

Why is it so Hard to Talk About Our Intellectual Disability? A Pilot Study Using Action Research

This research has been funded by the Social Sciences and Humanities Research Council of Canada (SSHRC).

Cette recherche a été financée par le Conseil de Recherche en Sciences Humaines du Canada (CRSH).

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Keywords

intellectual disability,
community and residential
integration, well-being,
collaborative action
research tools, technology

Mots clés

déficience intellectuelle,
intégration
communautaire et
résidentielle,
bien-être,
outils de recherche-action
collaborative,
technologie

Abstract

The label intellectual disability (ID) has long been problematic for those targeted as such and their families. Institutions that work with people with ID face many daily challenges including health, security, autonomy, well-being, self-acceptance, etc. These institutions have to prioritize what they think is most important for their clients and provide support for their community and residential integration. Despite this support, in the ID community there is still a lot of suffering caused by the misunderstood label. In this collaborative action research, we recruited five adults with mild or moderate ID to find out how they understood their ID and what it means when they say they want to talk about it. Findings reveal that they do have insight regarding solutions to the problem and that they think ICT (information and communication technologies), if used appropriately, could act as support in these matters. Finally, this study shows how collaborative action research tools are relevant to solving real life problems.

Résumé

L'étiquette de la déficience intellectuelle cause des difficultés aux gens la portent et à leurs familles et ce, depuis déjà trop longtemps. Les institutions qui travaillent avec des personnes déficientes intellectuelles font face à de nombreux défis qui incluent la santé, la sécurité, l'autonomie, le bien-être et l'acceptation de soi. Ces institutions doivent accorder la priorité à ce qu'elles croient être le plus important pour bien servir leurs clients, qui vivent un processus d'intégration communautaire et résidentielle. Malgré les services offerts, dans la communauté de la déficience intellectuelle, la souffrance persiste à cause de l'étiquette. Cinq adultes, aux prises avec une déficience intellectuelle légère ou moyenne, ont été recrutés pour une recherche-action collaborative. L'objectif de cette étude était de comprendre comment ces adultes construisent du sens sur leur déficience intellectuelle et saisir en profondeur ce que signifie pour eux, parler de leur déficience intellectuelle. Les réflexions des participants, à la fois éclairantes, pleines d'émotions et de sens ouvrent la voie à plusieurs pistes de recherche. Finalement, cette étude révèle comment les méthodes de recherche-action collaborative peuvent résoudre les vrais problèmes auxquels ces adultes font face dans leur vie quotidienne.

Deinstitutionalization in the world's richer nations is currently raising several issues related to quality of life for people who live with an intellectual disability (ID) (Leblanc et al., 2008). While their situation has evolved since the 1970s, there is still much to be done regarding their full integration into society, including public perception of people labeled with ID. Stigmatization has been largely problematic for their integration to society (Jahoda & Markova, 2004) because the label is firmly instituted in society and is continually being reinforced (Rapley, 2004). Since the decision to label someone with ID is external to the person with ID, one of the first steps in getting this person to understand the label is to help him or her come to grasp the meaning of the term. However, a problem arises since the literature and diagnostic manuals, such as the DSM IV, target professionals or informed readers. From previous research, we know that people readily accept living with a learning disability (LD), but the ID label is far more appalling for most of the population.

Recently, many qualitative studies have been conducted on the topic of labelling (Finlay & Lyons, 2005), on offering choices (Antaki, Finlay, Walton, & Plate, 2008; Jingree, Finlay, & Antaki, 2006), on self-advocacy (Beart, Hardy, & Buchan, 2004), and on well-being related issues (Dykens, 2005). In parallel to these themes, action research or participatory research is a growing trend for qualitative researchers who are interested in improving the lives of with people with ID (Curry & Cupples, 2001; Davidson et al., 2004; Leblanc et al., 2008; Mactavish, Mahon, & Lutfiyya, 2000). While the results of such studies shed the light on how to study the concepts and how people with ID construct meaning, they also point out the lack of means we have when trying to involve people with ID in participatory or collaborative action research.

What is Behind the “Intellectual Disability” Label?

In the past people labeled with “mental retardation” couldn't attend regular school programs. This also meant that they were excluded from the work force and didn't have access to home ownership. Today, even though the label “intellectual disability” has widely become adopted, various terms are being used

around the world and across different social settings to describe the characteristics of this group of people who are living with a level of cognition that limits their ability to function, adapt and become autonomous. For instance, “mental retardation” is still being used in the United States (although the term “intellectual and developmental disabilities” is being promoted), while “developmental disability” and/or “intellectual disability” are being used in Canada, “learning disability” is being used in the United Kingdom, “mental handicap” [handicap mental] is being used in France, and the expression “person living with an intellectual deficiency” [personne présentant une déficience intellectuelle] is being used in Québec (Brown, 2007). Even though terminology varies by geographic region and in different social settings, and even may be interpreted differently by different branches of one government, people who suffer most are those formally identified to have “mental retardation.” As specified in the DSM-IV (2000), the term refers to individuals who: a) are functioning at a significantly sub-average intellectual level (less than 70 IQ); b) have limited skills in either communication, self-care, home living, social skills, use of community resources, self-direction, academic skills, work, leisure, health and safety; and, c) have been identified before age 18.

Recent research trends in the field of cognitive psychology subscribe to the idea that intellectual disability is a social construct (Finlay & Lyons, 2005; Rapley, 2004). Indeed, over the last decades, the literature in the field of intellectual disability has been shifting from the medical model to the idea that intellectual disability could be socially constructed (Edgerton, 1993; Ferguson, 1987; Finlay & Lyons, 2005; Gallagher, 2002; Rapley, 2004).

No matter which model underpins the label, people targeted as “intellectually disabled” and their families have long been perplexed by the label. Some parents feel they have to protect their child from the stigma of the label (Jahoda & Markova, 2004). Many people who have been labelled feel powerless (Finlay & Lyons, 2005). Others simply reject the label (Finlay & Lyons, 2005). Some studies suggest that these people fail to understand the constructs behind the label (Finlay & Lyons, 2000, 2005). In counterpart, the literature also reveals that

people with ID readily accept their learning disabilities or their physical disabilities (Aspis, 1997; Finlay & Lyons, 2005). In a review of literature, Finlay and Lyons (2005) mention that a significant number of researchers found a tendency to either refute or not use the label to describe themselves. Based on a social model of disability, Finlay and Lyons (2005) analyzed what the label meant in its social context by defining denial categories. Following diverse categorizations emerging from semi-structured interviews conducted with 36 people, they came to the following conclusion: The point here is that to understand denial, we must understand exactly what version of the label is being denied and not assume the meaning of the label in everyday discourse is that given in professional texts. To reject the term when it is hurled in abuse, or used as a basis for denying people equal rights, does not mean that one is denying one's level of competence. What one is rejecting in the former context is the everyday meanings of the term on the street, that the recipient of the term is less worthy, is essentially different, and can be treated with disrespect. (Finlay & Lyons, 2005, p. 128)

Well-Being and Intellectual Disability

In order to lead a fulfilling life and achieve their individual potential, beyond the simple satisfaction of physiological and safety needs, Maslow (1943) suggested that human beings need to have a sense of belonging, self-esteem, and esteem from others to achieve their individual potential. Following Maslow's lead and inspiration, many researchers in the field of positive psychology are suggesting several measures to ensure quality of life. For instance, Bandura (1997, 2002) devoted his career to explain the impact of one's perception of self-efficacy while Deci and Ryan (2002) worked for decades to elaborate the self-determination theory in order to explain human motivation. For his part, Csikszentmihalyi (1990) studied the mental states that tend to foster a feeling of flow in people who are living the optimal experience. Fordyce (1997), who was also a tenet of positive psychology, suggested that happiness was comprised of fourteen fundamental skills that could be learned and mastered: 1) be more active and keep busy; 2) spend more time socializing; 3) be productive in meaningful work; 4) get better-organized and

plan things out; 5) stop worrying; 6) modulate your expectations and aspirations; 7) develop positive optimistic thinking; 8) get present-oriented; 9) work on developing a healthy personality; 10) develop an outgoing, social personality; 11) be yourself; 12) eliminate the negative feelings and problems; 13) maintain close relationships; and, 14) value happiness. In a similar perspective, Ryff (1989) proposed a positive framework based on a eudaimonic¹ well-being scale based on six domains: 1) self-acceptance; 2) positive relations with others; 3) autonomy; 4) environmental mastery; 5) purpose in life; and, 6) personal growth.

Research Problem

Since being diagnosed with ID is seldom an initiative taken by people with ID and that these people generally don't access the related literature, we are suggesting that the first step in gaining control over their lives is to understand what the label means. Like many other researchers (Finlay & Lyons, 2005; Jahoda & Markova, 2004; Leblanc, Paruthi, Davidson, Clément, Godbout, Leno, Moldoveanu, Payeur, & Turcotte, 2008) we are also suggesting that people with ID do have valid insight about what it means. However, gaps are likely to exist between the literature and their own definition, and it is essential to become aware of such gaps in order to enter in a dialogue with this population. In fact, with the three remaining large scale specialized institutions in the province of Ontario, Martin (2008) suggests that there is a need to document the changes that occur during the process of transition people with ID are experiencing.

Given this context, the researcher felt it was urgent to involve people with ID in her studies as co-researchers so they could co-construct the meaning of the labelling in order to voice the related problems and to give them the power to explain the emotional barriers they experienced and the problems they faced while going through a process of community and residential integration. This study asked the following questions: 1) For adults who live with an ID and who are going through a process of community and residential integration, what

1 Greek word meaning the realization of one's true potential

does their ID mean to them? and 2) What does it mean when they say they want to talk about their ID? The following section presents the methodology used to gain knowledge about how adults who are in a process of community and residential integration process explain their ID and what it means when they say they want to talk about it.

Methodology

This study was conducted in parallel to another study on paid employment as a key factor in the community and residential integration process (Davidson, submitted). Similarly to the latter study, the underlying values of this study required collaborative action research methods enabling participants to learn through the research process while participating to the data collection, and the analysis and the interpretation of the data. The following section presents the participants, the data collection settings, the research approach, the instruments used for the first month of our research and the approach to analysis and interpretation.

Participants

This collaborative action research recruited participants as co-researchers from the SMILE (Self-Advocacy and More for Independent Living and Employment) adult services program of LiveWorkPlay (LWP) in Ottawa (LiveWorkPlay, n.d.). In accordance with the DSM-IV (2000), the five participants had been identified as: a) functioning at a significantly sub-average intellectual level (less than 70 IQ); b) having limited skills in either communication, self-care, home living, social skills, use of community resources, self-direction, academic skills, work, leisure, health and safety; and, c) had been identified before the age of 18. They were recruited through an invitation to voluntarily sign-up for a problem solving session with a researcher who had already worked with On Our Own Together (OOOT) participants. OOOT was a project during which adults with intellectual disabilities lived on their own in a university residence during summer months to try to gain autonomous life skills (Davidson et al., 2004). The session was presented as one option among others that would be part of the regular SMILE program and weekly activities.

The findings reported in this article correspond to the first month of our research.

Participants who signed up for the problem-solving session were informed that they were involved in a research project in which they were to act as co-researchers on problems they were experiencing in their daily lives and they could withdraw anytime from the project. The group was composed of four women and one man, median age of 25. Housing arrangements were as follows: one lived with a friend in a condo they both owned, two lived with their parents, one lived in a transitional suite with a friend and one lived in a group home. As far as employment was concerned, four were doing volunteer work and didn't expect to get paid employment in the next few years. They preferred feeling good about living on their own before facing other challenges. Participants' characteristics are shown in Table 1.

Ethical Approval

This study received approval from the Carleton University Research Ethics Committee. The names of the participants are pseudonyms. However, LWP is an organization that promotes self-advocacy through public appearances such as television programs, news and public events. Therefore, LWP and the participants to this study were aware of the possibility that some individuals might be recognized. While sessions were not recorded because the participants didn't feel comfortable, the researcher took field notes during and after sessions.

Research Approach

Action research is defined as research in which the validity and value of research are tested through collaborative insider-professional researcher knowledge generation and application processes in projects of social change that aim to increase fairness, wellness, and self-determination (Denzin & Lincoln, 2003). Action research practices involve collaborative dialogue, participatory decision-making, inclusive democratic deliberation, and the maximal participation and representation of all relevant parties (Ryan & Destefano, 2000). During the research process, the action researcher helps transform inquiry into action

(Denzin & Lincoln, 2003). Thus, in collaborative action research, participants must become stakeholders, while the research strives to solve real problems they face and promote positive social change (Denzin & Lincoln, 2003).

Instruments

Because of the highly collaborative nature of our study, we needed tools that could help us do research using the language of the participants and to negotiate meaning to foster positive social change, in the format of focus groups. This is why the following study used an original collection of tools designed to “make inquiry socially relevant and doing it collaboratively or socially” (Chevalier & Buckles, 2008, p. 1) by a team headed by an anthropologist who has been working with communities around the world to involve them in a dialogue with leaders and policy makers regarding real-life problems. Such tools provide the means to really involve adults with ID in a collaborative action research. Indeed, Social Analysis Systems tools have been specifically designed to broaden and deepen diagnostic thinking about real-life situations so that the people involved may creatively solve problems and increase the effectiveness of decision-making (Social Analysis Systems Tools (SAS²), 2006). Moreover, SAS² tools facilitate collaborative thinking as well as collective diagnostic activities and collective diagnostic activities and group decision-making. Tools are selected in a process-driven perspective as a means to solve the situation at stake. This is why the use of one tool often leads to the use of another, until a decision is made.

In order to answer the two research questions, three different SAS² tools were chosen for this section of our study: Activity Map, Stakeholder Identification, and Socratic Wheel (see Chevalier & Buckles, 2008). The Activity Map and the Stakeholder Identification were used to answer the first research question: 1) For adults who live with an ID and who are going through a process of community and residential integration, what does their ID mean to them? The Socratic Wheel was used to answer the second research question 2) What does it mean when they say they want to talk about their ID?

Specifically, the Activity Map (Chevalier & Buckles, 2008, Process Manager) was used to list activities the participants do and in order to identify priorities they wanted to work on. The Stakeholder Identification (Chevalier & Buckles, 2008, Stakeholder Identification) was used to identify the key actors or stakeholders involved in a core problem or action. It helped identify dependent and independent variables and levels of difficulty. The Socratic Wheel tool (Chevalier & Buckles, 2008, The Wheel) was used to specify content of the problem we were addressing and to give an opportunity for self-assessment and goal setting. Due to the innovative nature of these tools and to the fact that we applied them creatively in this study, methodological precisions are given in the findings section, at the same time we are presenting the data.

SAS² tools were used for several reasons. First, they inspired the participants who were to give their point of view. Second, because these

Table 1. Participant characteristics

<i>Name*</i>	<i>Age</i>	<i>Gender</i>	<i>Current living conditions</i>	<i>Employment</i>
Olivia	29	F	Owens a condo with a friend	Volunteer
Paige	21	F	Lives with parents	Volunteer
Ashley	23	F	Lives in a transitional suite with a friend	Volunteer
Jake	25	M	Lives with parents	None
Nathalie	42	F	Lives in a group home	Volunteer

* *pseudonyms*

tools required all participants to write or draw elements of their experience on index cards during the data collection process, they fostered a democratic dialogue within the group where everyone had an equal opportunity to talk. Third, these tools provided opportunities to list their experiences, organize and prioritize them. Lastly, we believe these methods could be used by service providers in order to engage participants in sessions and to help people with ID become better self-advocates.

Approach to Analysis and Interpretation

The data emerging for this collaborative action research have been analyzed and interpreted with participants, at the very moment each tool was used. This means that participants were actively involved in the research process and the discussion that follows bears directly on their knowledge and experience of their current issue. In order to inform the reader on the iterative process between the choice of tool, the evolution of the dialogue and the manner in which the researcher decided to apply the tool to the group of adults with ID, detailed methodological information is offered at the same time as findings are presented. Likewise, participants' comments were paraphrased for two reasons: when they were considered incomprehensible for someone external to the group, or when sessions were not recorded because participants were not comfortable, but the researcher had recorded field notes in her journal.

Findings

The following section presents the analysis of the data and the group's interpretation of findings. Findings are voiced in the form of a first-person narrative to show the highly collaborative nature of the study and the approach to facilitation, while presenting data emerging from the Activity Map, the Stakeholder Identification tool and the Socratic Wheel tools. Globally, the innovative findings reveal how adults with ID construct the meaning of their situations, how they know what they need to do to achieve a better level of community and residential integration, but also in what

perspective their skills are limited and if they need help with some challenges they face. In the findings presented below, the participants reveal that talking about ID is more difficult than it appears because it involves much more than just talking about the subject.

Activity Map

The collaborative process started by having a conversation around the kind of activities my co-researchers did in the SMILE program that contributed to foster a higher level of community and residential integration. More specifically, eighteen important activities were listed by them on index cards. They then grouped activities that were similar and we discussed what would be the right title for each grouping. As evidenced in Figure 1, four groupings emerged from this exercise: learn to socialize, learn to be self-advocates, do leisure activities and gain independent living skills. Three activities remained independent from these groupings: learn communication skills, learn how to volunteer and learn how to get paid employment.

When looking at the map, Olivia said she was very impressed by how many things they did at LWP. Her statement was a good opportunity to ask the group if they could identify priorities. This involved determining level 1 (very high importance), level 2 (high importance) and level 3 priorities (moderate importance). As shown in Figure 1, they all agreed that to speak to people about LWP and get support for whatever was going on in their lives were level 1 priorities. To work on computers and learn to budget were level 2 priorities. Level 3 priorities included: to learn to take the bus, to learn to cook, to learn to get groceries and to get paid employment. I invited the group to use different visual codes such as smiley faces to characterize some of the activities. They used a smiley face for "talk" and a sad face for "learn how to clean," for obvious reasons.

Once the Activity Map was completed and the priorities identified, I asked my co-researchers if they could determine which level 1 priority they wanted to work on. They had a hard time deciding so I asked them if there was an activity they preferred. Paige stated that getting support was a thing they did all the time when they came

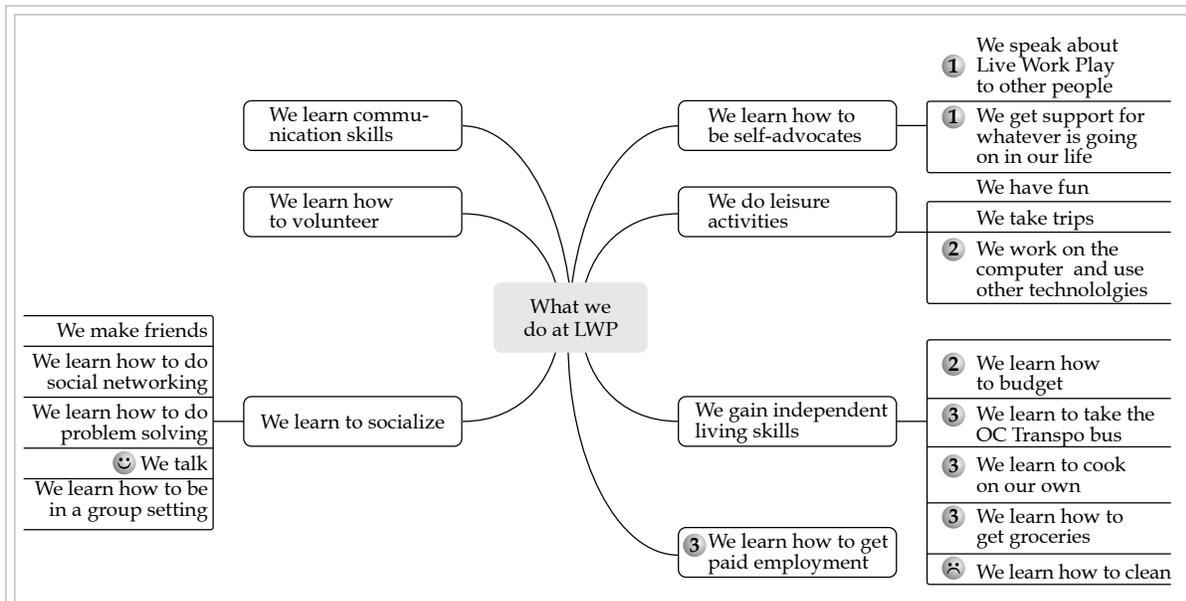


Figure 1. Activity Map

to LWP, so it was important. Everybody agreed with her. I asked the group if they wanted to work on speaking about LWP to other people. Olivia became very emotional and said: “Yes, this is my biggest challenge. I do it, but it’s very hard.” I tried to question her about what was difficult about it but she couldn’t answer. Paige and Nathalie stated that while it was easy to talk to some people, it was very frustrating to talk to other people because they didn’t understand and made them feel bad about themselves. Nathalie mentioned that she knew she had a 22Q deletion syndrome, a rare chromosomal disorder, but she didn’t know if the symptoms she experienced were linked to this disorder, or to something else. For example, she stated: “I’m a slow learner and I’m depressive. I know a lot of people are like that too, but they don’t have 22Q delusion (deletion) syndrome. People like me all have cat eyes. This is one thing I know, but I have no idea if the rest of the symptoms have anything to do with it.” The others acknowledged her explanation. Paige stated that it was very difficult to explain the speech problem she had and did not know how to explain it. We agreed that talking about our intellectual disability was a very big problem for the group and it had to be addressed. Although I didn’t clearly grasp why speaking to other people about LWP was the group’s biggest priority, I decided to go along and assumed the problem would clarify itself over time.

Stakeholder Identification Through the Rainbow Tool

The Activity Map and our discussion around it lead to the use of the Stakeholder Identification tool. Our core problem was “How to speak to people about LWP,” so I asked participants who were the people they had to speak to. As they listed the people they were speaking to, I asked them to write the names down on index cards. Using masking tape, I created a rainbow diagram on the floor by drawing a horizontal line with half a circle around it. I taped two semicircles inside the chart using the middle point of the horizontal line as their center. They were quite amused to see me try to create the shape of a rainbow on the floor. I suggested that the first section of the rainbow would be used to put the cards that depended on us, the second section for the cards that depended on LWP and the third section was for the cards that depended on others. Moreover, I divided the rainbow in three levels. The first level was for what was easy, the second for what was moderately difficult and the third for what was difficult. This format made the activity fun to do and still allowed to fill in a matrix (see Table 2 on the following page).

Once the rainbow diagram was completed on the floor, we stood around it and tried to understand it as a group. Olivia asked if it would ever be possible to learn to speak to organizers.

I asked them if they knew of strategies they could use to speak to such people. Paige stated that if she knew, she would speak to the church minister and to employers. I asked them why that depended on others. Paige said: "They don't know what it is to be intellectually disabled and they don't know how it feels to have the problems I have." When I asked her why this situation was difficult, she said she didn't like being teased about her speech and language disorder. When I asked Ashley and Jake what were their thoughts on this issue, they agreed. However, when I asked them if they had an idea about how this situation could change, they all replied: "I'm not sure." The discussion ended with an emotionally charged Olivia who said she had a lot of fun, but she couldn't think anymore. Her facial expression was showing some emotion I couldn't identify. Was she nervous, stressed, excited or happy?

This positive tension would be analyzed in the next session. It would be a good opportunity to do a self-assessment about our communication skills. This would help the group understand what speaking to other people about LWP really involves. The Socratic Wheel seemed like the appropriate tool to compare the views of each co-researcher that is, help them look at where they were and foresee where they could be in the future in terms of speaking to people about LWP.

Socratic Wheel

In the following meeting, we had a conversation about what it meant to speak to others about our intellectual disability. Participants said that people often thought nothing of them, and this didn't make them feel good. She discussed how her speech and language disorder was a matter of constant teasing at school, so she couldn't mingle. Ashley supporter her say acknowledging having been a witness of what people did to her. Paige added: "Well, you were born with it. If people say what do you mean you were born with it, there's nothing you can do, you're stuck." Jake agreed and said he was bullied in high school. Other students physically restrained him because of his ID. Finally, Olivia stated that to talk to others about our intellectual disability was about speaking in public and she had done that many times. Paige added that it was about speaking to get support and described her own intellectual disability. Olivia said she didn't know how to do that, but she knew how to mingle with people who liked her. Ashley kept on saying she wasn't sure.

I wrote the four categories they had mentioned on white index cards (mingling, talking to get support, talking in front of people, talking about their disability) and taped two orthogonal lines

Table 2. Stakeholder identification

<i>Speak to other people about LWP</i>	<i>Depends on us</i>	<i>Depends on LWP</i>	<i>Depends on others</i>
Difficult	Speak to organizers	Speak to staff	Church minister Speak to people to find trip money Employers
Moderate	Environment people Insurance agency (condo, trips) Elderly people Telephone company	Speak to family	Mayors and councilors
Easy	Special needs classes The A-Channel, Friends Media Government	Service coordination	

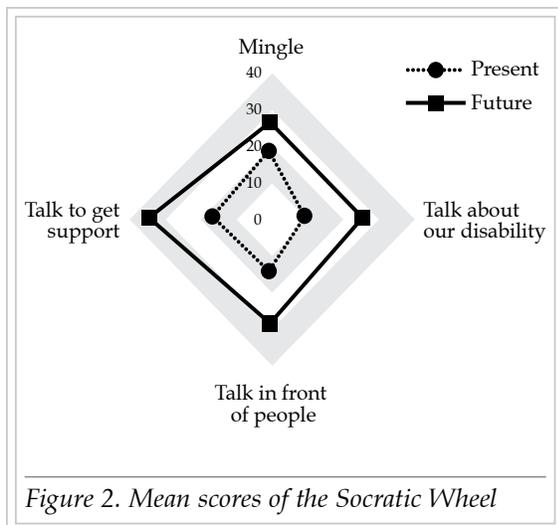


Figure 2. Mean scores of the Socratic Wheel

on the floor. This made participants giggle because I had become known as the masking tape technical person. I placed the four white index cards at the end of the lines and asked them to do a self-evaluation using a scale of 0 (I don't know how to do this) to 5 (I feel competent) for each card. I then asked each individual to write their name on four pink cards on which they had to rate each of the four categories. They started with a self-evaluation on their ability to mingle and each individual placed their card on where they thought they stood on the line (see Table 3). Most of the co-researchers wrote 5, as if the problem was already solved. This exercise was repeated for the four categories.

In order to get a better idea of what we needed to work on, I decided to stretch the line to get a scale from 0 to 10 and asked them to write on blue cards where they would like to stand in six months time (see Table 4). When the mean results are computed, as in the radar diagram

of Figure 2, we see that participants generally feel competent at mingling because their initial rating is generally high and the progress they see is not much higher. However, they don't feel as competent with talking to get support, talking in front of people and talking about their disability since the initial scores are lower than the first category and there is a larger gap between actual and aimed scores.

This collaborative action research was wrapped-up by having a conversation about what could be done to solve the problem of talking about ID. The group didn't really know what to do about it, but stated they needed help. I asked them if they could think of tools they could use to speak to people about LWP. Olivia said they could use PowerPoint (software), but didn't really know how to do it. She had seen public talks during which people did a PowerPoint presentation and thought she could use this too. Paige suggested the use of pictures or recordings. Jake agreed about the recordings. He stated that it would be fun to do videos. When I asked participants if it would be a good thing to use technology to explain what problems people with ID have in their daily routines, they said that was exactly what they meant. Therefore, technologies as part of a self-advocacy process were included in the second part of our research (publications forthcoming).

Discussion and Conclusions

The results of this study have provided evidence that people with ID can collaborate in research and can give each other valid insight drawn from their experience while going through a process of community and residential integration. Indeed, at the beginning of this

Table 4. Individual scores for future ambition

Future	Mingle	Talk about our disability	Talk in front of people	Talk to get support
Olivia	7	7	8	8
Jake	6	5	6	6
Ashley	7	6	6	10
Paige	6	8	9	10
Future	26	26	29	34

collaborative action research, participants described the activities they did at LWP and identified among a series of priorities, the one priority they felt like pushing ahead: to talk to other people about LWP. Seen as a way of talking about their intellectual disability, participants said they felt like talking about LWP. However, when thinking about how they could do this, the memories of their childhood history of bullying and helplessness surfaced. While reflecting together on the matter, they came to the conclusion that LWP acts as a shield or as a damper, absorbing part of the emotional pain that is caused by the ID label. It was only through reframing the situation by asking them what tool they could think of to foster better communication that the reflective process got on track again. This is how participants were able to speak up and state that it is very difficult to explain what it is to live with an intellectual disability to people who do not have this disability because these people will never know how it feels, and people with ID have difficulty talking about the subject. This provided an answer to our first research question, which was: For adults who live with an ID and who are going through a process of community and residential integration, what does their ID mean to them?

When inquiring into what it meant to talk about intellectual disability, which was our second research question, participants clearly saw a distinction between mingling, talking about intellectual disability, talking in front of people about intellectual disability and talking to get support for their disability. Without a doubt, participants felt like they needed to develop a higher level of competence when talking to get support and talking about their

disability. They agreed that the use of videos could help them gain a better level of control when self-advocating about ID.

This is the first study of its kind in the field of intellectual disability. So far, no other study has used this perspective to foster a dialogue through concrete data collection tools which allow to do the analysis and the interpretation with the participants, such as the SAS² tools we have chosen to conduct this study. Given the present context in Ontario, with the remaining specialized institutions for people with ID closing, there is a need for people with ID to grow out of the life of passivity and learned helplessness that has traditionally been constructed for them. Additionally, this study demonstrates that service providers can use action research to solve real life problems in the field, if provided with usable tools that have been designed to foster dialogue and reflection with participants. If used at a wider scale by service providers, action research could have sustainable impact for people with intellectual disabilities. First, it could be part of the cultural dialogue that we should try to foster between people with ID, service providers, government and society at large. Second, it could help people with ID to take control of their lives. These findings are in coherence with other studies as evidenced in the following section.

Coherence with Previous Research

Participants in this research reckon how the ID label affects their life as well as their relationships with others. They are undoubtedly suffering a great deal because of it. They feel powerless and trapped. In fact, this feeling of powerlessness and entrapment appears to be the

Table 3. Individual scores for present situation

<i>Present</i>	<i>Mingle</i>	<i>Talk about our disability</i>	<i>Talk in front of people</i>	<i>Talk to get support</i>
Olivia	3	2	5	4
Jake	5	5	5	5
Ashley	5	1	2	3
Paige	5	2	3	4
Present	18	10	15	16

major source of unhappiness and seems linked to two factors. First, they don't understand the label and second, the label changes their interaction with others. The atmosphere at LWP is obviously good for them because they get to socialize with each other on a daily basis. However, they feel isolated from the rest of the community and manifest an intense desire to socialize with other people in the community. Fordyce (1997) acknowledges that spending time socializing, working on a healthy personality and developing an outgoing, social personality were decisive factors to a happy life. Similarly, Ryff (1989) referred to self-acceptance, positive relations with others, autonomy, environmental mastery, purpose in life and personal growth as contributing factors to well-being. Looking back at what the participants stated regarding their inability to understand and to explain their ID, it appears valuable to infer that the cause of their suffering could be alleviated by having a better grasp on stigmatization effect of the label. The decision taken by the group to solve this problem is to tackle means and tools to explain ID to others, which in turns helps them to get a better grasp on what their ID is, hence reducing the stigmatizing effect of the label.

Related to the latter, many researchers view ID as a social construct (Finlay and Lyons, 2005). The life experience lived with our participants appears like a textbook example of the social construction of ID. Despite the fact that people with ID are labeled as such because of a low IQs and autonomy problems, the researcher has been impressed, not by the limitations that low IQ usually entails, but rather by the numerous talents the co-researchers evidenced throughout the research, including the astounding reflective abilities put in the process. Moreover the amount of caring ID co-researchers manifested throughout the process, for each other, for the researcher and for the group as a whole showed that the label fails short of accounting for all aspects of their personas. This is not to say that living with such label was not pervasive and did not account for their repeated compulsion to talk about it so much.

Implications for Practice

In the context of community and residential integration programs, institutions that work with people with ID tackle many challenges and

often don't have enough time do address all of them. Most institutions stress the importance of basic life skills mastery. Without saying that learning basic life skills is unimportant, the Activity Map we elaborated together clearly points out a vital need for self-advocacy. Suffice to say that if the co-researchers think it's a number one priority, then it's a good enough reason to put forward mechanisms to help them vent their concern.

However, this challenge should not be another responsibility transferred only to institutions that work with people with ID. The reasons behind this injunction are numerous, one of them stemming directly from this research. People with ID need to understand the nature and specific limitations related to their ID and to feel comfortable to explain it to others. Also, we, as a society, should feel involved in this matter and take the responsibility for the well-being of others collectively, as I have seen adults with ID do. If we could simply see beyond the label, a person of talents and qualities, this would act as a huge step in making everybody feel like a human being filled with his or her own dignity. This should be showcased at school and at home. For example, adding this element to the school curriculum would help dispel stereotypes towards people with ID.

Limitations

The participants in this study were recruited at LWP and were all attending SMILE adult services program. We recognize that the community and residential integration process is specific to this group and thus results are not fully transferable. However, given the broader deinstitutionalization initiatives in the world's richer nations, we can infer that other people with light or moderate intellectual disabilities are experiencing similar problems regarding understanding and explaining their ID. In addition, while a sample of five may not be representative of people with developmental disabilities, this number pertains to the particular group taking part in this pilot study.

The collaborative action research tools that were used with this group had impact in terms of giving them control and ownership of the information they shared, as well as in the analysis and the interpretation of their

situation. However, they presented certain limitations in terms of facilitation. For example, during the Socratic Wheel's facilitation, the researcher had to broaden the scale so that her co-researchers could assess what progress they wanted to make regarding some abilities they had previously identified as challenges. Despite the adjustment made in order to better discriminate where they were and where they wanted to be at the end of the process, one participant gave himself a perfect rating to all abilities.

Suggestions for Future Research

There is certainly a need to foster studies that will use tools that can assist people with ID in the collection, the analysis and the interpretation of data. These tools require being able to make efficient use of their own language and local knowledge structures. In the case of people with ID, these tools might help them explain ID to others and to themselves as a consequence.

Moreover, there is a need for innovative technology applications with people with ID. These innovations should keep in mind that information and communication technology (ICT) have high potential to improve the human condition, including that of people with ID. Applications that are most interesting are the use of mobile technologies for learning on-the-go, the use of technology to compensate for some disabilities and the use of technology to voice something as important as who they truly are.

References

- Antaki, C., Finlay, W., Walton, C., & Pate, L. (2008). Offering choices to people with intellectual disabilities: An interactional study. *Journal of Intellectual Disability Research, 52*(12), 1165-1175.
- Apis, S. (1997). Self-advocacy for people with learning difficulties: Does it have a future? *Disability and Society, 12*, 647-654.
- Bandura, A. (1997). *Self-efficacy: The exercise of control*. New York: W. H. Freeman.
- Bandura, A. (2002). *Auto-efficacité: le sentiment d'efficacité personnelle*. Bruxelles, DeBoeck.
- Beart, S., Hardy, G., & Buchan, L. (2004). Changing selves: A grounded theory account of belonging to a self-advocacy group for people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities, 17*, 91-100.
- Brown, I. (2007). What is meant by intellectual and developmental disabilities. In I. Brown & M. Percy (Eds.). *A comprehensive guide to intellectual and developmental disabilities* (pp. 1-15). Baltimore: Paul H. Brookes Publishing Co.
- Chevalier, J., & Buckles, D. (2008). *SAS²: A guide to collaborative inquiry and social engagement*. IDRC. New Delhi: Sage Publications. Retrieved February 24, 2009, from <http://www.sas2.net/>
- Csikszentmihalyi, M. (1990). *Flow: The psychology of optimal experience*. New York: Harper & Row.
- Curry, P., & Cupples, J. (2001). Ask the users. An action research project involving day service users in Luton showed the way for future vocational development. *Community Living, 15*(1), 18-20.
- Davidson, A. L., Leblanc, R., Leno, S., Clément, N., Godbout, S., Moldoveanu, M., Payeur, Y., & Turcotte, C. (2004). Le projet « On Our Own Together II »: à l'aube d'une ère nouvelle. *Revue francophone de déficience intellectuelle, 15*(2), 235-245.
- Deci, E., & Ryan, R. (2002). *Handbook of Self-Determination Research*. Rochester, NY: University of Rochester Press.
- Denzin, N., & Lincoln, Y. (2003). *The landscape of qualitative research*. California: Sage Publications.
- Dykens, E. (2005). Happiness, well-being, and character strengths: Outcomes for families and siblings of persons with mental retardation. *Mental Retardation, 43*(5), 360-364.
- Edgerton, R.B. (1993). *The cloak of competence: Stigma in the lives of the mentally retarded*. (Rev. ed.). Berkeley: University of California Press.
- Ferguson, P.M. (1987). The social construction of mental retardation. *Social Policy, 18*, 51-56.
- Finlay, W.M.L., & Lyons, E. (2005). Rejecting the label: A social constructionist analysis. *Mental Retardation, 43*(2), 120-134.
- Fordyce, M. W. (1997). Éducation au bonheur. *Revue québécoise de psychologie, 18*(2), 241-254.

- Gallagher, E. (2002). Adult clients with mild intellectual disability: Rethinking our assumptions. *Australia & New Zealand Journal of Family Therapy*, 23(4), 202-210.
- Jahoda, A., & Markova, I. (2004). Coping with social stigma: People with intellectual disabilities moving from institutions and family homes. *Journal of Intellectual Disability Research*, 48(8), 719-929.
- Jingree, T., Finlay, W., & Antaki, C. (2006). Empowering words, disempowering actions: an analysis of interactions between staff members and people with learning disabilities in residents' meetings. *Journal of Intellectual Disability Research*, 50(3), 212-226.
- Leblanc, R., Paruthi, R., Davidson, A.-L., Clément, N., Godbout, S., Leno, S., Moldoveanu, M., Payeur, Y., & Turcotte, C. (2008). The "On Our Own Together Housing Project" (Cooperative housing for people with intellectual disabilities). *Journal on Developmental Disabilities*, 14(3), 74-85.
- LiveWorkPlay (n.d.). Retrieved February 24, 2009 from <http://liveworkplay.ca/node/12>
- Mactavish, J., Mahon, M., & Lutfiyya, M. (2000). "I can speak for myself": Involving individuals with intellectual disabilities as research participants. *Mental Retardation*, 38(3), 217-227.
- Martin, L. (2008). Changes before the transition to the community: Experiences of persons in Ontario's closing institutions. *Journal on Developmental Disabilities*, 14(1), 127-137.
- Rapley, M. (2004). *The social construction of intellectual disability*. Cambridge, United Kingdom: Cambridge University Press.
- Ryan, K. E., & DeStefano, L. (2000). Evaluation as a democratic process: Promoting inclusion, dialogue, and deliberation. In K.E. Ryan & L. DeStefano (Eds.), *New directions in evaluation*, No. 85. San Francisco, CA: Jossey-Bass.
- Ryff, C. D. (1989). Happiness is everything, or is it? Explorations on the meaning of psychological well-being. *Journal of Personality and Social Psychology*, 57, 1069-1081.
- Social Analysis Systems Tools (SAS²). (2006). Retrieved February 24, 2009, from <http://www.sas2.net/en/tools/tools-introduction/>