID also expressed that they felt respected and valued throughout the process. Similarly, when reflecting on lessons learned from conducting inclusive research in Ireland, García Iriarte et al. (2014) reported that the people with ID in the research teams experienced gains in self-esteem and confidence. This approach also created more opportunities for the generation of new findings, which increased knowledge of the lived experiences of people with this label.

To enhance the quality and rigor of participatory research and ensure that people with ID experience such benefits, scholars have urged researchers to be unapologetic for their expertise and instead recognise and describe their role and contribution in the research process honestly and transparently (Bigby & Frawley, 2010; Walmsley, 2004). We hope to contribute to this area of research by reflecting on our own experiences of engaging in participatory research with people with ID. To foster self-awareness throughout the research project, a reflexive journal was maintained by the first author. A reflexive journal is a personal diary that provides an account or “paper trail” of the researcher’s interests, values, and assumptions, and logs any methodological decisions and their accompanying rationales (Henwood & Pidgeon, 1992). Reflexive journaling can apply to all four of the naturalistic criteria of trustworthiness as important information about both the researcher and the research process are recorded (Lincoln & Guba, 1985). The reflexive journal of the first author was revisited throughout various stages of the research process during peer debriefing or “supervision” with the second and third authors. During these sessions, working hypotheses were tested, meanings were explored and personal feelings were expressed. In this paper we begin with an overview of the research, followed by a series of reflections on the research process. We explore some of the challenges encountered when attempting to engage in participatory research with people with ID, and the potential to discursively reproduce stereotyped identities.

## The research

ID is commonly conceptualised as stigmatised identity with which one has to live (Beart, Hardy, & Buchan, 2005). However, within the literature the notion of a damaged identity is contested. Numerous studies exploring the identities of people with ID have reported that

this ascribed identity has little resonance with those who live with the label and that people with ID reject a stigmatised view of self (Finlay & Lyons, 1998). In contrast, it has been consistently reported that at least some people with ID appear to be unaware of their ascribed identity (Todd & Shearn, 1997). A major criticism of past studies exploring the identities of people with ID is the ascription of a stigmatised identity a priori and a failure to consider the alternative identities an individual may embody (Rapley, Kiernan, & Antaki, 1998). A further limitation is the dearth of research that meaningfully includes people with ID in the research process.

With these limitations in mind, this research<sup>1</sup> was guided by two overarching aims: (a) to explore the social construction of “intellectual disability,” particularly the personhood, identities, and social roles of people with ID, and (b) to increase the control, power, and meaningful participation of people with ID in the research process. As such, this research was qualitative and was conducted within a participatory research framework. The co-researchers were 18 members of an advocacy agency that supports people with ID based in regional Australia. Photovoice and conversational interviewing were used to collect member data. In addition, five staff members from the advocacy agency who expressed interest in being involved in the research were interviewed. The project spanned 1 year from initial contact with the advocacy agency through to a final reflection session. Causal layered analysis (Inayatullah, 1998), an in-depth, multilevel analysis that enables the factors that perpetuate social issues to be identified through the interaction of several different levels of understanding, was used to analyse both the member and staff interview data. For a detailed description of the research process and a summary of the research findings, please see Povee, Bishop, and Roberts (2014) and Dorozenko, Roberts, and Bishop (2015a, b).

### Participatory research: An impossible dream?

Participatory research in its purest or ideal form involves people with ID controlling the research and collaborating in all phases of the research process, including the specification of the research questions, design, data collection, analysis, dissemination, and the utilisation of the research findings (Turnbull, Friesen, & Ramirez, 1998; Walmsley & Johnson, 2003). There is also the complete dissolution of the distinction between the academic researchers and people with ID (Wadsworth, 1993). We had hoped that the research project would be truly participatory, led by people with ID with the sharing of power and control throughout the whole process. Unfortunately, the reality of the research project fell short of

our initial expectations. To ensure that the research met the requirements of a PhD, a specific research aim with corresponding research questions had to be stipulated. The methodology and methods, and, probably most challenging, a clear budget and timeline were also required. The structured and predetermined nature of the project was completely at odds with the guiding principles of participatory research with people with ID (Turnbull et al., 1998). The constraints of the academic system meant that the aims of the research had to be recalibrated. Rather than recreating participatory research in its purest form, our focus throughout the research process then became one of creating opportunities for the members to make decisions and exert control wherever possible.

Once the research had been formally approved by Curtin University (HR 94/2011), the advocacy agency was contacted to arrange a meeting with the members. At this meeting, the members were presented with a potential research topic: their “identities and social roles.” The research topic reflected my own interests, not that of the members. It is, however, acceptable for participatory researchers to identify a research problem and bring it to the community to see whether they consider it worthy of investigation (Chappell, 2000). Although not necessarily initiated, the research topic must be owned by people with an ID (Walmsley & Johnson, 2003). At this meeting some possible methodological options (including focus groups, one-on-one interviews, and photovoice) for exploring the research topic were also presented. These options were selected on the basis of available resources, the ability of the methodology to address the aims of the project and the acceptability and suitability of the methodology for people with ID (Park, 1993; Walmsley & Johnson, 2003).

All of the members expressed interest in using photography to capture their experiences. Once consent was established (see the “The issue of informed consent” section), the members were loaned a digital camera for the project. After the members had finished collecting the data, a time to meet with each member to discuss the photographs with them was arranged. Throughout the project, there was a tension between making sure that progress was being made according to the proposed timeline, while at the same time establishing close and trusting relationships with each of the members and working at a pace suitable for them. The time frame of participatory research projects is at the least medium term and usually long term (Cocks & Cockram, 1995). With this, we constantly felt as though we were juggling two demands: ensuring that the members were in control as much as possible and meeting our obligations to the university.

Once all the data (photographs and interviews) had been collected, each interview was transcribed and the process of analysis began. The members were not involved in the analysis of the data and had no role in writing the manuscripts derived from this PhD (the issues associated with representing the views of others are discussed in the section “Knowledge as a co-construction”). At the same time, we had to acknowledge that as academic researchers we had certain skills and expertise that lent itself to research. We were experienced at writing literature reviews, analysing qualitative data, and publishing research reports. It would be self-effacing (and dishonest) to deny our contribution to this particular part of the research project.

It has been argued that some participatory researchers attempt to “mould” their co-researchers with ID into the ideal of an “establishment researcher” to legitimise or justify their involvement in the research project (Bigby & Frawley, 2010; Williams, 1999). In this research, the members were authorities on their own lived experiences. They were experts on their own lives, experiences, feelings, and views. They were interested and motivated to be involved in the research and they had a wide range of skills that were invaluable to the project. The members’ involvement on the research process, however, fluctuated and did not always represent the “ideal” of participatory research. We argue that there is not a dichotomy between traditional disability research and the ideal of participatory research. Instead, a continuum exists with varying degrees of meaningful participation in and control of the research process and outcomes by people with an ID (Strnadová et al., 2016). Reflecting this conceptualisation, Bigby et al. (2014) proposed a framework that situates inclusive or participatory research approaches on a spectrum ranging from an advisory approach, through to approaches where people with ID initiate, lead, and implement their own research. Participatory research is an evolving process, rather than a measurable objective.

For the final phase of the research project, the members decided that they would like to display the photographs they had taken in a public photograph exhibition. The members were really enthusiastic to have this exhibition and wanted it to be done immediately. We were hoping to delay the exhibition for a few months, as our schedules at university were particularly demanding at that time. However, in the interests of participatory research, the wishes of the members superseded our own, and together we began the process of organising the public photograph exhibition. A space in the shopping centre was booked, partitioning was organised, the photographs selected by the members

were printed, and flyers and signage were made. The members distributed flyers through their networks and invited members of the community. An excerpt from my reflexive journal highlights just how busy this stage of the research project was:

Today I’ve been busy sending emails regarding the display. I have emailed the local newspaper, the Executive Assistant to the CEO of the Town (asking her to invite the CEO or a Community Development Officer to open the display) and the university PR department (I sent her quotes from the Members to include in the media release). I am starting to feel quite overwhelmed with the amount of work that is required for this display ... To be honest, I will be pleased when it is all over!

As is evident from the above excerpt, the final stage of the research project was particularly demanding. Reflecting on the research process as a whole, however, our contribution and level of involvement fluctuated and evolved. In the beginning, I was involved in the preparation and planning of the research project. During the data collection phase, however, my role shifted significantly as the members assumed control and executed all of the data collection. In the final phase of the project, the holding of a public photograph exhibition, the relationship between the members and myself experienced yet another shift becoming more collaborative. As roles and responsibilities changed throughout the research process, feelings of control and certainty also waxed and waned.

In order to move this research along the continuum toward “participatory research,” wherever possible I tried to divest myself of power so that the members could take control of the research process. The sharing control and power in the research process and recognising and tolerating uncertainty was one of the most challenging aspects of this research, as the following excerpt from my reflexive journal illustrates:

I am finding the lack of control really difficult. I am worried about not have an interview schedule planned. Will the digital cameras be returned? Will the Members want to talk to me? Will the photos work as a stimulus for conversation? Will I have enough information?

Having been socialised to a positivist worldview and quantitative methodologies, this sense of losing professional power and control was challenging, but very necessary. For the members to gain their own power in the research process, I had to be prepared to divest some of my power. Participatory researchers in the field of disability must be able to recognise the shift in power and control that occurs as the research evolves and be able to cope with the redefinition of their role.

## The issue of informed consent

Establishing informed consent was a continuing challenge throughout the research process. After the members indicated that they were interested in being involved in the research at the initial meeting they were provided with an information sheet and consent form, as per the university requirements. The information sheet and consent forms created for the project utilised simple language, bullet points, pictures, and the repetition of information. The documents were read through aloud and the members were asked if they needed anything clarified or had any questions. At this time, it was emphasised that participation was completely voluntary. The members interested in being involved in the research project were then provided with an information sheet and consent form to sign. I reflected:

When completing the consent forms, some of the Members did not know how to write their name or write numbers for the date. Members could not recall their own phone number in a lot of cases. I am also not sure that the Members knew what they were agreeing to... They just signed because they were told to. Informed consent is a real concern of mine. I do not feel that the Members have given informed consent.

It quickly became obvious that the static, one-shot approach to free and informed consent (although modified to meet the needs of people with ID) was not appropriate. Although this method to obtain consent was approved by the university research ethics committee, it was clearly insufficient.

In light of these limitations, process consent, whereby establishing informed consent was an ongoing process throughout the duration of the research project, was adopted (Munhall, 1988). At the beginning of each photovoice interview, the members were asked if they had any questions or any issues that they would like to discuss. At this time, the concepts of privacy and confidentiality were also reintroduced. Consent was renegotiated with the members as unexpected events occurred and new permissions were acquired when necessary (Munhall, 1988). The members were also reminded that it was their choice to be involved in the project and that they could stop their involvement at any time. Members were continually reminded that their remarks were being recorded as research data. This was particularly important when I felt that the members might have been revealing more than they were consciously willing to share publicly. Some members used the phrase “off the record” to denote information that was not to be included as part of the research.

## Who gains from the research?

Individuals with disability rarely directly experience the benefits of research such as improved outcomes or more equitable access to services and resources (Petersen, 2011). Furthermore, the actual research process has been criticised for contributing to the oppression experienced by people with ID (Dowse, 2009; Vernon, 1997). Guided by the principles of the social model of disability (Oliver, 1992), we entered into this project with the desire to redress some of what we perceived to be the wrongs of traditional disability research. But did the members actually benefit by being involved in the research project? The question of who stands to gain from the research is indeed an important one. Upon much reflection, we have concluded that we are undoubtedly the main beneficiary of this research. I have obtained data to complete my PhD, had the opportunity to present the research at two international conferences, and we have published about the process (Povee et al., 2014) and outcomes (Dorozenko et al., 2015a, b) of the research. I also feel that throughout the research project I learnt a great deal and gained a better understanding of myself. On the other hand, whether the members who were involved in the research benefited is much more difficult to determine. Knowing that we were likely to be the main beneficiaries of this research, we were particularly concerned by the need to avoid exploitation, make the research more equitable, and enhance the opportunities for positive outcomes for the members involved. How we attempted to do this is explored further in the following sections.

## *Reciprocity and challenging traditional research relationships*

Participatory approaches to research are characterised by greater meaningful participation and influence by people with ID in research than has traditionally typified the research process (Turnbull et al., 1998). People with ID are involved as more than research subjects or respondents; they are research partners or co-researchers actively engaged in some or all of the research process (Knox, Mok, & Parmenter, 2000; Stalker, 1998; Walmsley, 2001). People with ID have the opportunity to exert control and make decisions in the research process (Knox et al., 2000; Walmsley & Johnson, 2003). Guided by these principles, I attempted to forge a relationship with each member based on respect and reciprocity. According to Ribbens (1989), reciprocity in research can be described as a researcher’s willingness to introduce some vulnerability through self-exposure and the

mutual exchange of personal information. This involves being prepared to respond to direct questions asked by the interviewee, voluntarily revealing information about ourselves without being asked, and a willingness to really listen (Ribbens, 1989; Vernon, 1997). Conversational interviewing facilitated this process.

Conversational interviewing is a recursive process whereby the agenda for the interview is established interactively by both the researcher and the participant (Burgess-Limerick & Burgess-Limerick, 1998). There was no predetermined interview schedule; the questions asked built on the members' responses to previous questions and in previous interviews as well as the stories told by other members interviewed. The interviews were informal, flexible, and akin to a conversation. I made myself vulnerable by sharing personal information and stories with the members. My self-exposure created a space where the members felt comfortable to speak openly and freely with me. Rapport was easily established with the members involved in the study.

Ribbens (1989) and Vernon (1997) also describe reciprocity in research as a willingness to help or assist participants in ways that are not directly tied to the research. In this research, I was able to help the members by buying items in the city that were unavailable in the country town where they lived on their behalf, creating personal DVDs of their photographs to music, driving them to work or to the shops, and being available for a chat. This conveyed a sense of value for the person and partially addressed the power imbalance that typically arises between researcher and participant in research with people with ID.

In the research project, the members were considered partners and collaborators. Our roles changed and evolved throughout the research process. In the beginning, I was involved in the preparation and planning of the research project. I formulated the research aim and research questions and selected different methods that would be appropriate to explore the research question. In the data collection phase of the project, my role as a "researcher" experienced a significant shift. During this phase, the members assumed control and executed all of the data collection. They took photographs, videos, wrote letters, and told stories of their experiences. In the final phase of the project, the holding of a public photograph exhibition, the relationship between the members and myself was collaborative. Members took control and initiated the public photograph exhibition, and I facilitated and organised the event. I reflected:

The Member's took a great amount of pride in arranging the photographs and the banners. We worked in pairs placing and pinning all of the photographs. The display

was all ready to go by about 11:30 a.m. Throughout the day the display had lots of visitors. When someone came over they were greeted by one of the Members who spoke to them about the project and walked them through the display talking about the photos. The Members really relished in the opportunity to have their photographs displayed on a larger scale.

I began to feel that I was no longer the "expert" but rather an observer and facilitator. Reiff (1968) described this role as being a "participant-conceptualiser." As a participant-conceptualiser, the researcher is actively involved in the processes, while also attempting to conceptualise or understand them (Elias, 1994). Reiff (1968) argued that only by participation and involvement can theory and intervention be enriched.

An issue that commonly arises when engaging in participatory research is how to sensitively bring the research relationship to a close (Atkinson, 2013; Nind, 2009). Nind (2009) argued that entering a research relationship has the potential to extend the social network of a person with ID and cautioned that terminating the research group may cause friendships to end and leave people feeling rejected. It is important that academic researchers are mindful of the feelings and perspectives of their co-researchers.

In this study, the public photograph exhibition provided the opportunity for the members to celebrate their participation in the project and formally bring the research to a close. The members remain in contact with each other through their involvement in the advocacy agency and I continue to communicate informally with some of the co-researchers in this project.

### **"Empowering" people with ID**

When I drafted the proposal for this research project, in my naivety one of the key objectives was to *empower people with an intellectual disability by being active participants in research*. The concept of empowerment in research, particularly disability research, is contentious and not universally accepted (e.g., Stalker, 1998). Oliver (1992) argued that empowerment is not a gift to be bestowed by the privileged to those deemed less fortunate. Furthermore, it has been suggested that a universal or global measurement of empowerment may not be appropriate or feasible as empowerment is a dynamic, contextually driven, open-ended construct that differs across people, organisations, and communities (Zimmerman, 1995). As such, the concept of psychological empowerment was not specifically operationalised or measured in this study.

Instead, we were particularly interested in "empowering processes" (Zimmerman, 1995), which are defined as

those opportunities for people to control their own destiny and influence the decisions that affect their lives. In this study, empowering processes may be reflected in our attempts to create a research environment that fostered personal development and growth by providing the members with as many opportunities as possible to exert power and control in the research process (Petersen, 2011). Throughout the research process, I attempted to embrace the presumption of competence and ability (Fairweather, Sanders, Maynard, Cressler, & Bleck, 1969). This approach involved recognising the strengths and competencies that each member possessed and supporting them in their desire to be empowered. From the outset, I was mindful to acknowledge the voices, needs, and wants of the members. Read and Wallcraft (1992) offered a definition of empowerment, which I found particularly useful to refer to throughout the research process: “No one can give power to another person, but they can stop taking their power away. They can also help people to regain their own power. This is what we mean by empowerment” (p. 5).

With this in mind, respecting the abilities of the members and enhancing opportunities for personal development and growth became crucial. When reflecting on the research, the members exerted control over the photography process, taking as many photographs of whatever they deemed important over an unrestricted period of time. Some members used the black-and-white function, whereas others took short videos. Members also exerted control during the photovoice interviews, with some choosing to control the laptop and scroll through the photographs. The public photograph exhibition was also driven by the members. Control and ownership of the photographs and the narratives they elicit fostered a sense of pride among the members, as Jimmy<sup>2</sup> explained:

Basically, what the thing was all about was people getting to know what we can do ... and all I can say is well done guys cos you have got some really good skills there with the camera and I'm really proud of ya's.

Over the duration of the project, members also developed new skills and increased confidence and some took on a mentoring role, teaching and supporting other members to use the digital cameras. Learning and practising skills, working with others toward a common goal, and developing leadership skills is essentially empowering (Zimmerman, 1995).

In summary, it is difficult to determine whether the members were empowered by being involved in this research project. In my role as the academic researcher, I attempted to challenge the traditional research “setting” (Sarason, 1974) as much as possible. The skills and

abilities of the members were emphasised and I attempted to provide the members with many opportunities to exert power and control in the research process. It is, however, difficult to say definitively whether the members were empowered through their involvement in the research project. A measurement of empowerment designed to be used within a research setting with people with ID is possible, but it must be connected to the experience of the participants with ID as they state it, and be grounded in their life experiences (Zimmerman, 1995). This is a potential area of future research.

### Knowledge as a co-construction: Identities discursively produced

Research is socially co-constructed and the values and assumptions of the researcher undoubtedly influence the construction of data and the knowledge produced (Dowse, 2009; Rioux, 1997). Here, I critically reflect on a selection of excerpts from my interviews with the members, highlighting my role in discursively producing the identities of the members. It is not my intention to conduct a thorough conversational analysis on all of the interview transcripts of my interactions with the members. Rather, I wish to critically reflect on a few example interview excerpts of my interactions with the members. When analysing the member interview transcripts, some of the interactions made me feel uneasy. The following is a brief examination of these uncomfortable moments. Through this process, I am able to examine how I, as a researcher, both produced and maintained the very same restricted identities imposed on people with an ID that I had been so critical of. This section is divided according to three identities (or social roles) commonly affixed to people with ID: incompetent, childlike, and exceptionally happy (McManus, 2010; Wolfensberger, 1998).

#### People with ID as incompetent

The label of “intellectually disabled” is often conceptualised as a master status that is so pervasive that it overrides all other identities or social roles that the individual may have (Beart et al., 2005). With this master status comes the assumption of incompetence, low expectations, and limited opportunities. Upon reflecting on some of the uncomfortable interactions I had with the members, I soon realised that the low expectations placed on people with ID and the presumption of incompetence or inability was mirrored somewhat in my own interactions with the members. The following excerpt illustrates my presumption that Louise, who has ID,

would be unable to travel independently to her poker competition at the local tavern using public transport:

- Kate: And how do you get to the venue?  
 Louise: I normally get a bus or a friend to take me and bring me home.  
 Kate: Yep. And how are you with going on the buses?  
 Louise: Good. Yeah. Yep.

In this example, I assumed that Louise would have difficulties using public transport and felt compelled to ask her how she managed. It seems that in the case of ID the presumption of *incompetence* is axiomatic (Jenkins, 1998). This assumption is also evident in my interaction with Michelle, where I expected that managing finances would be a challenge for her:

- Kate: How do you go with your budgeting in everything? Are you good with, you know, doing your bills ...  
 Michelle: Nah.  
 Kate: No. It's hard, isn't it?  
 Michelle: (nods).  
 Kate: Yeah, it can be tough.

This excerpt once again highlights the low expectations afforded to people with ID and the presumption of incompetence or inability. Furthermore, in this example, not only am I questioning Michelle's ability to manage her money, I am also asking her about a very private matter: her personal finances. This excerpt is revealing of the (often unconscious) ascription of a childlike identity to people with ID.

### **People with ID as vulnerable and the eternal child**

People with ID are often cast in the role of the eternal child (Wolfensberger, 1998). As the eternal child, a person with ID never achieves adult status and is expected to have childish abilities, skills, behaviours, and interests. Upon rereading the interview transcripts and reflecting on my own emotional reactions during the interviews, I realised that I too at times (unknowingly) imposed the eternal child identity on the members that I interviewed. My presumption of a childlike identity is evident in my interaction with Jacob, a 22-year-old man with Down syndrome.

For the research project, Jacob took photographs of his collection of memorabilia from the film *Kill Bill*, which included a number of Samurai swords and figurines. When Jacob showed me these photographs during the interview, I was shocked that he had seen the film.

Similarly, when Jacob showed me a photograph that displayed his collection of thriller/horror movies and television series, I was equally surprised. The following exchange accompanied these photographs:

- Kate: *Dusk Till Dawn*. Do you like the scary ones?  
 Jacob: Yeah.  
 Kate: Yeah. You don't get nightmares?  
 Jacob: No.  
 Kate: No? I do (laughs) ... I think it took me about ten years to get over *Scream* it was that scary (laughs).

As my emotional response and questioning illustrates, I assumed that Jacob would find horror movies frightening. I am doubtful that I would have responded in such a way if interacting with another adult without ID. Not only did I find adult interests (such as liking horror movies) confronting, markers of adulthood also presented a challenge to my understanding of a person with ID. In the following excerpt I am talking with Lynette about her living arrangements:

- Kate: Is it just you most of the time?  
 Lynette: Most of the time, yeah.  
 Kate: Yeah? And how do you feel about that?  
 Lynette: Not too bad.  
 Kate: Don't get scared at night or anything like that? (laughs).  
 Lynette: (laughs and shakes head). No.  
 Kate: It must just be me. I think I'm a bit of a wuss.  
 Lynette: (laughs).

By living independently, Lynette presents a challenge to the childlike status so often affixed to adults with ID. Surprised by this living arrangement, I ask Lynette if she feels nervous living by herself. Once again, I assumed that Lynette, living independently, was particularly vulnerable. I also expected that she would have difficulties with this arrangement.

### **People with ID as happy and the Down syndrome stereotype**

A common rhetoric is that people with ID "make the most of what they have" and generally have a "bloody good life" (Dorozenko, Roberts, & Bishop, 2015b). People with ID, particularly people with Down syndrome, are also commonly stereotyped as being happy and loving (Wishart & Johnston, 1990). This very same phenomenon that I observed (and criticised) in this research was being reproduced in my own interactions

with the members. In some of the interviews, I asked the members to describe themselves. This question was often met with a long pause, after which I offered an example answer, pre-empting their response. Here is an example excerpt from my interview with Jacob, who has Down syndrome:

Kate: So did you have anything else that you wanted to tell me about you?

Jacob: (silence).

Kate: About what you ... What do you think you're like?

Jacob: (silence).

Kate: Do you think you're a pretty happy person?

Jacob: Yeah.

Here Jacob did not offer a prompt reply to my question, so I presented him an example answer ("happy"), which primed a particular response from Jacob ("yeah"). Coaching a response from Jacob in such a way treated him as deficient and unable to describe some of his own personal qualities. Offering the example answer "happy" also perpetuates the assumption that people with Down syndrome are joyful, good natured, and easy (Wishart & Johnston, 1990). In my interactions with the members, complimentary or positive stereotypes were not limited to those members with Down syndrome:

Kate: So if you were thinking about what you're like as a person, how would you describe yourself? It's a hard question, isn't it?

Freya: Yeah.

Kate: What do you think you're like? I think if I think about myself I think I'd be pretty happy. I love to hang out with my friends ...

Freya: Yeah me too.

Kate: My family ... are you the same?

Freya: (nods).

Once again, I offered the example response ("happy"), to which Freya agrees. Interestingly, I didn't offer Freya other example characteristics such as athletic, intelligent, or artistic. This implies that Freya (and all people with ID alike) experience limited emotions (happiness only). This stereotype may result in low demands or expectations being placed on people with ID and limited opportunities because it is assumed that regardless they will be satisfied or content (Wishart & Johnston, 1990). In addition, offering the example answer, "I love to hang out with my friends ... my family", to which Freya agrees, further implies a restricted identity; people with ID have limited interests (family and friends only).

This finding is comparable to a study conducted by Antaki, Walton, and Finlay (2007) that examined how staff at residential homes for people with ID proposed outside activities and offered choices to residents. It was reported that when staff introduced an activity to a resident the social aspect of the activity was emphasised (e.g., associating it with a given person), but often failed to mention the intrinsic qualities of the activity or important aspects, such as its location or what is involved. Antaki et al. concluded that staff interactions with residents perpetuated the assumption that the identities and interests of people with ID are primarily social, with little appreciation of other aspects of life.

Critically reflecting on my interactions, I did not explicitly label a member "intellectually disabled," nor did I allude to "having difficulties learning" in any of the interactions. However, as the previous examples illustrate, a disabled identity can be affixed not just by naming, but also by treating someone as disabled. I noted that the imposition of a restricted identity was more likely to occur in my interactions with members that were nonverbal. In these interactions I was more likely to ask leading questions or offer example answers that were biased by my own values and assumptions. Reflecting on these interactions I felt like an accessory or an accomplice to the restricted identities so commonly attached to people with ID. This led me to feel a great deal of guilt and question my own values. Smith (2011) warned of this potentially negative self-regulatory function of critical reflection and reflexivity. Excessive reflection and rhetorical awareness of decisions and actions in research can serve to isolate the researcher from the broader social context in which they occurred. Judging one's actions completely divorced from the social context in which they inhabit can produce a state of self-criticism and self-condemnation (Dowling, 2006; Smith, 2011). Overly self-critical introspection can serve as a barrier to authentic learning and impact on the motivation to persist with research (Smith, 2011).

Interestingly, during the interviews and immediately following, I did not feel uncomfortable or as though I had behaved inappropriately. The members and their parents/guardians (who were at times present at the interviews) did not appear to be upset by my comments. It was only when the exchanges between myself and the members were presented devoid of context that I realised that I too affixed a restricted identity. This demonstrates just how socialised we all are to those deeply embedded and pervasive processes that serve to construct people with ID as the "other."

## Conclusion

Reflections on the process of doing participatory research with people with ID make evident that researchers are always products of their culture and history and bring with them their own orientations and values that undoubtedly enter into and shape the research (Northway, 2000). Dowse (2009) argued that it is crucial that reflexive accounts of doing participatory research with people with ID are made overt, so that these experiences can become legitimate and fruitful objects of study. We have endeavoured to place ourselves under scrutiny and honestly reflect on our experiences engaging in participatory research with people with ID. In doing so, we hope to assist future participatory researchers to create projects that increase the control, power, and meaningful participation of people with ID in the research process.

Questioning and reflexivity are fundamental to the principle of developing ethical research (Bishop, 2007). Our values, attitudes, personal histories, and the boarder social context in which we inhabit, will inevitably enter into and shape our work. Even as researchers with an awareness and understanding of the oppression experienced by people with ID, we were still not immune to committing this fallacy. Unknowingly, at times our decisions and actions in this research were reflective of the dominant culture, illustrating just how subtle and pervasive these oppressive social processes can be. An ability to observe the broad trends or the obvious that are obscured by dominant worldviews is fundamental, as is an understanding of context (Bishop, Sonn, Drew, & Contos, 2002). Continued critical reflection can assist disability researchers to develop this important self-awareness (Bishop, 2007).

We urge future researchers engaging in participatory research with people with ID to engage in reflexive journaling and peer debriefing to promote reflexivity (Northway, 2000). Reflexive journaling can help the researcher become attuned to their own positioning, values, and worldviews (Bishop & Dzidic, 2014). Similarly, peer debriefing or supervision can enable working hypotheses to be tested and meanings to be explored. Lincoln and Guba (1985) argued that the peer debriefing process can help to “keep the inquirer honest” (p. 309) as interpretations are challenged and biases are probed. Ideally, this reflexive journaling and peer debriefing should include reflections on discussions with the people with ID who have been engaged in the participatory research process.

Despite the fumbings and faux pas that may arise when engaging in participatory research, we strongly advocate this approach to research with people with

ID. This approach can create opportunities for people with ID to have a voice, exert control, and make decisions in the research process. Directly challenging this power imbalance enables academic researchers, and the field of disability research more broadly, to grow and be a part of the empowering process.

## Notes

1. This research formed the first author's PhD. The second and third authors supervised this research project. “I” is used to denote the thoughts, feelings, and actions of the first author. Excerpts are taken from the reflexive journal of the first author.
2. To protect the anonymity of the members in this study, they were assigned pseudonyms.

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## ORCID

Kate P. Dorozenko  <http://orcid.org/0000-0002-8411-099X>

Lynne D. Roberts  <http://orcid.org/0000-0003-0085-9213>

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