WAYS OF KNOWING, WAYS OF BEING: EXPLORING A GOOD LIFE THROUGH PARTICIPATORY AUDIO/VISUAL METHODS WITH PEOPLE LABELLED WITH AN INTELLECTUAL DISABILITY

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Thesis submitted to the University of Ottawa
in partial fulfillment of the requirements for the
Doctorate in Rehabilitation Sciences

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To my brother Stéphane Boulanger who lived his life with sincerity and to the very fullest.

And to the memories of Justin Clark and Richard Ruston.

Dissertation Abstract

Purpose and objective: A good life includes opportunities to practice self-determination, to participate in and contribute to society, to have meaningful relationships, and opportunities for self-development as well as physical, emotional, and financial health and security (Verdugo et al., 2012). People labelled with an intellectual disability (PLWID) have had limited opportunities to experience these good things in life and to share their own perspectives about a good life. The purpose of this study was to learn from PLWID who face significant barriers to communication about what they most value as part of a good life. My research was situated within the sociohistorical context of the province of Ontario. My main research questions were: (1) What is a good life from the perspectives of PLWID who use various forms of augmentative and alternative forms of communication (AAC)? (2) What can we learn from past advocacy efforts? (3) What are the possibilities and limitations offered by participatory audio/visual methods for enabling PLWID to articulate their vision of a good life?

Methods: To explore these research questions, I conducted three separate but related studies. The first study consists of six narratives of intellectual disability advocacy that has taken place in Ontario. A focus group session advised me regarding the choice of narratives to be included in the study. To conduct the second study, I adopted various research methods, included participatory audio/visual methods, inclusive research methods and narrative approaches. I facilitated a series of five workshops for five participants labelled as having an intellectual or developmental disability and facing significant barriers to communication and six supporters living in the Ottawa Region. Combining audio/visual and inclusive methods and drawing from augmentative and alternative communication (AAC), supported decision-making (SDM) and Supported Conversation for Adults with Aphasia (SCA™), participants, supporters and I explored a good life. A total of 34 video vignettes communicate participants' perspectives. Finally, to conduct the third study, I used audio/visual methods to document the participatory process of exploring a good life with participants and their supporters.

Results: The results reveal that the desire for assistance to practice autonomy and the desire to contribute to shaping supports and services has been at heart of intellectual disability advocacy efforts. Further, PLWID value participation and relationships as part of a good life. Participation in arts and sports are especially important as are relationships with family and friends. Results demonstrate that using participatory audio/visual methods combined with strategies drawn from SDM, AAC and SCA™ provide practical assistance to PLWID when thinking about and communicating their visions and ideas of the good.

Conclusion and implications: The findings of this research indicate the need to continue exploring methodological approaches that facilitate the participation of PLWID and others who face barriers to communication and cognition in research and beyond. The three studies support a radically individual and relational conceptualization of autonomy and decision-making. As such, they suggest the need to rethink accepted ideas about self-determination, including reasoning and decision-making. Finally, the results support the need for individualized assistance that accommodates each person's cognitive and communication abilities to enable meaningful participation. They also suggest the need for fundamental systemic changes that begin with practicing equality and forms of radically inclusive democracy in all our relations.

Acknowledgments

I would first like to thank my advisor Professor Roanne Thomas who made the completion of my dissertation possible. Thank you Roanne for your support, patience, and expert guidance. I would also like to extend my gratitude to my thesis committee members who have provided helpful advice. Thank you to Dr. Ravi Malhotra for your thorough reading and valuable suggestions. Thank you to Dr. Hélène Laperrière for your unwavering support. I am grateful to all three for your positive encouragement and commitment. Thank you also to the participants, family members and supporters who took part in this research, with special thanks to Julia Tuschak, Krysia Pazdzior, Rick Prophet, Sheri-Lynne Styles, Philippe Hennessy, Marie Claire Hennessy, James Hennessy, Ilyasse Youssoufi, Amina Bennoude, Fahima Abdi, Minda Bojin, Maggie Hart, Molly Bruce, Marge McCabe, Terry Boyd, and Rian Alston for your generous contribution of time and expertise to this study. This research would not have been possible without the generous support of the Social Sciences and Humanities Research Council through their Joseph-Armand Bombardier CGS Doctoral Scholarship and the financial support of the School of Rehabilitation Sciences at the University of Ottawa. A special thank you to Marie-Christine Ranger for your moral support and to Alysson Rheault for your assistance. Ultimately, I thank my brother for sparking my desire to engage in research, my teenagers for encouraging me to finish and my mother for always believing that I would.

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List of Abbreviations and Acronyms

AAC	Augmentative and alternative communication
ARCH	ARCH Disability Law Centre
CHC	Central Human Capabilities
CRPD	United Nations Convention on the Rights of Persons with Disabilities
LICO	Low Income Cut Off
OAC	Ontario Advocacy Coalition
ODSP	Ontario Disability Support Program
OACL	Ontario Association for Community Living
PFO	People First Ontario
PLWID	People Labelled with an Intellectual Disability
SDM	Supported decision-making
Social Inclusion Act, 2008	Services and Supports to Promote the Inclusion of Persons with Developmental Disabilities Act, 2008
SCA™	Supported Conversation for Adults with Aphasia

Chapter 1 – Introduction and Organization of the Dissertation

The overarching purpose of this dissertation research was to explore the perspectives of people labelled with an intellectual disability (PLWID) on a good life and to create and share knowledge about the conditions that make it possible for PLWID to articulate their vision. The research was situated within the sociohistorical context of the province of Ontario. My main research questions were: (1) What is a good life from the perspectives of PLWID who use various forms of augmentative and alternative forms of communication (AAC) and, (2) What can we learn from past advocacy efforts? (3) What are the possibilities and limitations offered by participatory audio/visual methods for enabling PLWID to articulate their vision of a good life?

In this chapter, I present the research problem, the study purpose and objectives. I then outline the organization of the overall dissertation. In the literature review, I first describe the theories and frameworks regarding a good life that inform my dissertation. This is followed by a discussion of the barriers to a good life that are faced by PLWID to a good life. I then situate the study in the province of Ontario and share a few thoughts on democracy and how it relates to my overall theoretical perspective. Finally, in the last section of this chapter, I present the theoretical approaches that helped me to attain my specific research objectives.

Research Problem

Too often, PLWID are deprived of opportunities and supports to create a good life. In Ontario, it is estimated that 0.78% of the population has a diagnosis of intellectual or developmental disability representing roughly 66,484 citizens (Lunsky et al., 2013). It is estimated that 0.6% of Canadians are diagnosed with a developmental disability (Statistics Canada, 2012). The labels “intellectual or developmental disability” are applied to a truly diverse group of people whose other identity markers make them members of a multitude of social categories. The labels apply to people across a wide spectrum of cognitive and adaptive abilities. We know that the meaning of disability as well as who counts as disabled fluctuates in relation to the historical period and the prevailing economic arrangements (Malhotra & Rowe, 2014, p. 3). Diagnoses are constantly changing and, as Davis puts it, "Definitions produce diagnoses, which in turn produce definitions" (Davis, 2013, p. 90). For example, over one hundred years ago there were people labelled as imbeciles, idiots and incurables, this was then replaced by "mental deficiency" in the 1930s (Noll & Trent Jr., 2004, p. 3) and an updated version is still in use in French 'déficience intellectuelle.' Those considered mentally deficient and institutionalized in the 1960s for example, may not be today due to changing attitudes, advances in medical knowledge and supports available in the community. Currently, in North America, 'intellectual disability' (ID) is frequently used. Developmental disability is another term commonly used in Ontario, for example Developmental Services Ontario (DSO). Developmental disabilities are said to encompass intellectual disabilities and other conditions affecting development such as Fetal Alcohol Syndrome.[1]

Despite this diversity, PLWID and/or as having developmental disabilities are likely to share experiences of marginalization, poverty and lack of opportunities to make decisions about their daily lives, as well as exclusion from political processes. In Ontario, there is an official discourse to promote "social inclusion, individual choice, independence and rights" and to support PLWID to make "informed decisions" (*Social Inclusion Act, 2008,* Reg. 299/10, PART II, s. 4). However, the conditions for individual choice and opportunities to live independently rarely exist. Like Johnson and Walmsley with Wolfe (2010), I have been "concerned that the

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[1] However, in Ontario, families supporting children and adults living with Fetal Alcohol Syndrome have struggled to access supports via Developmental Services Ontario.

emphasis on inclusion does not sit easily with a view of people with intellectual disabilities as active agents in creating good lives” (p. 175). And while inclusion as a goal has had some positive results such as the closure of large institutions, the gaps between discourse and practice has led to an 'illusion of inclusion' (Metzel & Walker, 2001) or as another example of ‘rhetoric running ahead of practice’ (Weinghart, 2021).

PLWID have had little say in the design of policies that directly affect them. According to Abbas (2014), one of the main barriers faced by PLWID when critiquing these policies is the belief in their lack of credibility, capacity and authority to take part in such discussions. Although researchers increasingly involve PLWID in all stages of research, those who face greater barriers to communication are often left behind. The label of intellectual disability is deeply entrenched in an ideology of deficit (Kliewer, Biklen & Petersen, 2015) thus imposing a ‘cloak of incompetence’ (Callus, 2019) on people so labelled. In addition to negative biases regarding mental capacity, beliefs regarding ways of communicating that fall outside of the norm, such as the use of AAC,[2] represent additional challenges to the quest for a good life. Research suggests that significant barriers to speech can mask competence (Kagan et al., 2010) and significant difficulties with speech may be interpreted as a lack of humanity (Edwards, 2001). Not surprisingly, communication disabilities are said to contribute to social isolation (Communication Disabilities Access Canada, 2022). Considering that humans are differentiated from other species by their capacity to reason, as the label “homo sapiens” suggests, it quickly becomes apparent that to be viewed as incapable of reasoning is extremely problematic. Researchers (Bogdan & Taylor, 1989) have long observed that even individuals with the most

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[2] Alternative and augmentative communication (AAC) can include the use of strategies such as gestures and facial expressions, technology such as speech generating devices such as a Dynavox and software such as GoTalk NOW of which many are now compatible with personal tablets.

severe impairments, can and do express feelings and preferences but the uncommon ways they do this are viewed with skepticism. The current legal definition in Ontario of a developmental disability includes ‘significant limitations in cognitive functioning and adaptive functioning’ (*Social Inclusion Act, 2008*). Cognitive functioning is defined as “a person’s intellectual capacity, including the capacity to reason, organize, plan, make judgments and identify consequences.” Adaptive functioning is described as “a person’s capacity to gain personal independence, based on the person’s ability to learn and apply conceptual, social and practical skills in his or her everyday life” (*Social Inclusion Act, 2008,* c. 14, s. 3 (2)). In other words, the *Social Inclusion Act, 2008* conceptualizes cognitive and adaptive abilities as qualities held by an individual. PLWID are defined as having limited capacities to perceive, to remember, to reason, to understand, to learn, to judge, for intuition and for language (American Psychological Association, 2020) but there is no mention of the environmental factors that interact with the person’s characteristics to produce these limitations.[3] Charlesworth and Banaji (2019) have found that deeply ingrained societal biases regarding race, skin-tone and sexuality have changed however, those about disability, age and weight remain stubbornly stable.

Study Purpose & Objectives

This research responds to the need to listen to and to learn from PLWID about their perspectives on a good life and to reflect on pathways that may narrow the gaps between rhetoric on social inclusion and genuine opportunities to live a good life. To narrow this gap, I used creative methods to explore a good life from the perspectives of PLWID who face significant barriers to communication. This study was also an opportunity to learn about past advocacy efforts and about facilitating participation and decision-making in the context of participatory

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[3] *The Accessibility for Ontarians Act, 2005* (AODA) does identify environmental barriers as that which prevents full participation in society.

visual research. Like Francis (2012), I am interested in the positive project of how to facilitate the articulation of the “epistemic standpoints” (p. 373) of people with intellectual disabilities. As a result of this inquiry, it became apparent that rethinking and clarifying certain foundational concepts such as autonomy, reason and capacity was necessary to better reflect the diversity of ways of knowing and being.

In this dissertation, I endeavor to maintain my focus on the contributions and perspectives of PLWID. Like other researchers in intellectual disability, (Tuffrey-Wijne, Bernal, & Hollins, 2008, Mietola, Miettinen & Vehmas, 2017), I believe that there is an ethical obligation to rethink the assumptions that have guided the treatment of PLWID and to seek out the perspectives of people with disabilities about a good life regardless of barriers to participation and communication.

The specific objectives of this dissertation are:

1. To document and analyze the history of intellectual disability advocacy in Ontario
2. To explore a good life from the perspective of PLWID using participatory audio/visual methods
3. To explore, document and analyze conditions for PLWID who face barriers to communication to engage in the research process.

Organization of the Dissertation

This is a manuscript-based dissertation; the main findings of the research are presented in three manuscripts. Table 1 summarizes the three studies associated with my research, along with the overall structure of my dissertation. This dissertation contains three manuscripts in accordance with the guidelines for students and supervisors in the doctoral program in Rehabilitation Science at the University of Ottawa. The manuscripts are prefaced by an introduction, a general literature review, and a methods chapter. Each manuscript also contains literature reviews and methodological discussions pertinent to the corresponding study, as well as a list of references specific to that manuscript. I conclude my dissertation with an overall discussion in which I integrate the results of the three studies and discuss their implications. The dissertation is written in APA style (seventh edition, 2019). The reference list for Chapters One, Two, and Six is located at the end of the dissertation.

Table 1

Organization of the dissertation

Chapter	Chapter title	Objective	Method	Affiliated Manuscript and Key Journal Requirements
1	Introduction and Organization of the Dissertation	Describe the research problem Present the organization of the dissertation Present a summary of the relevant literature regarding the research problem and overarching theoretical framework for this dissertation. Present specific theoretical frameworks	NA	NA
2	Methodology	Describe the dissertation methodology	NA	NA
3	Intellectual disability advocacy narratives: A series of tableaux	Document and analyze the history of intellectual disability advocacy in Ontario	Historical narrative, story as method	Results Manuscript 1 (Chapter 3) to be submitted to: *Canadian Journal of Disability Studies* Maximum 6000 words (excluding references, notes and table)
4	Using audio/visual methods to	Explore a good life from the perspective of PLWID using	Participatory audio/visual research	Results Manuscript 2 (Chapter 4) to be

	explore a good life from the perspectives of people labelled with an intellectual disability	participatory audio/visual methods.	methods with PLWID	submitted to: *Disability Studies Quarterly (DSQ)* Maximum 12,000 words (excluding references, notes and tables)
5	Decisions, Decisions, Decisions! Supporting Decision-Making in Audiovisual Participatory Research With People Labelled With an Intellectual Disability	Explore, document, and analyze the conditions for PLWID to meaningfully engage in the research process.	Audio/visual research methods and narrative methods	Results Manuscript 3 (Chapter 5) to be submitted to: *The International Journal of Social Research Methodology* Maximum 8000 words
6	Overall discussion and conclusion	Present an integrated discussion of all findings and implications for intellectual disability research, education, and policymaking.	Descriptive synthesis	NA

Theoretical Underpinnings & Literature Review

To begin this section, I situate myself as a researcher, practitioner, and sibling. I also share my philosophical beliefs and how they have informed the design and implementation of my research. I then discuss the literature and the theoretical perspectives that have guided this study. I also present environmental factors that have thwarted opportunities for PLWID to live a good life. Finally, I situate my study within the context of the province of Ontario and describe the theoretical frameworks that helped me attain my specific objectives.

Personal Philosophical Orientation

My research and community-based video work is grounded in my experience of being a sibling to my younger brother who was labelled with an intellectual disability. Before he passed away early in 2021, Stéphane and I did many presentations about his life in the community and about the importance of having the freedom and the assistance to make his own decisions and access to individualized funds to help him implement them. Together, we took part in many advocacy activities such as Respecting Rights supported by the ARCH Disability Law Centre. Respecting Rights is a group led by self-advocates working collaboratively with lawyers, social workers, and supporters to deliver education rights and to advocate for good supports and services for PLWID. We also took part in a local advocacy group called DANEO (Disability Advocacy Network of Eastern Ontario).

As a researcher, I aim to learn from each participant's strengths, interests, and individual communication styles to facilitate self-expression and to have fun whenever possible in the process. Inspired by Rancière's (2012) method of equality, I see the research process as an opportunity to practice equality in the moment, not in some distant ideal future. Practicing equality in our daily interactions may help us as researchers, family members and citizens to avoid reinforcing social practices that deprive so many people from choosing their own paths and from opportunities to thrive. PLWID and others with cognitive and communication disabilities have much to contribute to their communities and their continued exclusion results in an important social deficit (Label Free Channel, 2009, 02:00).

A Good Life: Autonomy, Contribution and Relationships

I now turn my attention to the concept of a good life and a discussion of three elements most relevant to my dissertation: autonomy, contribution, and relationships. As I discuss autonomy, I present two important ontological and epistemological assumptions that underpin this dissertation: (1) the radical specificity of each human life and, (2) the deep relational quality of being, knowing and doing.

I chose the construct of ‘a good life’ for this thesis because it has an expansive and generative quality that lends itself well to an exploratory approach. The concept of a good life was broad enough to give participants the opportunity to identify what was most important in life from their perspective. In other words, it was my attempt to intervene as little as possible in the focus of the research. In much intellectual disability research, the concepts of a good life, quality of life, social inclusion and belonging are used interchangeably. As I searched the literature, I noted many similarities among different approaches to a good life. Researchers in quality of life (QoL) (Schalock, Bonham & Verdugo, 2008, Verdugo, Navas, Gómez & Schalock, 2012), in critical disability studies (Runswick-Cole & Goodley, 2013), capabilities approach theorists (Nussbaum, 2001), intellectual disability researchers (Elks, 2019), family members (Etmanski, 2000) and human rights legislation such as the Convention on the Rights of Persons with Disabilities (CRPD or the Convention), identify common elements of a good life. Participation, contribution, recognition of rights, relationships, self-development and self-determination and physical, emotional, and financial well-being, were deemed important.

The opportunity to practice self-determination or autonomy is central to this study. Disability activists, researchers, philosophers, and family members recognize autonomy as an essential component of a good life. The right to make one’s choices in life is at the heart of disability rights movements and is expressed through the adoption of slogans such as “Nothing About Us, Without Us,” “We can speak for ourselves,” and “Just because I don’t speak doesn’t mean I have nothing to say.” In quality of life research, self-determination is listed as one of the eight life domains (Schalock et al., 2008) and its QoL indicators are “Choices/decisions, autonomy, personal control, personal goals” (p. 182). Communication is an essential aspect of self-determination (Verdugo et al. 2012). Runswick-Cole and Goodley’s (2013) participatory research conducted with people with disabilities identifies ‘Power and control’ as an essential resource for increasing resilience. They ask, “To what extent does taking control over the way care is delivered maximize one’s life chances?” (p. 74). Nussbaum (2001) includes ‘Control over one’s environment’ (political and material) as one of ten Central Human Capabilities (CHC). Elks’ (2019) identifies ‘Voice and choice’ as a common theme in his review of four frameworks and theories about a good life for PLWID. Voice and choice include making decisions, shaping one’s life and having the necessary supports to understand and to communicate one’s choices (Elks, 2019). Autonomy is also central concept in rehabilitation (Blackburn et al., 2018). According to May (2008), exercising autonomy is important because “if one cannot contribute to creating one’s life, then in some sense it isn’t one’s own life that is being created” (p. 90). Welch (2013) argues that it is through the process of decision-making that one develops one’s individuality and creates a unique life path.

Self-determination is defined as “the right or ability of a person to control their own fate” (Oxford Learner’s Dictionaries, 2021). It is synonymous with autonomy, with ‘auto’ referring to the self and ‘nomos’ referring to laws or rules (Online Etymology Dictionary, 2021). Put simply, autonomy can be understood as living according to one’s rules (Online Etymology Dictionary, 2021) and having the authority to make decisions for oneself free from external coercion. Independence is another word used interchangeably with self-determination and autonomy in the literature. Although the word independence is often used in disability research, policy, and advocacy (e.g., The Independent Living Movement), in this dissertation, I will avoid it since it connotes that one must not be dependent on others to act according to one's own rules. Instead, I will use self-determination and autonomy interchangeably.

Autonomy is also a foundational concept in law and in democracies (Nedelsky, 2012). Human rights legislation at all levels of government affirms the right to autonomy. For example, it is one of the CRPD's general principles (Article 3) and, in its preamble the Convention affirms the right to "individual autonomy and independence, including the freedom to make their own choices" (United Nations, CRPD, 2006, (n)). The *Canadian Human Rights Act, 1985* states that "all individuals should have an opportunity equal with other individuals to make for themselves the lives that they are able and wish to have and to have their needs accommodated" (p.1).

Despite the recognition of autonomy as an essential element to a good life and Canada's ratification of the CRPD in 2010 and the Optional Protocol in 2018, opportunities for PLWID to practice self-determination continues to be limited. Silvers and Francis (2009) explain how liberal theory that guides the thinking behind important social institutions contributes to the denial of autonomy for certain people. A liberal theoretical standpoint values individualism and pluralism and thus tolerates a diversity in ideas about the good (Silvers & Francis, 2009). However, Silvers and Francis (2009) point out that liberal theory requires that individuals adhere to an "austere process for arriving at these notions" (p. 477) of the good thus imposing the idea that there is a correct way and a wrong way of thinking and articulating ones' ideas of thinking and articulating ones' ideas. In other words, many versions of the good are acceptable but only if an individual can prove that they arrived at their idea independently without the assistance and interference of others. The conceptualization of autonomy as the ability to do things on ones' own, the goal of increasing independence through improving individual functioning (i.e., without human assistance) has also plagued the field of rehabilitation (Turcotte & Holmes, 2021). The conceptualization of reasoning as an intrapersonal and independent process has contributed to the denial of rights. Others considered capable of reasoning the correct way (e.g., family members or professionals in social work, health and education, public guardians) have often made decisions for PLWID. Adhering to such conceptualizations of autonomy and reasoning maintains discriminatory practices that limit opportunities for PLWID and others who require varying levels of direct assistance for cognition and communication.

Following Silvers and Francis (2009), I believe that the inability to reason without assistance should not be a motive for the denial of rights, respect and membership to the human species, no more than the ability to walk, to hear or to see. Silvers and Francis (2009) argue that individuals should not be excluded from discussions of the good just because they require the help of others to assist with reasoning and communication. They describe this type of assistance as “prosthetic cognition” and develop a theory of trusteeship in which they describe the role and necessary skills. I present their ideas in greater detail in Chapter 3 (Manuscript 1). Before moving forward with a discussion of contribution and relationships, I briefly present how a relational understanding of autonomy and reasoning shifts the location of this process from an individual's mind to the interaction between individuals situated in time and space. Like many theorists, (Nedelsky, 2012, Silvers & Francis, 2009, Welch, 2013, Kong, 2014, Mackenzie & Scully, 2014), I adopt a relational understanding of autonomy and draw on their work to articulate the deeply relational aspect of autonomy.

According to Nedelsky (2012), “constructive relationships are necessary for autonomy to flourish throughout one's life” (p. 4). Welch (2013) argues that Indigenous philosophy provides a framework for the highest level of autonomy that goes beyond and is more radical than liberal conceptions of autonomy. As an example, she describes that, within American First Nations communities direct instruction is considered rude, an insult to one's intelligence; instead, children are encouraged to think for themselves. For this reason, storytelling plays a vital role in Indigenous education (Welch, 2013, p. 210) reflecting Arendt's (1973) idea that storytelling "reveals meaning without committing the error of defining it, . . . it brings about consent and reconciliation with things as they really are" (p. 107). An Indigenous philosophical standpoint encourages thinking and making choices based on one's own beliefs and lived experience or shared through stories. This overall philosophical perspective supports the highest level of individuality while recognizing interdependence.

Feminist moral philosophers such as Mackenzie (2014), argue that autonomy is deeply relational and "requires extensive and ongoing interpersonal, social, and institutional scaffolding and can be thwarted by social domination, oppression, and disadvantage" (p. 42). Relationships can facilitate or represent a barrier to autonomy (Scully, 2014). Greater dependency on the direct support of others does not necessarily lead to a loss of autonomy. The possibility for self-determined action is lost not because one is dependent upon the assistance of another. The possibility of exercising autonomy always exists but it can be denied by others in the moment or can be denied by default when adequate social supports are inexistent.

Making decisions is an important part of practicing autonomy. Many PLWID and others facing barriers to cognition and communication require support to make decisions. The need for support may be due to a cognitive impairment, a mental health condition or simply, a lack of experience in making one's own decisions. Although providing 'support with decision-making' and 'supported decision-making' both involve assisting a person who requires direct human support, Browning (2018) specifies that 'supported decision-making' aims to increase the person's legal capacity.

Francis (2012) cautions against the assumption that some are incapable of formulating and articulating ideas of the good. Article 12 of the CRPD demands that signatory states “provide access by persons with disabilities to the support they may require in exercising their legal capacity” (United Nations, CRPD, 2006) thus formally recognizing making decisions with supports. Decision-making supports are specific to each individual but can include peer support, advocacy, access to assistive technology and information in a variety of formats, speech-to-speech interpretation, and additional time. The need for direct human cognitive and communication assistance for the exercise of autonomy exists on a spectrum of more or less extensive supports and of varying duration and should not be viewed as an exception to the human experience (Silvers & Francis, 2009). Advocates from across Canada have advocated for formal recognition of this alternative decision-making model since at least the 1970s (Stainton, 2017). The Yukon, British Columbia, Alberta, Saskatchewan, and Manitoba (Coalition on Alternatives to Guardianship, 2014, p. 38) have incorporated various forms of supported decision-making and/or recognize support for decision-making in their laws regarding legal capacity.

Autonomy is a key component to a good life, and I have pointed out its centrality to disability rights movements, rehabilitation, theories on a good life and to law. There is a need to rethink the way autonomy is understood. Although liberal theory that informs Canada’s laws is often criticized as promoting individualism, I have presented ideas by Silvers and Francis (2009) that suggest that the institutions we have created are not sufficiently individualistic in the sense that they do not recognize the full diversity of ways of reasoning and articulating ideas about the good. I now turn my attention to two other essential components of a good life: contribution and relationships.

The very idea that PLWID make valuable contributions to society is radical. Historically, at least since the move to industrialization and the adoption of capitalism, PLWID have been perceived as burdens[4] and as a problem to manage.[5] PLWID are often viewed through a deficit lens as receivers of support from family and from society via social programs, seldom as valuable contributors. In fact, when PLWID do have opportunities to contribute as family members, volunteers or employees, their contributions are sometimes patronizingly reframed as something that simply keeps them busy, rarely as a benefit to others. And yet, the opportunity to contribute to society, to one's family and community, like autonomy, is an essential element of a good life.

In a comparable way that a liberal conception of autonomy, reason and decision-making as processes that must be done independently of the support of others, a narrow conception of contribution inhibits the ability to see PLWID as valuable contributors. I begin my discussion by clarifying the idea of contribution. With the help of Etmanski (2000), Abbas (2014), McKearney (2018), I then attempt to expand the idea of contribution to make room for PLWID. The Cambridge University Press (2021) defines contribution as "something that you (…) do to help produce or achieve something together with other people, or to help make something successful." The Latin root of contribution means to bring together and to unite (Online Etymology Dictionary, 2021). Elks (2019) shows how contribution is closely tied to participation and social inclusion in various theories and frameworks on a good life. In this dissertation, I prefer the idea of contribution over participation because it combines the idea of being present

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[4] Even local jails saw them as a burden (Brown, 1984).

[5] Early on via institutionalization far from big cities. Today, those without family support continue to live in congregated settings albeit in usually smaller numbers and in urban areas. Prior to the 1950s, sedative drugs were used alongside physical treatments, restraints, and isolation. Antipsychotic drugs were introduced after the 1950s to manage behaviour (Allison & Moncrieff, 2014).

and being part of something larger. I see participation and having the opportunity to experience something alongside others as an essential first step, whereas paying attention to contribution creates a subtle shift from simply ‘being there’ to being part of co-creating and shaping the experience.

Human rights legislation at all levels of government and frameworks relating to a good life recognize the importance of enabling contributions. The *Ontario Human Rights Code (1981)* refers to the recognition of dignity, worth, and the right “to contribute fully to the development and well-being of the community and the Province” (Chap. 53, p. 249). The CRPD states that people with disabilities must have the same opportunities to participate and to contribute meaningfully to society. Stein’s (2007) Disability Human Rights Framework also focuses on enabling contributions for the benefit of the individual and the benefit of society. Contribution can be helping others (Runswick-Cole & Goodley, 2013), contributing to community (Schalock & Verdugo, 2002), participating in political life (Nussbaum, 2001), developing one’s gifts to share them with others and making a difference (Elks, 2019). Being able to contribute seems to be both a right and a pathway to citizenship, membership and belonging. But what happens when the unique gifts, talents and efforts of certain citizens are not recognized as valuable contributions?

The belief persists that PLWID are primarily unproductive individuals who represent a burden for families and for society. Contributions by people with intellectual disabilities often remain undervalued (Abbas, 2014, p. 11). Abbas suspects that their contributions are left unrecognized due to the peripheral spaces in which they occur. These include spaces such as the home, disability-specific activities such as advocacy groups, day programs, summer camps, Special Olympics and other sports and arts programs designed for people with intellectual disabilities. Abbas (2014) dispels the myth of idleness of PLWID who are unemployed. She does this by revealing the many contributions made by PLWID as volunteers, as advocates and as caring and supportive family members and friends.

Canadian parent, writer and co-founder of Planned Lifetime Advocacy Networks (PLAN), Al Etmanski wonders what contributions might look like for PLWID who have more severe cognitive impairments and how might such contributions be facilitated. Haines (2015) and Channon (2014) found that people with the most severe impairments are at a disproportionate risk of occupational deprivation, and the lack of activity was linked to greater risk of mortality. Etmanski suggests that contributions may include:

> to show up and be present
> to marvel at the ordinary
> to see beauty everywhere
> to listen with silent intensity
> to serve with gentleness and respect
> to nurture with kindness and curiosity
> to play with enthusiasm and humour
> to make the truth visible
> to accept my vulnerability and that of others
> (2000, p. 153)

McKearney (2018) agrees that such contributions are important and may be realized in numerous ways. During his research at L'Arche,[6] McKearney (2018) observed that L'Arche assistants learned to see members as "surprising, eccentric and charismatic agents who can powerfully affect the ethical lives of others" (p. 41). By listening and sharing stories about funny and moving moments spent with L'Arche members, assistants learned to be open to being affected by the sometimes-surprising ways of being of the people they support. Assistants learn that the capacity to contribute to the personal development of others is not dependent on

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[6] L'Arche is an international organization founded by Jean Vanier to support to people with intellectual disabilities not to be confused with the ARCH Disability Law Centre based in Toronto, Ontario.

individual cognitive capacity. It is, however, dependent on the willingness of others to recognize unexpected and unusual behaviours as gifts (McKearney, 2018). Likewise, Etmanski (2000) hopes that a focus on these non-material contributions may “limit and perhaps eliminate judgments of unworthiness” (2000, p. 155). He also hopes that it may lead society to create the conditions that would enable PLWID to share their gifts.

Similarly, Abbas (2014, p. 17) suggests paying attention to the activities of PLWID as intrinsically valuable, not solely as steppingstones to paid employment. To this end, artist and activist Sunny Taylor writes that society should “question the significance of work” (Taylor, 2004, p. 6) and the habit of measuring worthiness based on “productivity as a worker, ...employability or salary” (Taylor, 2004, p. 6). Taken together, Taylor, (2004), Campbell and Oliver (1996) and Nedelsky (2018) argue that radical changes to our social institutions are required to shift the current focus on productivity, competitiveness, and accumulation to a recognition of the value of cooperation, unique ways of being, creating beauty, and providing care. In summary, contribution, like autonomy, can be understood relationally. Expanding the notion of contribution to include the ability to affect and care for others, to advocate and to behave in surprising and eccentric ways allows for a recognition of these gifts to the greater good. Paying attention to them can also prompt critical reflection regarding deeply embedded social norms.

Relationships are also recognized as an essential element of a good life and yet they are often a neglected aspect of the lives of PLWID. To support the quest for a good life by PLWID, Johnson et al. (2010) suggest paying attention to relationships. According to Johnson et al. (2010) and Gladstone (2014), understanding the role of relationships and getting them right is essential to successfully supporting a good life for PLWID. Relationships provide opportunities to give and receive support and to share life's difficulties. Friends, family, intimate partners, neighbours, teachers, employers, personal assistants and acquaintances can all contribute to a good life. These relationships potentially create connections with social, learning, housing, and employment opportunities and, in this sense, they are a "primary vehicle" for inclusion (Lord & Hutchison, 2007, p. 13). Research shows that the lack of connection and social isolation impacts negatively on mental and physical health and overall quality of life (Gilmore & Cuskelly, 2014).

The word relationship is defined as "the state of being related or interrelated" (Merriam-Webster Dictionary, 2022) or "the way in which two or more people feel and behave towards each other" (Cambridge University Press, 2021). It is interesting that the Anglo-French root of the word relation signifies connection and correspondence but also the "act of telling or relating in words." Similarly, relacion from Old French, signifies a "report, connection" and relationem from Latin "to relate, to connect through telling, reciting and narrating" (Online etymology dictionary, 2021). Relationship means connection but its root also signifies to understand and to tell a story. Perhaps this is because telling stories facilitates connection like the l'Arche assistants who shared stories about the surprising and sometimes quirky things that happened with members. Stories contribute to understanding and connection through recounting lived experiences, as self-advocates and rights advocates know so well. I will discuss storytelling further in the chapter on methodology.

People with disabilities identified relationships as a resource that increases resilience (Runswick-Cole & Goodley, 2013). At the same time, Ignagni et al. (2016) research reveals that PLWID propose "that intimate relationships in their lives must be claimed as a right and as a matter of disability justice" (p. 133). The CRPD affirms the equal right to relationships (Article 23). Researchers have identified additional articles that support relationships. For example, the right to live independently (Article 19), the right to mobility (Article 20), the right to privacy (Article 22), education (Article 24), the right to participation (Article 30). In a recent video, self-advocates (Respecting Rights, 2021) refer to the CRPD and demand the right to choose the kinds of relationships they want. Affiliation with humans and other species are also listed by philosopher Martha Nussbaum as part of the ten Central Human Capabilities, while the QoL (Schalock et al., 2008) framework and others stemming from research in intellectual disability (Elks, 2019) also include relationships as essential to a good life. Research by Johnson et al. (2010) and Gladstone (2014) reveals that relationships are valued above employment.

PLWID, their family members and allies also identify relationships as a core element of a good life. According to author and artist Andrew Bloomfield, "our quality of life depends upon good relationships" (Friends of Andrew Bloomfield, 2014, p. 4) and connecting with others is the reason for being (Bridges-Over-Barriers, 2010, p. 8). Likewise, Community Living British Columbia states that "the best way to keep safe is to have family, friends and people in our lives that know and care about us" (2011, p. 8). There is an abundance of literature and research that supports the importance of relationships and connections for PLWID and their pursuit of a good life. However, little attention is paid to relationships and social isolation is a reality for many PLWID. In some cases, PLWID are outright "prevented from having friendships, from relationships and from bringing up their children" (Ignagni et al., 2016, p. 133). Relationships are mentioned in Ontario's *Social Inclusion Act, 2008* but they appear as an afterthought. Social networks of adults with an intellectual disability are often limited to immediate family members and staff with fewer friends than people with other disabilities (Lippold & Burns, 2009). Older adults with intellectual disabilities also experience far fewer friendships and fewer opportunities to provide help to family members (McCausland et al., 2018). Those living in long term care institutions or group homes had the least friendships outside of residents and staff and fewer contact with family than PLWID living with family or living independently (McCausland et al., 2018). Social isolation is known to reduce life expectancy (House, 2001).

Participation, contribution, belonging, relationships, self-development, self-determination, emotional, physical and material well-being, respect and rights are all valued experiences that contribute to a good life. In this review, I focused on self-determination, contribution and relationships. Supporting self-determination and autonomy enables PLWID to create their own unique path and to contribute to society. Contributing to one's family or community is beneficial to the individual, a way to reinforce one's membership to a group and to actively take part in co-creating these structures. Relationships are both intrinsically and instrumentally valuable in multiplying possibilities for connection and for social change. Bergum cautions that "'we can only live well autonomously if we live well together' – the notion that moral good and happiness is rooted in our relationships with others' (MacDonald, 2007). There are a variety of creative ways to support PLWID and others who experience various difficulties with cognition and communication to articulate their standpoint, to exercise autonomy and to make decisions in accordance with their values and preferences. In Chapter 5, I describe in greater detail how visual methods, AAC and supported decision-making, contributed to participation in the exploration of a good life. Having clarified my overall relational and radically individual standpoint, established three key concepts associated with a good life, I now describe some of the consequences of exclusionary conceptions of reasoning and decision-making as well as a lack of adequate 'social scaffolding' for PLWID.

A Coercive Environment

In this section, I expand on the idea that autonomy can be thwarted by the lack of social supports. I draw on Nedelsky's relational rights perspective (2008) to present the environment and conditions often faced by PLWID in their quest for a good life. According to legal theorist Nedelsky (2012), the lack of resources and protection available to women or, in this study PLWID can from a relational perspective, be understood as a form of structural coercion that keeps them in dangerous situations since it deprives them of making choices that would enhance their autonomy. From this perspective, freedom from coercion is not only understood as direct pressure exercised by an individual on another during the decision-making process but the wider social context in which decisions take place. Many factors can contribute to creating a coercive environment. Living in poverty,[7] the lack of adequate personal assistance for activities of daily living, of information presented in plain language and alternative formats, and the lack of affordable housing creates a coercive environment which forces many people with disabilities to live in congregated settings such as group homes, long term care facilities, nursing homes, hospitals, homeless shelters, and even prisons (Ombudsman of Ontario, 2016, Spindel, 2013, p.5). And, as Nedelsky remarks, the resulting situations for women experiencing abuse, sometimes "call for violent self-defense" (2012, p. 176). Individual resistance by PLWID, is easily framed as challenging behaviour requiring medication (McGillivray & McCabe, 2006),

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[7] With few opportunities for a formal education or paid employment (Siperstein et al., 2013), many PLWID depend on income supports such as the Ontario Disability Support Program (ODSP). Lamentably, ODSP leaves people far below the Low-Income Cut-Off (LICO) and often fails to cover basic needs such as food and shelter forcing them to use food banks and to depend on family and friends. Researchers have established a close relationship between poverty and disability (Elwan, 1999). Canadians considered to have "very severe disabilities" and who require the most supports struggle to adequately secure food and housing with their meagre $14, 390 (Statistics Canada, 2012) annual income. Only 19% of PLWID are employed (Statistics Canada, 2012). Of those employed, over 50% have reported experiencing discrimination (IRIS, 2011, p. 18).

restraints, or the intervention of the police as in the case of Nichele Benn who lived in an institution in Nova Scotia (“Rally supports,” 2014).

In this coercive environment, PLWID at a remarkably high risk of abuse (Mahoney & Poling, 2011, Keitly & Connelly, 2001) with 83% of women with disabilities experiencing sexual assault in their lifetime (Sanare Centre, 2021). Of women with disabilities, those with psychiatric and cognitive disabilities are the most at risk (Cotter, 2018). This is significant considering that almost 50% of Ontarians labelled with an intellectual also have a psychiatric diagnosis (Lunsky et al., 2013, p. 93). Many are prescribed psychotropic medications to manage the condition but also to manage their behaviour (Sullivan, 2011, p. 547). Over-medication for prolonged periods of time can have deleterious health effects (Lunsky et al., 2013) and the combination of different antipsychotics can be deadly (Lunsky et al., 2013).

Nor is the input of PLWID sought after. For those who receive publicly funded supports and services from the Ministry of Children, Community and Social Services (MCCSS), few formal mechanisms exist to voice concerns. There is no standard process to present and process complaints nor is there an independent appeal process to deal with disagreements regarding allocated supports or amount for individualized funding. There are also few mechanisms for PLWID, and others, to voice concerns about supports and services funded through the Ministry of Health and Long-Term Care (MHLTC). PLWID are increasingly accessing publicly funded home care services through this ministry.[8] For some, personal support workers enter their homes on a weekly or daily basis to assist them with personal care and/or to provide medical services. Despite the necessary and intimate nature of these services, there is no formal mechanism

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[8] When I first requested personal assistance for my brother through the LIHN, they refused and suggested that I contact services specifically for people with developmental disabilities. I tried again a few years later emphasising the physical manifestation of his need for personal assistance and a file was opened for him.

through which service users may document issues or help shape policies relating to home care. The Champlain Local Integrated Health Network (LIHN) responsible for overseeing home care services has a Health Professionals Advisory Committee but no such committee exists to allow service users to exert a direct influence on their services. Even the advisory board to the Law Commission of Ontario's Legal Capacity, Decision-making and Guardianship project did not include representation by self-advocacy groups led and controlled by PLWID.

In this environment, what Farmer (2005) would label as structural violence, PLWID experience poorer health than Ontarians without an intellectual or developmental disability (Lunsky et al. (2013). People with intellectual disabilities and those with psychiatric disabilities are particularly at risk of ‘diagnostic overshadowing’ (Ali & Hassiotis, 2008) a phenomenon wherein medical professionals discard symptoms of illness because they attribute them to the intellectual, developmental, or psychiatric disability. Consequently, the underlying illness triggering the symptoms is not diagnosed and appropriate treatment is not received, sometimes with fatal outcomes (Mencap, 2014). PLWID experience what Stevens calls a ‘death disadvantage’ dying “20-25 years earlier than adults in the general population” (2019). Effectively enjoying a much shorter life span than the general population (Lauer & McCallion, 2015, Patja et al. 2000), especially those with a severe intellectual disability. Those with the most severe impairments experienced the lowest level of activity, received the least amount of support from staff and experienced the worst health outcomes (Channon, 2014) reflecting what has been described as the ‘inverse care law’ (Tudor Hart, 1971). The inverse care principle also describes the financial situation of Canadians with the most severe impairments mentioned above. In other words, the more one needs support, the less one receives. These structural factors interact to severely limit the practice of autonomy by PLWID and following Nedelsky (2012), I agree that in some circumstances of significant environmental coercion, it may be necessary to intervene against the ‘will and preferences’ of a person to foster the greatest level of autonomy.

When PLWID do exert control over their daily lives, it often occurs as a result of the support of committed individual family members, friends, or support workers. Browning’s (2018) research confirms this revealing that formal support services provided “inadequate and often misdirected contribution of formal support services” continuing to apply a “‘one size fits all’ approach” to service users. The “lack of funding and staffing, inaccurate beliefs, and inflexibility of policy both at a personal and organizational level” contributed to the failure of adequately supporting PLWID. Whereas informal supports which include family members, “had continuity and a deeper understanding of the person, considered broader options, and were willing to dedicate large amounts of time and effort” (Browning, 2018). Many PLWID and their circles of support practice informally SDM. However, laws in Ontario fall behind other Canadian jurisdictions (LCO, 2017) by refusing to recognize the relational nature of decision-making. Instead, the courts maintain an individualistic understanding of mental capacity and do not allow for the type of cognitive assistance described earlier and without which many cannot adequately exercise their right to autonomy.

In summary, PLWID experience structural coercion that limit their ability to make choices that reflect their values and needs and respect their rights. They experience poorer physical and mental health compared to non-labelled Ontarians. Opportunities to make decisions about important life events, to take part in shaping policy and engaging in relationships of their choice are limited. As Kong (2017) explains, “contexts that deride or doubt, or institutions that systemically exclude, can be directly implicated in the incapacity of one’s agency” (p. 39). Protecting the rights of citizens includes ensuring networks of support (Kong, 2017). Having described social conditions that illustrate the gap between rhetoric and reality, in the section that follows, I briefly outline the system of supports and services designed to promote "social inclusion, individual choice, independence and rights" and intended to assist PLWID to make "informed decisions."

Provincial Context of This Dissertation

The purpose of this section is to situate my dissertation in the province of Ontario and to describe aspects of the publicly funded supports and services offered to PLWID. In the late 1800s, institutionalization was the first publicly funded service provided by the province specifically for PLWID. After years of advocacy on behalf of parents and the recognition of the costly nature of total institutions (Power, Lord & DeFranco, 2013, p. See 48 Rioux and Prince, supra, n. 3.), the Province of Ontario formalized a community-based approach via the 1974 *Developmental Services Act*. Between 1974 and 2009, Ontario's Ministry of Children, Community and Social Services (MCCSS) closed all its medium and large state-run institutions. MCCSS gradually shifted from a central approach to a decentralized community-based system.

In Ontario, state-funded services are governed by the *Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act, 2008* (*Social Inclusion Act, 2008*). In contrast with other social services, developmental services emerged from grassroots efforts led by parents (Ombudsman of Ontario, 2016). MCCSS develops policy and administers services and supports via nine regional offices. Provincially, 316 community-based agencies receive funding from MCCSS to deliver supports and services directly to PLWID (Office of the Auditor General, 2020). Direct funding agreements are also made with PLWID their families primarily through a program called Passport and occasionally via brokerage arrangements. A similar program of individualized funding is financed by the Ministry of Health and Long-Term

Care. Direct Funding is administered by the Centre for Independent Living Toronto (CILT) and was preceded by the Special Services at Home (SSAH) program, Ontario's individualized funding scheme sparked by parents of children with intellectual disabilities. Like Passport, Direct Funding allows people with disabilities to choose and train their own support staff. However, to be eligible, people must demonstrate their capacity to manage their budget independently[23] and so the program "primarily serve[s] people with physical disabilities" (Kelly, 2015, p.6). In other words, individualized funding programs in Ontario either exclude those with cognitive disabilities or other conditions that may limit their ability to manage their budget, assume that family members will manage the funding or allow service providers who may be in a situation of conflict of interest to manage the individualized funding. Supports and services for PLWID are discretionary as opposed to Ontario's Disability Support Program (ODSP) which is an entitlement program to those who qualify. Regional offices use a ranking system to allocate funds when they become available and when existing services and spots offered by agencies become available and match the profile of PLWID on waitlists (see Spagnuolo, 2016).

According to MCCSS's (2020) website, the services and programs designed for PLWID aim to "support inclusion" and to assist them to "live more independently," to "participate in a wide range of activities in their communities…just like everyone else." The *Social Inclusion Act, 2008* was introduced as part of the process of Transformation of developmental services in Ontario. Family members took part in the process in an advisory role and had to advocate for the participation of PLWID, however as I will describe in Chapter 3, they were quite disillusioned by the experience.

Some aspects of a good life like choice, rights, inclusion, participation and well-being appear in the *Social Inclusion Act, 2008*. However, the Act does not clearly define these terms, nor does it provide adequate guidance on how to actualize these goods in the lives of PLWID (McCauley & Matheson, 2016). Furthermore, they are overshadowed by the much more detailed attention paid to behavourial interventions, individual capacity and well-being primarily understood narrowly as physical health and administration of medication.

The Act's title refers to social inclusion and agencies are expected to promote inclusion yet, nowhere does the Act define this term. It is also unclear how agencies are expected to promote independence and choice. Little is said about rights other than that each agency must create a list of rights and ensure that service users are aware of the list. Well-being is interpreted primarily from a medical point of view (physical health and medication). Agencies are expected to provide information to PLWID, as needed, about sexual health, self-esteem, communication and relationships but there are no details to guide the type of information or the manner and frequency in which it should be given. Instead, the *Social Inclusion Act, 2008* provides much guidance on how to implement 'behaviour intervention' (mentioned 36 times) and to manage 'challenging behaviour' (mentioned 17 times). The suggestion to take into consideration potential environmental causes of the so-labelled 'challenging behaviour' is presented following a list of individualized measures of containment and correction such as physical restraints, mechanical restraints, isolation, medication, teaching skills and reinforcement (Section 15 (5) 3 of Regulation 299/10). The attention and detail given to managing 'challenging behaviour' demonstrates the endurance of the medical model in Ontario's approach to people labelled with an intellectual disability and how, following Nedelsky (2012), laws are not neutral documents but a reflection of societal values and beliefs.

Services and supports for PLWID have been criticized for the lack of consistency in prioritization, delivery, level of support and cost across the nine regions (Office of the Auditor

General, 2014, 2020, Ombudsman of Ontario, 2016) and a lack of clear care standards (Office of the Auditor General, 2014). The Ombudsman of Ontario (2016) and the Office of the Auditor General (2014, 2020) report that those with the most complex medical and/or behaviourial support needs are the least likely to receive the support they need again reflecting the 'inverse care' principle (Tudor Hart, 1971). Waitlists are interminable (Ombudsman of Ontario, 2016) and worsening (Office of the Auditor General, 2020). Due to the lack of responsiveness and inadequacy of supports, institutionalization persists, now 'by default' (Ombudsman of Ontario, 2016) and in settings such as privately owned group homes, long term care facilities, hospitals, jails and psychiatric units (Ombudsman of Ontario, 2016). Despite the Auditor General's recommendation dating back to 1997, there is no process in place to assess the quality of services rendered to PLWID and the Ministry collects insufficient data about services and people served via the agencies (Office of the Auditor General, 2014). Overall, the Ombudsman of Ontario (2016) has described the system and process of obtaining services as 'multilayered and inconsistent, bewildering, confusing, daunting and complex.'

The Auditor General's Office, the Select Committee on Developmental Services, self-advocacy and family-led groups and networks and the Ombudsman's office have proposed many recommendations to improve the system. In 2014, the Select Committee on Developmental Services recommended transforming the system into an entitlement system and eliminating all waitlists, but this was rejected by MCCSS (Ombudsman of Ontario, 2016). ARCH Disability Law Centre lawyer Kerri Joffe recommended that the province provide funding to support Regional Peer Advocacy Committees (Joffe, 2010) led by PLWID to address systemic concerns and deliver accessible rights education to service users across the province (Joffe, 2010, p. 108).

Recently, the self-advocacy group Respecting Rights based at ARCH, has created a poster for MCCSS policymakers ‘5 Things to make Developmental Services Better’:

1. People’s Voices Need to Be Heard. The government should learn from self-advocates by having regular accessible and supported meetings with them. Self-Advocates must be part of helping to make developmental services better.
2. Making Complaints Accessible. People who use developmental services need a safe, accessible way to complain when there is a problem with their services. Complaints should make services better.
3. Same Rights for Everyone. Everyone who uses developmental services should have the same rights. Rights in developmental services should be written in a law so everyone must follow them.
4. Better Staff Training. Developmental services staff need better training about legal rights for people with disabilities.
5. Accessible Technology. If the government decides to use technology in developmental services, it must be accessible and in plain language. People must be given supports to use it (Respecting Rights, 2021).

Family organizations and self-advocates from the greater Ottawa region have asked the Ministry to engage in “meaningful and regular dialogue with a wide range of stakeholders, including self-advocates, families and service agencies” (Letter to Rupert Gordon, 2021, 26 January). The Ombudsman of Ontario (2016) has also recommended that the Ministry increase consultation and communication with developmental services users. The demand by self-advocates, families and allies to contribute to shaping the supports and services reflects more radical forms of inclusion and what I understand as a desire for more radically democratic practices. From a radical democratic and what Schostak (2019) calls a radically inclusive perspective, solutions are understood as temporary and as the result of much discussion and recognized compromise. Arendt (1998) reminds us that “the essential human condition of plurality, the acting and speaking [or communicating using alternative and augmentative means] together...is the condition of all forms of political organization” (p. 202). Radical inclusion means accepting that certain community members can force a community to rethink its values and compel it to do the arduous work of restructuring itself (Schostak, 2019).

To truly reflect the value of pluralism, all members must have opportunities to take part in developing social institutions. Different ways of doing and being must be recognized, respected as valid but also serve as opportunities for social change. Supporting PLWID who face considerable barriers to communication to take part in decision making, to exercise autonomy and to articulate their perspectives creates opportunities for current social institutions to do things differently. Taking it further, Schostak (2019) invites everyone to place democracy not only in public institutions but also “into the domain of face-to-face social relations... (to blur) ...the neat neoliberal boundary between the private and public domains” (p. 1107) reflecting Rancière's method of equality (2012). For Clifford and Simplican (2015), the CRPD’s built-in requirement that governments involve people with disabilities in monitoring rights is a good example of implementing the on-going process of the struggle for justice. Both the *Accessibility for Ontarians with Disabilities Act, 2005* (AODA) section (b) and the more recent *Accessible Canada Act, 2019* require consultation with people with disabilities when preparing and updating their accessibility norms and reports. “Each attempt to address the consequences of decisions by demanding otherwise excluded voices are included is a radical act that drives towards a society of equals” (Schostak, 2019, p. 1112). All policies, programs and systems designed to support

PLWID begin in dialogue and unless they are included from the onset and have genuine power to change outcomes, these systems will fail to catch up with the rhetoric.

To sum up this section, provincial policy reflects some of the essential elements to a good life such as autonomy (choice, independence, rights) and, to some extent, contribution via its promotion of community participation. However, it continues to draw from a deficit framework to define intellectual disability. The Act also shows up as a legacy to the century-old practices of containing and controlling behaviours through the normalization of physical and chemical restraints. Finally, the province has no formal and accessible process to engage meaningfully with PLWID and their trusted allies regarding policy.

Summary of Theoretical Underpinnings and the Literature Review

In this presentation of the theoretical underpinnings of my dissertation and literature review, I discussed theories and frameworks that inform my understanding of a good life and guide my research with participants. Following Elks (2019) and others who have employed this concept such as Etmanski (2000), Bloomfield and Bloomfield (2013), Johnson et al. (2010), I believe that a good life is a useful and unifying concept to explore priorities with PLWID. My discussion highlights the systemic forms of coercion that limit opportunities for PLWID in search of a good life. Supports and services designed for PLWID have yet to match the vision and meet the requirements set out by disability activists, theorists and the Convention. The CRPD connected to a QoL framework provides an interesting starting point to explore a good life with PLWID. Do these theories, frameworks and policy reflect what PLWID express as valuable to them?

Specific Theoretical Frameworks

In this section, I describe the social model of disability, the disability human rights framework and quality of life framework used to reach the following specific objectives:

- For Objective 1, to document and analyze the history of intellectual disability advocacy in Ontario, I used the social model of disability, as well as the United Nations Convention on the Rights of Persons with Disabilities (CRPD) to guide my interpretation of advocacy events. A participatory approach informed the selection of advocacy events.
- For Objective 2, to explore a good life from the perspective of PLWID using participatory audio/visual methods, I used the QoL and CRPD frameworks as springboards for discussion.
- For Objective 3, to explore, document and analyze conditions for PLWID who face barriers to communication to engage the research process, I was also guided by a social model of disability and the CRPD.

The Social Model of Disability

A socially rooted understanding of disability was first articulated in the mid 1970s by the founding members of the UK disability rights group UPIAS (Union of Physically Impaired Against Segregation). The term ‘social model of disability’ was coined by Michael Oliver and, as Barnes (2020) explains was never meant to be an all-encompassing theory of disability. Instead, its value lay in its effectiveness to shift the analysis regarding disability from individual to social causes. The model shines a light on the social, physical and cognitive structures that contribute to injustice. The conceptual separation of impairment from disablement represented an important “paradigm shift” (Shakespeare and Watson 2002, p. 23). Thus, “disabled people began to think of themselves in a totally new way, and became empowered to mobilise, organise, and work for equal citizenship" (Shakespeare and Watson, 2002, p. 5). The social model spurred interventions that led to the removal of barriers present in social structures such as physical environments, attitudes about impairment, policies and legislation. As Mulvany notes, "Central to this work is a focus on the rights of people with disabilities and the consequences of the development of a collective identity for social action and social change" (Mulvany, 2000, p. 584).

My first encounter with the social model was during my masters in disability studies. The social model struck me as a revelation, first as a sibling struggling to understand the social exclusion, underestimation, and devaluation of my younger brother and all other PLWID I had come to know, second, as a student in disability studies attempting to articulate this social perspective. The social model of disability has helped frame my research as well as collaborative video and storytelling work with PLWID. According to Rice et al. (2015), the social model's strength is its simplicity and clarity. The model has been criticized for being too simple and for negating the body. Some have advocated that it be abandoned (Shakespeare and Watson, 2002) whereas as others advocate for adjustments (Malhotra and Rowe, 2014).

Shakespeare (2014) has embraced an interactional approach of disability that describes the phenomenon "as the outcome of the interaction between individual and contextual factors, which includes impairment, personality, individual attitudes, environment, policy, and culture" (p. 77). According to Barnes, (2020), the social model continues to be a relevant 'heuristic device' that reminds researchers, practitioners, and policymakers to remain focused on the social structures and has the potential to transform consciousness and to provide an overall orientation and understanding of the exclusion of persons with disabilities (Oliver 1996), including people with intellectual disabilities. A nuanced social model of disability that acknowledges these interactions between individual and contextual factors is compatible with my overall framework of radical and relational individualism. Following Muir and Goldblatt (2020), I believe that the social model of disability is compatible with a relational view of rights since it shifts the focus away from the person with a disability as the locus of the problem to an analysis of the social environment in which the person is embedded.

Disability Human Rights Framework

Ignatieff points out that laws cannot order people to care about one another (Ignatieff 1984 in Cushing, 2003, p. 3). Although I agree, legal documents, like the CRPD and other international conventions, are formalized articulations of expectations regarding ways to live well together. These expectations are based on beliefs such as the equal value of individuals, the relational quality of autonomy and reasoning (CRPD, Article 12).

The disability human rights approach stems from the efforts of disability rights groups and the lived experiences of their members. My first introduction to the Convention at a People First of Canada conference left me wondering how a long and dry text-based legal document would be of practical use to self-advocates with intellectual disabilities fighting to close institutions and advocating for real opportunities to live well in the community. However, my advocacy work as a sibling and as part of local and provincial advocacy groups has changed my perception.

The CRPD was the first convention developed with the primary stakeholders as equal partners and worked together successfully to negotiate each article of the Convention. As such, it represents an important landmark in the history of disability rights movements (Mittler, 2015). Family groups and self-advocates with intellectual disabilities contributed significantly to its formulation, especially Article 12: Equal recognition before the law (Mittler, 2015, CBC, 2019). Article 12 reflects an understanding of relational reasoning and decision-making requiring signatory states to recognize the legal capacity of all persons with disabilities and, to ensure that they have access to the supports they need to exercise their legal capacity. Values that underpin the Convention are respect for dignity, autonomy, making one's own choices and independence. Again, like the social model, the CRDP represented an important paradigm shift but this time with the aim to benefit people with disabilities in all areas of their lives using the law (Harpur & Bales, 2010). The Convention contains negative civil and political rights that protect people with disabilities from discrimination and oppression. It also contains positive social, economic, and cultural rights and the human right to development and as such provides clear guidance regarding the obligations of signatory states to their citizens with disabilities. The Convention facilitates the institutionalization of a socially rooted understanding of disability. Although the Convention contains fifty separate articles, it recognizes "the universality, indivisibility, interdependence and interrelatedness of all human rights" (United Nations, 2006, Preamble, (c)). Canada first ratified the Convention in 2010 and recently ratified the Optional Protocol in 2018 allowing Canadians to address complaints directly to the United Nations Committee on the Rights of Persons with Disabilities.[9]

There is increasing interest in a rights framework in relation to intellectual disability (Stainton & Clare, 2012). Some have noticed a shift in disability policy language from an 'ordinary life' to one of rights (Johnson et al., 2010). For Stainton and Clare (2012), the CRPD is a template and manifesto for advocacy efforts and a guide for policy development. In Ontario, self-advocacy groups and family advocacy groups are increasingly referring to articles of the CRPD to argue for better living conditions. Respecting Rights self-advocates through the ARCH

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[9] A complaint can be directed to the Committee once all complaint resolution options available in Canada have been exhausted and many more criteria are met. For more information see the ARCH Disability Law Centre: https://archdisabilitylaw.ca/resource/factsheet-the-crpd-and-the-optional-protocol/

Disability Law Centre continue their work to advance the rights of PLWID. Finally, the Convention although an essential guidepost for the kind of society we would like to build, is only as effective as the capacity and willingness of citizens to advocate for its full application (Verdugo et al., 2012).

For Objective 2: To explore a good life from the perspective of PLWID using participatory audio/visual methods, the research process was also guided by the social model and the Convention. To facilitate the exploration of a good life, I used a quality of life framework and its eight domains of life.

To facilitate the exploration of a good life with participants, I chose Verdugo, Navas, Gómez and Schalock's (2012) quality of life framework with eight life domains. These authors link clusters of CRPD articles to each domain of life. The eight domains are categorized under three broad factors (Schalock, Bonham & Verdugo, 2008) as personal development and self-determination, (independence), interpersonal relationships, social inclusion and rights (social participation), emotional well-being, physical well-being, and material well-being (well-being).

Several reasons informed my choice of the quality of life framework for this study. First, QoL increasingly informs research, monitoring, and reporting as well as quality improvement of services and supports for people with intellectual and developmental disabilities in the United States and in Canada.[14] Verdugo et al. (2012) propose that signatory States such as Canada, that have adopted the CRPD, use the assessment of QoL life domains and its associated indicators to provide a comprehensive picture of the standing of the rights of PLWID. Second, QoL is a multidimensional concept that considers both individual and environmental factors that impact on a person's life situation. It can include subjective well-being via self-reporting and objective indications of well-being via direct observation (Verdugo et al., 2012). Third, there is agreement internationally about the core eight domains of life (Bigby et al., 2014). As mentioned earlier, the eight domains of a QoL framework link to many elements of a good life described in other theories and frameworks. Finally, QoL is also relatively accessible with its eight life domains, as opposed to the fifty articles of the Convention on the Rights of Persons with Disabilities for example.

Accessibility is an important aspect of conducting participatory research with PLWID (Walmsley & Johnson, 2003). However, it was also essential to include the CRPD as a guide for exploring a good life with participants since a human rights approach has been key to struggles by disabled people for justice. The Convention is a very long document and would have been overwhelming to work with in a participatory research study. Linking the articles of the Convention to specific life domains (Verdugo et al. 2012), made it easier to explain each domain and, when needed, provide additional examples based on CRPD articles. By using QoL, a framework increasingly used in developmental services alongside the CRPD, it is my hope that awareness of disability human rights may increase.

I made minor adaptations to the QoL framework inspired by the CRPD as I found the language of the CRPD helpful to better describe certain life domains. For example, instead of using indicators such as “Activities of daily living” and “Adaptive behaviour” proposed in Verdugo et al. (2012) to describe Personal Development, I preferred to use CRPD descriptions such as the development of one’s talent, creativity, personality, and abilities found in Article 24: Education. I also privileged the word Participation over Social inclusion. Participation is a term used throughout the Convention whereas there is very little consensus on the meaning of social inclusion (Teachman 2016, Cobigo et al. 2012). I have also added communication as part of the life domain Self-determination. Verdugo et al. (2012) link self-determination to the CRPD’s

Article 21 - Freedom of expression and opinion and access to information which concerns the right to access support to communicate via all forms of communication. Runswick-Cole and Goodley's (2013) Network of Resilience developed as a result of a participatory study with people with disabilities, also recognizes the importance of communication as essential to self-determination.

Summary of Literature and Theoretical Considerations

In this chapter, I presented the overall organization of the dissertation. I outlined the theories and frameworks informing the notion of a good life, I discussed the barriers faced by PLWID in their search for a good life and, I situated the study in the context of the Province of Ontario. Finally, I presented the theoretical underpinnings of the dissertation, including my personal philosophical orientation and specific frameworks that contributed to attaining my research objectives. This chapter describes the context for the studies and is the foundation for my selected methodology, as well as the subsequent manuscripts.

Chapter 2 – Methodology

Having established the theoretical and sociohistorical context of my research, in this chapter, I situate the literature on participatory audio/visual methods in the wider context of participatory research. I also review more specifically inclusive research methods involving PLWID. These two approaches allowed me to explore the overarching goal to create and share knowledge about a good life from the perspective of PLWID as well as exploring and documenting the conditions that enable them to articulate their perspective. As mentioned in the previous chapter, my main research questions were: (1) What is a good life from the perspectives of PLWID who use various forms of augmentative and alternative forms of communication (AAC)? (2) What can we learn from past advocacy efforts? And (3) What are the possibilities and limitations offered by participatory audio/visual methods for enabling PLWID to meaningfully take part in research? To answer these questions, I have chosen inclusive research methods with people labelled with an intellectual disability (Walmsley & Johnson, 2003), audio/visual methods and narrative approaches. These approaches are well suited to help me reach my research objectives which include finding ways to listen to and learn from PLWID who face barriers to cognition and communication. It is important to point out that this research took place before the Covid-19 pandemic.

Research Design

I now describe the three broad methodological approaches used to achieve my research goals beginning with inclusive research methods, following with audio/visual methods, and ending with narrative approaches.

Inclusive Methods with People with Intellectual Disabilities

In 2006, when I first began working collaboratively with members of People First to co-create a documentary film, the literature on inclusive research methods with people with learning disabilities was limited. However, the work *Inclusive Research Methods People with Learning Disabilities* by Walmsley & Johnson (2003) provided useful guidance. The authors propose the following principles:

- The research problem must be one that is owned (not necessarily initiated) by disabled people.
- It should further the interests of disabled people; non-disabled researchers should be on the side of people with learning disabilities.
- It should be collaborative – people with learning disabilities should be involved in the process of doing the research.
- People with learning disabilities should be able to exert some control over process and outcomes.
- The research question, process and reports must be accessible to people with learning disabilities (p. 64).

These principles informed this study and I discuss each principle in greater detail in Chapter 4. The choice of participatory approaches served as a challenge to make the research process and its products as accessible as possible to those most concerned by the subject. Although the research problem was not initiated by PLWID, my decision to adopt the concept of a good life was partially motivated by a desire to adopt a broad and holistic starting point to allow research participants to identify their own priorities.

To conceptualize participatory research involving PLWID, Bigby et al. (2014) identify three broad levels of involvement: (1) Advisory, (2) Leading & controlling and, (3) Collaborative (p. 5). I adopted inclusive research methods in each study albeit at different levels:

In Study 1, on the history of intellectual disability advocacy in Ontario, I involved supporters primarily in an advisory mode. The extent of participation resided in prioritizing stories and events that were chosen for inclusion as advocacy stories.

In Study 2, about a good life from the perspectives of PLWID, I worked with research participants in a collaborative modality where control was “dispersed among the group” and roles were “shared and distinctive purposes between academics and people with intellectual disability” (Bigby et al., 2014, p. 5) co-exist. The most obvious roles for myself as a researcher were to provide an initial framework for the study and to coordinate practical matters of logistics. Participants brought their life experiences and understandings of the world as well as their own motivations for joining the study. Together, we used our respective strengths and skills to explore the overarching goal of the study. A collaborative group approach also reflects Walmsley and Johnson's (2003) recommendation of a 'team approach' when working with PLWID. It also reflected my own experiences as a sibling, an independent support worker as well as collaborative filmmaking with PLWID.

Drawing further lessons learned from a UK research collaborative comprised of PLWID and researchers, Johnson et al. (2010) list the following essential elements which informed the overall design of the research:

- Time and trust.
- Sharing expertise – a two-way process.
- Making the process explicit and checking back regularly that the aims of the group (in this case each participants perspective on a good life) are being furthered.
- Reciprocity – disabled people give as well as receive (p. 167).

In the case of Study 2, checking back was done on an on-going basis throughout the research process. We faced a variety of challenges as we worked to craft our conditions for collaboration. Support with decision-making and communication was key. As suggested by Boxall and Ralph (2009), supported decision-making (SDM) approaches were incorporated into the study. I discuss SDM and related concepts and practices in Chapter 5 wherein I describe decisional moments that took place during the research process.

I endeavored to use existing tools and strategies and to further develop and/or create new ones to support meaningful participation. Since participatory research is, to a great extent, dependent upon dialogue (Boxall & Ralph, 2009, p. 48), I incorporated a variety of AAC strategies into the research process. Beyond individual AAC approaches, I explored a variety of strategies such as active listening skills, the use of personal photographs, sketches, and video clips as well as pictograms to facilitate communication and mutual understanding. A new strategy for me involved presenting information in an easy read format. Easy read consists of placing clear images or symbols on the left of the page and related short and clear sentences on the right. Easy read documents contain only essential information, avoids jargon, and presents information in an order that contributes to understanding. Although this format is more accessible, it does not replace the need for verbal and/or signed explanations.

In Study 3, on making decisions in the context of participatory research, participants received direct support to visually communicate their ideas and to analyze the results.

Audio/Visual Methods

I chose audio/visual methods to conduct research with PLWID who face barriers to cognition and communication for a variety of reasons. In this section, I discuss my choice of visual methods in the context of participatory research with PLWID. Although my experience with the visual arts began a long time ago with drawing and painting, and while I do practice and enjoy photography, video has become my medium of choice. I now use my drawing skills to visualizing concepts, models, and theories for explanatory purposes, sometimes strictly for my own understanding, sometimes for the purpose of communicating ideas with others. Communicating and thinking visually are certainly my preferred modes. They have also been at the heart of my previous experiences of doing collaborative work of creating video-based stories with people with disabilities. My work is motivated by an ethical imperative to adopt methods that will maximize the participation of collaborators. For these reasons, I agree that audio/visual research methods offer more than conventional text-based methods. I now discuss four reasons for privileging audio/visual methods: social justice argument, the production of diverse types of knowledge, epistemological plurality, and reflexivity. Although I have separated my discussion into these four distinct categories, there is overlap between them. Pink has argued for the development of visual ethnography as a response to the positivist approach to social science. “This was precisely against the idea of visual methods as modes of data collection and in favour of visual ethnography as a process of producing knowledge” (Pink, 2013, p. 31). I agree with Pink that visual methods are so much more than just a different way of collecting research data.

The use of audio/visual methods in research contribute to social justice since they are respectful of varying levels of literacy and communication styles allowing a greater diversity of participants may take part in research and contribute to our understanding of lived experiences and phenomenon. These methods can be used to facilitate communication during interviews and group sharing sessions. Taking it further, Goodley and Moore (2000), suggest that “it is a cop-out to point to university criteria for research evaluation as a reason for not pursuing more innovative forms of scholarly activity” (p. 877) when conducting community-based disability research. These methods contribute to communicative access (Simmons-Mackie et al., 2007) thus expanding potential audiences for research results.

Audio/visual methods have the advantage of conveying embodied forms of knowledge like voices, movements, environmental sounds, facial expressions, clothes, behaviour, etc. Referring to an online publication where researchers embedded video interviews, Pink (2013) remarks that this approach "bring participants' voices and bodies more clearly into their work, thus achieving thus achieving something of the multivocality that the emphasis on reflexivity developed in the 1990s called for" (p. 206)." They can also facilitate identification and connection with a research participant (Clarke, 2016). Audio/visual methods allow for sharing knowledge via "different communicative modalities (language, paralanguage, gestures, eye movement, bodily positions, material and social artifacts in the immediate context, etc)" (Hydén & Antelius, 2010, p. 591). Audio/visual methods personalized the results, allowing readers/viewers to see what is important to participants and to see glimpses of the research process.

Audio/visual methods honour multiple ways of knowing or 'epistemological pluralism' (Miller et al., 2008). Selin and Gano (2015) argue that visual research methods are more inclusive and assist researchers to move beyond words incorporating "the material, visual and affective" (p. 90). Hannula et al. (2014) argue that each modality has different qualities. According to them, verbal, written or visual modes of expression each offer their own truths that cannot easily be translated from one medium to another. For this reason, it is important for different mediums to co-exist. Epistemological plurality through visual methods facilitates building the 'circle of equal differences' that Santos (2014) refers and the recognition of a plurality of knowledge "Throughout the world, not only are there very diverse forms of knowledge of matter, society, life and spirit, but also many and very diverse concepts of what counts as knowledge and the criteria that may be used to validate it" (p. 28). By being accessible to more people, visual methods increase the diversity of people who may participate in evaluating an intervention. Using audio/visual methods throughout my own research process allowed me to avoid a one size-fits-all approach to the process of facilitating reflection and the articulation of participant perspectives of a good life.

Audio/visual methods encompass a variety of practices including photovoice, photo novella (fotonovela), drawing, digital storytelling, videovoice, participatory video and video diaries. The photographs, drawings, or videos may be come from private or public archives or, they may be generated by researchers or by participants (Cox et al., 2014, p. 4). In this dissertation, photography, video, and drawing were used to facilitate communication and increase accessibility, to collect data and to represent results.

In this research, participants were supported to generate audio/visual material, search for new images on the Internet and to use pre-existing images from their personal archives. This "methodological abundance" (Hannula et al., 2014) allowed participants to use the approaches most suited to their communication style and needs. Whenever possible, participants used their own voice when sharing important aspects of a good life. In some cases, it was necessary to use a computer-generated voice and to include the voices of trusted supporters.

Haw and Hadfield (2011) identify five modalities for using video in social science research. Although they refer specifically to video, their framework is also useful for thinking about visual methods in general. The five modalities are:

1) Extractive: using video to record specific interaction so that it can be studies in more depth by the researcher.

2) Reflection: using video to support participants to reflect upon actions, understandings and constructions.
3) Projection and provocation: using video to provoke participants to critically examine and challenge existing norms, traditions and power structures.
4) Participation: using video to engage participants in a research project in ways that allow them to shape its focus and outcomes.
5) Articulation: using video to help participants voice their opinions and communicate these to others (Haw & Hadfield, 2011, p. 2).

I made use of audio/visual methods in each study albeit in different modalities:

In Study 1, a historical narrative of intellectual disability advocacy in Ontario, visual methods supported participation.

In Study 2, audio/visual methods were extensively used to facilitate communication and to support participation in the research process and articulation of their ideas on a good life.

Finally, in Study 3, I used video in an extractive modality as I recorded the workshops and photo-documented the individual data collection session (average of 6 sessions per participant).

Narrative Approaches

Finally, I chose narrative approaches in this dissertation since, following McAlpine (2016), stories are best suited to describing lived experience. In addition to audio/visual methods, narrative approaches are an accessible and engaging way of describing events. Sharing experienced-based stories or personal narratives has been essential as a strategy of resistance within the self-advocacy movement. It is also recognized as a meaningful way of including marginalized voices in areas including intellectual disability research (Atkinson et al., 2000; Goodley, 1998; Meninger, 2006), feminist research (Stone-Mediatore, 2003), legal studies (Malhotra & Rowe, 2014) and communication studies (Ellis, 2009). Couser (2000) suggests that disability autobiography allows us to explore ways in which "disability may create culture." (p. 307), whereas Hydén and Antélius (2010) remind us of the possibilities of telling our own stories as a means of participating in the construction of our identity (p. 598).

Narrative approaches, especially when combined with audio/methods, allow PLWID to emerge as unique and specific individuals not clinical cases. Said differently, these approaches allow them "to reclaim their lives as their own and to provide counter-narratives" (Nind, 2008, p.14). When I first began working with People First Winnipeg members in 2006, self-advocates shared their stories in person during conferences and some were published in newsletters or booklets. The use of audio/visual methods was marginal. Since my beginnings with People First members and our co-creation of *The Freedom Tour* documentary (2008), the use of audiovisual in self-advocacy movements has exploded. However, as accessible, and powerful personal narratives may be in countering hegemonic narratives of disability, telling one's story or sharing one's opinions and perspectives typically requires an ability to write, communicate orally or sign. For PLWID who do not write nor use words or sign language, or who use them very little, telling stories remains a creative and methodological challenge for which audio/visual methods combined with AAC and supports for decision-making are well suited to address.

I used narrative approaches in each study albeit in different ways:

In Study 1, on the history of intellectual disability advocacy in Ontario, I used narrative approach to share stories of past contributions made by parents and self-advocates to the development of the province. Through these narratives, we learn about the priorities of self-advocates and parents as they fought for change.

In Study 2, about a good life from the perspectives of PLWID, video vignettes provide visual accounts for experiences and people that participants chose as important to a good life.

In Study 3, about meaningful participation of PLWID who face barriers to cognition and communication in research, I use a narrative approach to describe decisional moments with each participant supported by visual documentation of the process.

Setting, Sample and Recruitment for Studies 1-3

A total of 15 participants took part in these studies. While this sample size may appear to have limitations, Malterud et al. (2016) introduce the concept of information power for qualitative research studies with fewer participants. To achieve high information power, the study aim, among other factors, must focus on a rare experience such as engaging in participatory research with PLWID who face barriers to communication while the sample must include “experiences not previously described” (Malterud et al., 2016, p. 1755). Malterud et al. (2016) point out that fewer participants are needed when a study is headed for an “in-depth analysis of narrative or discourse details from a few selected participants” over a longer period (p. 1756).

For Study 1, participants met the following inclusion criteria: Participants identified either as a self-advocate or as someone who has advocated alongside or on behalf of others and who expressed an interest in the history of intellectual disability advocacy in Ontario.

To recruit participants, I shared an easy read poster (see Appendix A) with the DANEO coordinator. DANEO’s coordinator distributed the poster to the network’s members. DANEO is a network of self-advocates, family members and allies advocating for a rights-based approach to supports for PLWID. I was, at the time of recruitment, a family member of DANEO's Steering Committee. Requests for participation in research were regularly shared with network members.

A total of four supporters were recruited via DANEO to take part in one focus group session. The focus group session took place in the evening at the L'Arche Ottawa's community centre on Rossland Avenue. One self-advocate shared their views on one of advocacy events via a telephone conversation.

For Studies 2 & 3, participants met the following inclusion criteria: Participants either self-identified or were identified by a primary support person as having an intellectual or developmental disability and as someone who faces barriers to communication. More specifically, I asked if they experienced barriers to communication on a daily basis and if these barriers impacted relationships.

I asked if participants identified as having or as being labelled with an intellectual or developmental disability because these labels continue to be problematic. Many in self-advocacy movements reject it, hence the qualifier “labelled with.” The slogan “Label jars, not people” also expresses the unease. Finally, some people considered by others as intellectually disabled, like my brother, only recognized people with visible physical impairments, not cognitive impairments as persons with disabilities. To recruit participants for Studies 2 & 3, I created short recruitment videos (see Appendix B) and easy read posters (see Appendix C) about the study in both English and French. I posted these on social media and shared with them DANEO and local service providers. I also offered to present the study and respond to questions in person if desired. No agency or community group requested such a presentation. One participant who took part in Study 1 also took part in Studies 2 & 3 as a supporter.

The five participants labelled with an intellectual or developmental disability who took part in these studies were diverse in terms of age (range 21-52), gender (two women, three men), language (two English, one bilingual French and English, one Arabic as mother tongue and

French as second language, one American Sign Language) and modes of AAC (supported typing, writing, verbal with verbal support, whispering, facial expressions, and gestures). Six supporters also took part in Studies 2 & 3, and I discuss their roles further in Chapter 4.

Studies 2 & 3 took place at a new media arts drop-in place called the*Space* Ottawa located on McArthur Road. the*Space* Ottawa is an independent community-funded studio that tailors its mentorship and educational approach to people who have been labelled with a developmental or intellectual disability and who wish to work on creative media arts projects.

Data Sources, Data Collection and Analysis for Studies 1-3

In this section, I describe the data collection and analysis approaches in greater detail. Although data analysis and interpretation are vital components of the knowledge creation process, participatory research studies tend to focus on data collection. With respect to data analysis, Nind (2011) urges inclusive researchers to take on the challenge of “finding out what can be achieved by exploring ever-more sensitively supportive approaches to breaking down barriers, opening up possibilities and achieving access (see Nind and Seale, 2009)” (p. 355). In their discussions of data analysis, Garcia-Iriarte et al. (2009) describe it as “a cyclical process of praxis (action and reflection) that provided opportunities for change (Prilleltensky, 2001)” (p. 15). Nind's and Seale's work (2009) enhances this perspective as they argue that analysis “emerges from repeated engagements in reciprocal learning through thinking about data and the ‘best bits’ or most important messages” (Nind, 2011, p. 359). These descriptions characterize the participatory approach to analysis conducted in these studies. In other words, analysis consisted of an iterative process of discussing advocacy stories, sharing stories through audio/visual methods, and thinking about the themes that emerge from these discussions.

Study 1: Historical Narrative of Intellectual Disability Advocacy in Ontario

Data collection for Study 1 consisted of a search for historical data via primary and secondary sources. This search included consulting peer reviewed and grey literature, media archives such as the Canadian Major Dailies, Hansard transcripts, the Canadian Legal Information Institute (CanLII) database, government and non-governmental reports and advocacy organizations publications. I used search terms such as 'retarded', 'mental handicap', 'mental defective', 'developmental disability', 'intellectual disability', 'People First', as well as names of known self-advocates and advocates to locate information. When searching and selecting stories for inclusion, I gave priority to uncovering advocacy actions initiated by or directly involving people labelled with an intellectual or developmental disability. I organized these initial results chronologically and presented them to focus group participants as a wall-mounted visual timeline. Another source of data for Study 1 were the results of the focus group session. With participants' consent (see Appendix D for the consent form), I video recorded our discussion and transcribed it. The focus group participants helped to identify the most noteworthy events for inclusion. To limit the scope of the study, I chose to retain a maximum of six significant events in intellectual disability advocacy in Ontario.

The following questions were used to spark discussion with the focus group participants:

- What is important for self-advocates and advocates to know about their history?
- How should we prioritize stories?
- Which stories do you find most significant or interesting? Why?
- Which stories surprised you? Why?

- In what ways can these stories inform the advocacy both at an individual and group level?
- In what ways do these stories inform us about a good life as it relates to PLWID?

Focus group participant played a role in the analysis of the initial results of my literature search. Final analysis of the results was done using a narrative approach.

I initially organized the results chronologically representing them visually as a timeline. The focus group participants and my desire to include key events such as the beginnings of the parent-led and self-advocacy movements informed my final selection of the six narrative tableaux. The decision to include the experience of advising the Ministry regarding the transformation of developmental services in Ontario was made as a result of the focus group discussion. I collected additional data (e.g., grey literature) to tell a story of each event. I then analyzed the six tableaux searching for commonalities among the advocacy events. I present the results of this analysis in Chapter 3.

Study 2: Using Audio/visual Methods to Explore a Good Life with People Labelled with an Intellectual Disability

Data collection for Study 2 was done using participatory audio/visual methods. I conducted a series of five workshops to explore a good life and collect visual data with participants regarding a good life. We used the last workshop to analyse the results as a group. The workshop format which I initially planned to take three to four hours, was reduced to a maximum of two hours. During these workshops, participants and I got to know one another as we shared our perspectives on a good life.

As participants and I explored ideas about a good life, I took notes, and we used a team approach to create storyboards which are like visual scripts. These storyboards served as visual shot lists to guide participants' audio/visual data collection. I provided direct support for data collection to participants who requested it. Supported decision-making approaches were used to assist participants to make choices about audio/visual data should be collected. I describe and discuss supported decision-making further in Chapter 3 and 5. I then used written and visual notes as a guide to take photographs and video record events, people and places identified by participants as important to a good life. Over a seven-month period, we collected data during workshops and between workshops in locations chosen by participants.

To begin our exploration of a good life, I presented the Good life wheel (see Appendix E). The Good life wheel helped us to think broadly. I created the Good life wheel to visually organize and illustrate the eight quality of life domains in relation to the CRPD based on Verdugo et al.'s table (2012, p. 1040). Each quality of life domain along with its related CRPD articles served as springboards to help us discuss, think about, document and articulate visions of a good life from the perspective of participants. I describe this further in Chapter 4.

Discussions during workshops followed a 'Round Robin' approach to ensure that all participants had an equal opportunity to share. During each workshop, I facilitated the process of sharing the audio/visual data thus far collected with the group. To guide our discussions about a good life, I formulated questions inspired by the following frameworks:

1. Capabilities approach (Nussbaum, 2001): Do I have real opportunities to be and do what I have reason to value?
2. Paying attention to relationships (Johnson et al., 2010): Do I have real opportunities to develop relationships and to partake in activities that are meaningful to me.
3. Duty to contribute (Etmanski, 2000): Do I have genuine opportunities to contribute to my community?

4. Disability Human Rights Framework (Stein, 2007): Do I have real opportunities to develop my talents for my own betterment and that of my community? If so, what do these opportunities look like? What makes them possible?

Data Analysis

The exploration of a good life with participants involved many discussions at various times and in different contexts (e.g.: during workshops, during individual sessions, checking with supporters via email and telephone conversations). Taking time to review pictograms, photographs, and video clips gave us the opportunity to think about the most important or, as Nind and Seale (2009) put it the ‘best bits’ that should be included in the video vignettes. This process of thinking about a good life was facilitated by visual supports and strategies from SDM, AAC and Supported Conversation for Adults with Aphasia (SCA™).

Once images and video were collected, I created short sequences in FinalCutProX, a professional video editing software. We then watched the sequences during the following workshop. I sometimes paused on certain images to ask participants what they thought. I took note of their reactions and adjusted the vignettes accordingly. I describe this process in greater detail in Chapter 5 wherein I examine decision-making processes with participants.

Data collection and analysis for Study 3: Decisions, Decisions, Decisions! Supporting Decision-Making in Audio/visual Participatory Research with People Labelled with an Intellectual Disability

To collect data for Study 3, I combined video and photo documentation and observational notes based on workshops, individual meetings, telephone calls and email communication. I mounted a video camera onto a tripod to document each workshop. The video footage allowed me to reflect on the workshop process. In addition to video documenting the workshops, I documented one individual data collection session with each participant using photography. I documented this process myself to avoid adding another layer of work for supporters already providing much assistance. I made necessary adaptations to the data collection and analysis process which I describe further in Chapter 5.

Ethical Considerations

My general approach to ethics is strongly influenced by a relational ethics (Bergum & Dosseter, 2005). Ethical approval (File number: H09-17-14) for these studies was given on November 27th, 2017, by the University of Ottawa's Health Sciences and Science Research Ethics Board (see Appendix F).

Summary of Studies and Methods

In summary, inclusive research methods, audio/visual methods and narrative approaches allowed me to explore the three research questions mentioned above. Considering the importance of direct human assistance that was necessary to support participation in the research process, it is difficult to imagine how this research could have taken place during the pandemic restrictions. The next three chapters present the three individual studies described in this chapter and conducted as part of this dissertation by articles. In the next chapter, I write about the first study through which I explored the history of intellectual disability advocacy in Ontario thus providing the sociohistorical context for this dissertation.

Chapter 3 – Intellectual Disability Advocacy Narratives: A Series of Tableaux

Relationship of Manuscript 1 to the Dissertation

The following manuscript presents narratives of disability advocacy efforts in Ontario for, by and in collaboration with people labelled with an intellectual disability (PLWID). These historical narratives provide an account of notable events and actions that have taken place in Ontario for the improvement of the quality of life and advancement of the rights of PLWID. The analysis of these events was informed by the social model of disability, relationality, and the United Nations Convention on the Rights of Persons with Disabilities (CRPD). The narratives make visible the important contributions made by PLWID and their families to the evolving understanding of disability. They also reveal the importance of having the necessary supports to advocate for oneself, including making one's decisions and the opportunity to take part in systemic advocacy to shape the policy and programs designed for PLWID. For rehabilitation sciences and disability studies, the results of this study point to the need for greater recognition of these contributions and to the need to support individual and systemic advocacy opportunities as an essential component of a good life.

This manuscript was written in APA format (Seventh edition, 2019) to meet the guidelines for the *Canadian Journal of Disability Studies*. An abridged version of this manuscript will be submitted to the journal. The manuscript will focus on Justin Clark's story, the *Advocacy Act, 1992* and family and self-advocates' involvement in MCCSS's Transformation process.

Abstract

Purpose and objective: There is a rich history of disability activism by, for and with people labelled with an intellectual disability (PLWID) in Ontario but it is scarcely documented. The purpose of this chapter is to document and analyze the history of intellectual disability advocacy in Ontario. By sharing these narratives of advocacy, I aim to make visible their contributions to evolving understandings of disability and their involvement in the social development of the province of Ontario. Furthermore, I pay attention to the efforts made by self-advocates and advocates for people labelled with an intellectual disability as a way of promoting social justice (Clarke, 2004).

Methods: In keeping with the use of narrative and experience-based storytelling by disability advocates, I structured this study as a series of short stories, or narrative accounts. I conducted a focus group session to consult with advocates regarding the choice of advocacy stories to be included in the study. The qualitative examination of advocacy events is informed by social model of disability and the CRPD.

Results: The six advocacy narratives included in this study reveal that for self-advocates in Ontario, the right to make one's own decisions and the supports required to do so appear as a common thread across narratives and throughout time.

Conclusion and implications: The findings of this study reveal that PLWID have contributed to current understandings of disability. They also support the need for individualized assistance that accommodates the cognitive and communication abilities of PLWID and others with similar needs.

Canadian Journal of Disability Studies, 6000 words.
Current: 15, 136 words.

There is a rich history of disability activism by, for and with people labelled with an intellectual disability (PLWID) in Ontario but it is scarcely documented. The purpose of this chapter is to document and analyze the history of intellectual disability advocacy in Ontario. By sharing these narratives of advocacy, I aim to make visible their contributions to evolving understandings of disability and their involvement in the social development of the province of Ontario. Furthermore, I pay attention to the efforts made by self-advocates and advocates for people labelled with an intellectual disability as a way of promoting social justice Clarke (2004).

Self-advocates and family members and allies have adopted a variety of tactics and strategies to resist exclusion and marginalization. In this chapter, I present a series of six tableaux, a structure inspired by historical flash stories. Through these tableaux, I share important stories of (1) grassroots organizing by parents; (2) organizing by self-advocates; (3) Justin Clark's fight to leave the Rideau Regional Centre; (4) Ontario's *Advocacy Act, 1992*; (5) the struggle for an alternative to substitute decision-making and (6) family and self-advocates' involvement in Ministry consultations to transform Ontario's developmental services system. These stories of advocacy are important to tell for many reasons. Most importantly, stories allow individuals and communities to call to mind events and experiences from the past thereby making it possible to recognize one another's contributions, to ensure that they are not forgotten. In this study, I combine primary and secondary sources and results from a focus group discussion to document and analyze advocacy efforts led by PLWID and family members. The study covers the period starting in 1948 with the first attempts by families to organize and concludes in 2009 with the end of family member and self-advocate participation in a Ministry-led process of transforming developmental supports and services in Ontario.

I begin with a background to provide context for the advocacy stories. This is followed by each of the six tableaux. I conclude this chapter with a discussion of the participation of self-advocates and family members in the development of policy that directly affects them. I also discuss the role of advisors, advocates, decision-making partners, and independent facilitators that surface in the advocacy stories as approaches that facilitate self-determination and participation in decision-making.

Background

Before presenting the tableaux, I provide some brief context, both provincial (Ontario) and national (Canada) to situate the advocacy stories. Long before the rise of specialized institutions, people labelled with an intellectual disability, then referred to as idiots, feebleminded or incurable, lived in the community, often with their families, and sometimes with other families as boarders. There is little documentation available about the daily lives of PLWID living in the community. The history of PLWID is often told based on patient files kept by institutions. Institutions, according to Ferguson (1988), represented continuity of the custodial approach adopted by almshouses for the poor. Simmons (1982) has pointed out that institutions were created in response to complaints about the “idiotic and paralytic cases” (p. 5) who were taking up space for example in the Provincial Lunatic Asylum in Toronto that could be occupied by those who could be cured. Brown (1984) documents how local prison wardens complained about the “lunatics” and “idiots” who were a nuisance to other inmates, and how they represented “an unwanted drain on district funds” (p. 36) because they could not be put to work like other inmates. Overriding benevolent aspirations has always been a concern with keeping costs of asylums and later institutions, as low as possible (Simmons, 1982) and separating ‘idiots’ who might contaminate the rest of the population, including debtors and criminals was one means to achieve such ends (Brown, 1984).

The Orillia Asylum for Idiots opened its doors in 1876. It was Ontario’s first institution dedicated specifically to people who, today, would be labelled as having an intellectual or developmental disability. To populate the new institution, thirty-five people were transferred from the London Asylum and nine from prisons (Williston, 1971). The province would eventually open two other large institutions: The Rideau Regional Centre in Smith Falls in 1951 and the Southwestern Regional Centre in Chatam-Kent in 1961. In total, Ontario owned and operated sixteen large and medium-sized institutions[10] designed for people labelled with intellectual disabilities between 1876 and 2009. The provincial government built many of these institutions in rural areas where they provided much-needed employment for the locals. Institutions, like the almshouses for the destitute poor, played a deterrent role remaining a last resort for families and a warning to those who did not conform “If you do not behave, the institution awaits you!” (Oliver, 1999, pp. 163–173). Institutions also kept poor people with disabilities away from populated urban areas where, over the years, they had been perceived as objects of pity, charity and with the eugenics movement, increasingly as a social menace. By the mid-1970s, over 10,000 PLWID were incarcerated in government-run facilities located across the province (Queen’s Printer for Ontario, 2018).

Despite the lack of community-based opportunities for PLWID, most families did not commit their sons and daughters. Most children and adults with intellectual disabilities remained with their families even during the height of institutionalization of the 1950s and 60s (Clarke, 2004, p. 471) when doctors and other health professionals strongly encouraged parents to send

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[10] For more about these institutions, see Government-operated institutions for people with a developmental disability: https://www.mcss.gov.on.ca/en/dshistory/firstInstitution/list_institutions.aspx

their children away (Richards, 1963). Many factors contributed to the eventual closure of Ontario's institutions. Parents who had kept their children at home as well as those who were concerned about their child's well-being in the institutions, demanded alternatives.

The publication of a damning article by journalist Pierre Berton in 1960 bolstered the message by parents demanding community-based supports. In the article, Berton detailed the dangerous and inhumane living conditions he had witnessed at the Orillia Asylum. He warned the public: "you have been told about Orillia" (2013) and urged Ontarians not to blame the Department of Health of the time but themselves for allowing such a situation to continue. By this time, provincial governments recognized that institutions were costly both legally and personally (Rioux & Prince, 2002, as cited in Power et al., 2013). Therefore, when the federal government enacted the Canada Assistance Plan (CAP) in 1966, moving funds, dollar for dollar to provinces to support their social programs, a decision was made to transfer responsibility for the care of PLWID to the Ministry of Community and Social Services. As a result of the CAP, children and adults who had been patients under the Ministry of Health suddenly became residents when the management of institutions shifted to the Ministry of Community and Social Services. For McCauley and Matheson (2016), the move also signaled the intention of the province to "divest itself of responsibility for the care of people with mental disabilities, transferring responsibility for meeting daily living supports to local communities" (p. 4).

The *Developmental Services Act, 1974* provided the legislative framework for community-based supports and services. It also formally marked the beginning of a lengthy process of deinstitutionalization which has yet to be completed. The following Act to replace the *Developmental Services Act, 1974* is the present *Social Inclusion Act, 2008*. The new Act was developed as part of the Transformation process initiated by the Ministry of Community and

Social Services to close its last three largest institutions and to continue the shift towards community-based supports and services.

Historians’ traditional emphasis on the asylum era, according to Jarrett (2015), has distorted our understanding of the lives of people with intellectual disabilities. The focus on the history of institutions has created an impression of a “permanent saga of exclusion” (Jarrett, 2015). Similarly, Clarke (2004) notes that the emphasis on institutions has “created a false ‘rupture’ between the ways in which pre-industrial and industrial communities treated” (p. 470) people labelled with intellectual disabilities. Instead, Jarrett (2015) argues that the closure of specialized institutions “represents...a return to a societal norm” where people with intellectual disabilities, while never free from discrimination, were part of their communities and family networks.

Regardless of the ministry responsible, the approach, or the decade, a chronic lack of funding and waitlists have plagued publicly funded services for PLWID. Since the construction of the first institution in Orillia to today’s increasingly community-based supports and services, waitlists have been described as ‘immensely long’ (Simmons, 1982), “growing faster than capacity” (Office of the Auditor General of Ontario, 2014, p. 337), ‘interminable’ (Ombudsman of Ontario, 2016) and ‘long and increasing’ (Office of the Auditor General of Ontario, 2020, p. 2). In 2014, the Auditor General calculated “that at the current rate, it would take 22 years before everyone received residential supports as long as others were not added to the list” (p. 337). It is against this backdrop that families and self-advocates have advocated for opportunities to take part in all aspects of society including the personal supports and structural changes necessary to make that a reality. They have also led by example by creating their own structures.

Framework

My decision to focus on the history of advocacy in Ontario with special attention to the role of PLWID and family members situates this study in the broad field of social history. The advocacy events included in this chapter focus on the lives of so-called ordinary citizens who have made important contributions to the social development of the Province of Ontario as well as evolving understandings of disability. Thus, my purpose is to make visible the contributions of people with intellectual disabilities and their families to evolving ideas about disability and how, with the right supports, people can live a good life in the community. I also assembled these stories as a sibling and active advocate in search of a better understanding of the struggles of the recent past.

I structured this study as a series of short stories, or narrative accounts, in keeping with the prevalent practice of experience-based storytelling as a method for disability advocacy. Storytelling or sharing experience-based stories is a common method of advocacy used by People First members and members of other advocacy groups. These stories challenge dominant discourses about the limited potential of PLWID, they correct erroneous medical prognoses and inaccurate psychological and behavioural assessments. The decision to structure this chapter as a series of tableaux also lends itself well to producing an easy read version of the advocacy events thus ensuring access to a wider audience that includes self-advocates.

Like many researchers who adopt narrative approaches, I believe “that the ‘story’ is the one, if not the fundamental, unit that accounts for human experience” (McAlpine, 2016, p. 34). According to McAlpine (2016), “story as method” is an approach used across many disciplines and “has close ties to life history and biography, because like them it involves telling stories, recounting – accounting for – how individuals make sense of events and actions in their lives with themselves as the agents of their lives” (McAlpine, 2016, p. 34).

Methodology

This chapter weaves together a diversity of sources to provide an account of significant advocacy efforts in Ontario’s intellectual disability history. To assemble the six tableaux, I used a combination of primary sources (newspaper articles, policy documents, meeting minutes, legal records and focus group) and secondary sources (peer-reviewed literature) to address my first aim to document and analyze the history of intellectual disability advocacy in Ontario. In the following section, I summarize the purpose of historical narratives, then I discuss the data collection process associated with the focus group discussion.

The search for this study included consulting peer-reviewed and grey literature, media archives such as the Canadian Major Dailies, Hansard transcripts, the Canadian Legal Information Institute (CanLII) database, government and non-governmental reports and publications, including websites by advocacy and other community-based organizations. I used search terms such as 'retarded', 'mental handicap', 'mental defective', 'developmental disability', 'intellectual disability', 'People First', and names of known People First self-advocates and advocates to identify news articles and legislation related to PLWID. When searching and selecting stories for inclusion, I gave priority to advocacy actions initiated by or directly involving people labelled with an intellectual or developmental disability. To provide insight into the perspectives of individuals involved in these efforts, I searched for direct quotations of key participants. I drafted a list of significant advocacy events based on my initial search of the literature. Based on this initial search, I created a large poster of a timeline that I later hung on a wall to support the focus group discussion.

The participatory element of this study comprised of a focus group held in Ottawa, Ontario. Ethics approval was obtained by the University of Ottawa's REB (see Appendix F). I recruited participants via a Disability Advocacy Network of Eastern Ontario (DANEO) (see Appendix A for recruitment poster). Five mothers responded to the ad: four participated. One self-advocate also responded but could not attend. The focus group discussion took place at the Ottawa L'Arche Community Centre, a location I chose because it is well known in the intellectual disability community, it is physically accessible and available.

The following questions guided the focus group session:

- What is important for self-advocates and advocates to know about their history?
- How should we prioritize stories?
- Which stories do you find most significant or interesting? Why?
- Which stories surprised you? Why?
- In what ways can these stories inform the advocacy both at an individual and group level?
- In what ways do these stories inform us about a good life as it relates to PLWID?

I presented participants with the visual timeline of events based on my initial literature review and my knowledge of intellectual disability history. The timeline served as a springboard from which participants could comment and think about the guiding questions. This portion of the discussion was brief and instead, the participants (all mothers) focused primarily on their experiences of advising the Ministry of Children, Community and Social Services (MCSS) on the transformation of developmental services in Ontario. I present the results of the discussion in Tableau #6: Advising the Ministry on Transformation.

Data Analysis

I initially organized the results chronologically following a narrative approach. The focus group informed the selection of advocacy events presented in the six tableaux, as did my desire to include key events such as the beginnings of the parent-led and self-advocacy movements. Justin Clark's story was included for the same reasons and additionally because he is a prominent figure not only in Ontario's disability history but in Canada as well. The decision to include a story of the *Advocacy Act, 1992* was motivated by my desire to keep this important and unexpected event from fading from memory. I included the story about the fight for an alternative to substitute decision-making because the controversial question of mental capacity and who has the right to decide has been an ongoing point of struggle and disagreement among self-advocate, parents, and professionals. Finally, the choice to include the last tableau on the Transformation of developmental services in Ontario was based exclusively on the results of the focus group discussion. Further data (e.g., grey literature) was collected to create a chronological account of each event. These six tableaux were then analyzed using a thematic approach to identify commonalities among them and to discuss implications. Figure 1 provides a chronology of the tableaux.

Figure 1

Sequence of tableaux

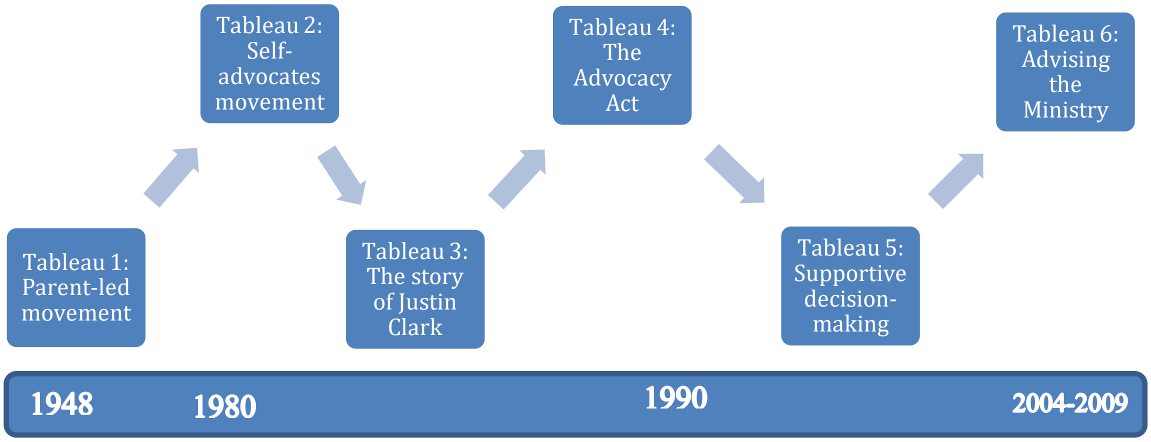

Tableau #1 – Getting Together, Getting Organized

> "Power is never the property of an individual; it belongs to a group and remains in existence only so long as the group keeps together."
>
> –Hannah Arendt, 1970, p. 44

In this first tableau, I focus on the parent-led movement in Ontario. This tableau illustrates the importance of group efforts that aimed to create community-based supports and services for PLWID. Here in Ontario, the parent-led advocacy movement was sparked by a letter written in 1948, when Victoria Glover, who was raising her grandson, wrote a letter to the Toronto Star about children then labelled as "retarded": "I think it is time something was done for parents who from a sense of faith and hope in a merciful providence want to keep them at home living a normal life" (Anglin & Braaten, 1978, p. 6). A year later, her plea for support inspired the formation of the first Parents Council in Toronto. Local councils eventually set in motion the founding of the provincial Association for the Mentally Retarded (OAMR) in April

1953. From these initial small gatherings, the Canadian parents' movement was born and, by 1958, they incorporated the national Canadian Association for the Mentally Retarded (CAMR). Panitch (2008) specifies that "it was primarily young mothers who founded and joined these groups, seeking mutual support and starting schools in church basements and family homes when their children were approaching school age" (p. 35).

Through the OAMR, parents who believed that their children should live at home and be part of their community stressed that "mentally retarded people had the same rights as other citizens" (Simmons, 1982, p. 158). Parent advocates focused on similarities with other non-labelled children (Kyle, 2019, Simmons, 1982, Simplican & Leader, 2015) and worked with professionals who were sympathetic to their goals. This collaboration made the OAMR a unique organization that drew on the credibility of lived-experience and the authority of research-based knowledge (Roeher & Webb, 1971).

An important focus of the movement led by 'community parents' as Panitch (2008) describes them, was deinstitutionalization. Although many factors contributed to the closure of institutions,[11] the voluntary sector, especially parents and eventually self-advocates, are recognized as the "main impetus" (Radford & Park, 2000) and "motivating force" (Williston, 1971, p. 59) behind the closure of institutions and other significant changes in developmental disability policy. The provincial government supported the Associations' activities through limited funding but the greater portion of revenue came from fundraising activities primarily conducted by mothers (Panitch, 2008). To support themselves, they charged membership fee,

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[11] Pierre Berton's article in 1959 (Berton, 1959), and two tragic events involving Rideau Regional Centre residents led to the commissioning of the Williston Report (1971) by the Minister of Health and the government's response via the Welch Report (1973) and the recognition by governments that they were costly financially, legally and personally (Rioux & Prince, 2002, as cited in Power et al., 2013)

sold Christmas cards, organized community events, and received gifts from donors. Some Associations received funds from United Appeal or United Community Fund (Williston, 1971).

In 1964, representatives of the OAMR took part in a Federal-Provincial Conference on Mental Retardation alongside various government departments. According to Williston (1971), this conference was a real turning point for changes in developmental services in Ontario. The resulting Blueprint document was the starting point for many pieces of legislation outlining community-based services for PLWID such as "education in home care, pre-school training, education, sheltered workshops for adult training, recreation and camping" (Williston, 1971, p. 59).

To demonstrate that their children could also learn and develop their abilities, parents, through their local associations, led by example by creating and managing private schools throughout Ontario for children excluded from the education system. Working collaboratively with the Department of Education (Williston, 1971), they designed and delivered teacher training (Anglin, & Braaten, 1978, Simmons, 1982, Williston, 1971) for the schools they managed.

Beginning in 1965, parent associations "either sponsored or operated adult workshops, pre-school programs, residential programs, residential camps, recreational, home care and public education programs" (Williston, 1971, p. 59). They also created training courses for staff working at newly established sheltered workshops. Some projects spearheaded by the Associations such as sheltered workshops and segregated schools would later be criticized by both parents and self-advocates. Initially created by the Associations as a steppingstones to paid employment, some PLWID, like Pat Worth, criticized sheltered workshops and sought more meaningful opportunities (Fine, 1986). Sheltered workshops would eventually be recognized as discriminatory for not respecting labour laws on minimum wage (Galer, 2014). Similarly, some advocate parents would later regret the creation of separate schools and instead fight for full inclusion in regular schools. Audrey Cole, whose son Ian did not meet admission requirements to attend public school, remembers that she pressured her local Ottawa AMR in the late 1960s to demand a special program but later admitted that "That was the worst thing I ever did, becoming an activist for segregation" (Panitch, 2008, p. 70).

Working collaboratively with like-minded professionals, parents propelled their concerns onto provincial, national, and international agendas. Through their diverse advocacy activities, they managed to influence the direction of developmental services policy and to lay the foundation for community-based supports and services. An important success for the associations advocating alongside other grassroots groups was the eventual *Education Amendment Act, 1980* commonly referred to as Bill 82, which ensured access to all children with disabilities to public schools. In summary, this first tableau illustrates how parents, particularly mothers (Panitch, 2008), worked collectively to establish the foundations of community-based services and supports for PLWID.

Although parents accomplished a great deal since their modest beginnings in the early 1950s, a controversial and polarizing case concerning forced sterilization reveals some limits of parent-led advocacy. The case of E. (Mrs.) v. Eve (1986) concerned a mother who had formally requested guardianship of her 24-year-old daughter to subject her to forced sterilization (Sterilizing mentally disabled - an emotional issue, 1986; Starkman, 1981). What would eventually be known as the Eve Decision revealed the importance of listening to self-advocates' perspectives. As media coverage increased, the case caught the attention of Association members and self-advocates across the country. Parent members were so divided on forced sterilization that a small group of mothers realized that only the voices of self-advocates could get the

Association out of the impasse (Panitch, 2008). Panitch (2008) explains how, in 1981, with the support of these mothers and eventually CAMR, self-advocates Barb Goode, Peter Park, David Lincoln and Harold Barnes became intervenors in the Eve case via the Association's Consumer Advisory Committee. Thanks to the insistence and persistence of self-advocates, the case went all the way to the Supreme Court of Canada (Worrell, 1988). After a long five-year process, the final Eve Decision 1986, prohibited, for the first time in history, forced sterilization by recognizing the integrity of the body regardless of mental capacity. The case demonstrated the value of including the voices and perspectives of people with developmental disabilities in matters that concerned them, thus opening a door for further participation. Peter Park, an intervenor who had survived 18 years at the Oxford Regional Centre in Woodstock, Ontario, remembered, "it was the first time that people labelled with an intellectual disability won at the Supreme Court – speaking for ourselves" (Hutton et al., 2017, p. 46).

Through these experiences, self-advocates had learned "how to use the courts and work with lawyers to fight for their rights" (Canadian Institute for Inclusion and Citizenship, n.d.). For Peter Park, the experience was remarkable because in the end "it brought us all together, People First and the parents' movement all together about one thing. We realized with that that we could work together towards a common issue" (People First of Canada, 2015, 04:53). According to Vanhala (2009), experiences such as these also contributed to the establishment of People First of Canada, the national self-advocacy organization to help bring provincial chapters together such as People First Ontario.

Tableau #2 – People First Ontario: We Can Speak for Ourselves

In this second tableau, I focus on the development of the self-advocacy movement in Ontario and more specifically, the People First movement. This tableau illustrates the importance of an independent voice for PLWID. Although the parents' movement had begun to welcome self-advocates into their movement, some dreamed of their own independent movement. Peter Park who had taken part in the Eve Decision and acknowledged the possibility of working with parent Associations, also said, "I wanted something that people could control themselves and have their own destiny and that sounded like a pretty damn good thing…I wanted it to be people who were labelled with mental retardation…they need something not controlled by somebody else, they need to speak out for whatever is bothering them" (People First of Canada, 2015, 01:08). Park, who would eventually be known as the grandfather of People First, remembers how some "People at the Association I was at attempted to stop me from starting up People First in Ontario" (Hutton et al., 2017, p. 46). Some encouraged self-advocates to join the parent-led Association's Consumer Advisory Committees. But a meeting with David Baker, the human rights lawyer at the recently incorporated Advocacy Resource Centre for the Handicapped (ARCH)[12] encouraged self-advocates to move forward with their idea (Hutton et al., 2017). The first People First chapter in Ontario was co-founded in 1982 by Peter Park and Patrick Worth, both institutional survivors.

Over the years, People First members like Richard Ruston have expressed concerns about Community Living Association's Consumer Advisory Committees. According to Ruston, members' lack of autonomy in decision-making in these committees is problematic:

> It's really important to have a People First group, we're a very autonomous organization. Nobody makes our decisions as a movement, we make them ourselves, we run our own meetings, we run our organization, we have people that we pay to do some work, we have

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[12] ARCH is a non-profit legal clinic specializing in disability law. It was incorporated in 1978 and is primarily funded by Legal Aid Ontario. ARCH, previously known as the Advocacy Resource Centre for the Handicapped was incorporated in 1979. The ARCH Disability Law Centre is not to be confused with L'Arche founded by Jean Vanier.

> volunteers. With the council, it’s been a competition. For the last fifteen years, and like when you go to a meeting like “Oh we already talked to the self-advocates already” and we’re going “What?,” that’s not right. People First Ontario is totally separated, it has its own board, has its own entity. (People First of Canada, 2015, 11:27)

Ruston argues that People First is different because its members can speak more freely:

> We don't have to go in front of the Board and say “Oh, we need your approval to do this.” In the past years, it's getting harder because this Council is getting bigger and bigger by the day and we're losing the members because of money (People First Canada, 2015, 12:05).

The desire to act autonomously was a key factor that led to the development of the People First movement. The founders of People First chapters, many of whom had survived years of institutionalization and had been denied access to education, faced challenges quite different from those faced by parents when they first organized at the grassroots level.

To act autonomously, People First chapters required support. The role of advisor was created to assist members in their advocacy work. Some advisors were paid, but most were volunteers. According to Worrell (1988), the role of an advisor was to listen to members and to respect their choices and decisions. Again, according to Worrell (1988), advisors had to build relationships of trust with members and identify with self-advocates’ perspectives. Advisors should avoid leading the group and instead facilitate the development of leadership and decision-making skills. They also helped members with a variety of tasks, such as research and sharing information accessibly and assisting with meeting structure. The road to autonomy has never been easy since, without access to funds, local chapters struggle to find a space for meetings and independent advisors.

From the beginning, when local People First chapters lack funding to conduct their activities, many Associations for the Mentally Retarded provided a space for People First meetings and a staff to act as an advisor. These situations were sometimes difficult to navigate and could lead to a conflict of interest. Advisors were employed by an Association that also provided direct support services to the same People First members. On the one hand, their role was to support members to advocate for change and, on the other hand, they had an interest in protecting their relationship with their employer. Some advisors were criticized for taking control of the chapter they were meant to support. According to Beth French, an advisor to the national People First organization, “some People First groups have fired their advisors for not listening to them” (Fine, 1991, p. D5) while other groups kept quiet, fearing retaliation if they openly criticized them.

Despite these difficulties, People First members spoke up for themselves and advocate for changes that were not always popular with the Associations. For years, People First members did not like the word “retarded” in the Association’s name and wanted to change it to something less stigmatizing. As Peter Park explained, “It made you feel knee high to a grasshopper” (Park et al., 2003, p. 370). It took four years of advocacy before the Associations for the Mentally Retarded finally agreed to change their name. In the end, ‘Community Living’ was chosen because, as Park explained, with the right support, everyone can live in the community.

Self-advocates and members of parent-led Associations differed in their perspectives on reproductive rights and language, sometimes, they also disagreed on advocacy tactics. For example, in 1990, the provincial New Democratic Party government sided with the Ontario Public Service Employees Union (OPSEU) representing employees working in institutions who demanded a temporary halt to deinstitutionalization. OPSEU argued that community supports were inadequate (Fine, 1990). Although no one disputed this claim, the government quickly halted the deinstitutionalization process which had begun in the mid-1970s with the *Developmental Services Act, 1974*. Without consulting with People First or Community Living Associations to explore other solutions, the government had sided with OPSEU. Appalled by this decision, People First Ontario members held a sit-in in the Minister of Community and Social Services' boardroom (Fine, 1991). According to a People First member, “community-living associations were ‘not too thrilled about what we did. They thought we was a bit too pushy’” (Fine, 1991, p. D5). Unlike the parent-led Associations that preferred a more conciliatory approach to advocacy, People First members did not shy away from more direct methods such as this one to apply pressure. According to journalist Sean Fine (1991), “The sit-in was a sign that the leaders know how to reach beyond the established associations and government, to the media and the public” (p. D5).

In summary, involvement in important litigation cases like the Eve Decision contributed to the establishment of People First. Some members of parent-led associations resisted the development of independent self-advocacy groups while others encouraged it, but despite important disagreements, ongoing collaboration between the two movements has continued albeit on an unequal footing. While this advocacy work was taking place in the community, some remained trapped in institutions.

Tableau #3 – Justin Clark’s Fight to Leave Rideau Regional

This third tableau about Justin Clark’s struggle to leave one of Ontario’s large institutions illustrates the importance of interpersonal, communication and advocacy supports to exercising one’s autonomy. Returning to the early1980s, unlike Peter Park, Patrick Worth and other self-advocates who had left institutions and were busy building an independent self-advocacy movement, Justin Clark remained incarcerated behind the walls of the Rideau Regional Centre (RRC), one of Ontario's largest institutions. In 1981, Justin Clark was 19 years old and had been at RRC since the age of two when his parents had left him there on the advice of doctors. Justin was born with cerebral palsy and had limited opportunities to communicate until he learned Blissymbolics at age 12. Gradually, he learned to communicate with staff and friends by pointing to words and symbols on the Bliss board. Occasionally, Justin had left RRC grounds when staff and volunteers who had become friends invited him for dinner or on an outing. One day, Normand Pellerin, a good friend, and staff at RRC, invited him to travel to Québec with another resident and a family member. The CEO of RRC contacted Justin's father for permission. Mr. Clark, who was a prominent Ottawa lawyer, refused and applied to County Court to obtain guardianship of his son. If successful, Justin would be declared mentally incompetent, and lose the right to make his own decisions.

Upset by his father's decision, Justin shared his frustrations with his close friends who helped him find a lawyer. Marilou McPhedran, who was a lawyer with ARCH, Ontario's legal aid clinic specializing in disability law, worked with Justin to prepare his affidavit. The Ontario government and Justin's parents had barred him from seeking legal counsel from ARCH, so McPhedran had to sneak into Justin's room to record his statements. She recounts how, at one point, she was escorted out of the RRC: "Sometimes being a lawyer following the rules does not serve justice" (McPhedran, 2018, p. 284).

McPhedran helped Clark to present a writ of habeas corpus, one of the oldest legal tools, dating back to the Magna Carta, to contest unjust confinement and to free himself from RRC. During his court case, various expert witnesses were called to evaluate Justin's mental capacity, placing "it everywhere from a 6-year-old to that of an adult" ("Palsy victim testifies," 1982, p.

14) demonstrating that mental capacity assessment was far from an exact science. Judge John Matheson, who presided over Justin's case, recognized his maturity and courage: "I really have a feeling we are under-estimating Justin's toughness…I think Justin knows enough about life in the raw as any of us" ("Palsy victim testifies," 1982, p. 14).

Speaking on his own behalf, Justin said "I wish that people who think I cannot decide things for myself would take the time to talk to me so that they could understand how much I really know" (McPhedran, 2018, p. 288). Judge Matheson did just that and in 1982, ruled in Justin's favour declaring him capable of making his own decisions (Clark v. Clark, 1982). Matheson, who experienced facial injuries and seizures as a result of his participation in the Second World War, said years later "society will remain healthy only if people avoid making decisions for others, even if they're handicapped" ("The fight goes on," 1990).

Justin and two other RRC survivors moved to Ottawa and were supported by friends who volunteered for Foyers Partage, an Ottawa group home administered by a local church. A year would pass before the Ministry of Community and Social Services would agree to contribute to daily personal support costs ("Money for palsy," 1983) for Justin and the two other survivors. Justin's victory was undoubtedly a result of his courage and determination but also of committed friends like Pellerin and allies such as the lawyers at ARCH and staff who taught Justin to use Blissymbolics.

Almost ten years after his high-profile case, Justin gave a talk entitled "Where you live can make you vulnerable" at a Community Living conference. Justin told the audience: "If people think of you as a person who has many possibilities, they will create a space for you to grow…if people think of you as a person with limits, they usually don't give you as much space and you grow less" and added "Often people believe because we have a disability, we cannot make decisions...They make choices for us. They choose where we live, what we will do with our lives and when" ("When others make the choices", 1991, p. A23).

Judge Matheson's recognition of Justin's capacity to decide for himself represented a life-changing victory for Justin Clark that also inspired others to leave RRC (Sweetman, 1991). Lawyer Dulcie McCallum who took part in preparing The Convention on the Rights of Persons with Disabilities in 2006, credits Justin Clark's case as having played a vital role in shaping it, especially Article 12 regarding the right to legal capacity for all persons regardless of mental capacity (Gutnik, 2018). Despite this important victory, many PLWID did not benefit from the similar legal, interpersonal and communication supports nor did they have similar cognitive abilities to prove sufficient mental capacity to decide for themselves. Many would not leave Ontario's large institutions until the early 2000s and some as recently as 2009 when the Ministry finally closed them.

Looking back, the 1980s had been a decade of hope and excitement for disability rights movements across Canada. 1983-1992 was the UN Decade of Disabled Persons. Mental disability had been added to the *Charter of Rights and Freedoms, 1982* albeit at the last hour and not without resistance (Vanhala, 2011, p. 58). The 1981 *Obstacles Report* recognized people with disabilities primarily as rights-bearing citizens (Power et al., 2013). This report by the federal Special Committee on the Disabled and the Handicapped upheld the following principl

es: 1) Canadians with a disability should enjoy the same opportunities to participate fully in all spheres of life, 2) all Canadians were responsible for making the changes necessary to achieve full participation and, 3) people with disabilities were the best positioned to know what kinds of supports would lead to implementing this vision. The 1980s also saw the foundation of the national self-advocacy group People First of Canada. Significantly, Justin Clark's highly publicized landmark case shattered deep-rooted conceptions about people labelled as ‘retarded,’ or ‘palsy victim’ as incapable of deciding for themselves. His story also demonstrated the importance of committed interpersonal supports as well as access to advocacy services.

Tableau #4 – The Push for a Province-Wide Non-Legal Advocacy System

In this fourth tableau, I present the community-led push for a province-wide non-legal advocacy system for Ontarians considered vulnerable. In this tableau, I focus on the *Advocacy Act, 1992* an impressive accomplishment by Ontario disability groups that transformed Ontario into a leader in providing supports to citizens considered most vulnerable to abuse and exploitation. Concerned Friends of Ontario Citizens in Care Facilities (Concerned Friends) formed in 1980 after Betty Hatt placed an ad in the Globe and Mail asking if others were appalled by the lack of care their loved ones received in nursing homes. Motivated by the numerous deaths, lack of palliative care, and other forms of abuse and neglect they saw in long-term care facilities (Spindel, 1992), Concerned Friends submitted *A Proposal to Establish Advocacy Ontario* to the Liberal Attorney-General in 1982. The group pointed out that advocacy services for Ontarians in vulnerable situations were dispersed and inconsistent. And despite good intentions, many social service workers were at risk of conflicts of interest with clients since they were expected to provide both case management and advocacy services to adults in need of support: “It is difficult, if not impossible to effectively advocate for a client with one's own employer” (Beatty et al., 1986, p. 2). For this reason, separate and independent advocacy services would be necessary.

Relationships between OACL, PFO and ARCH had strengthened after jointly taking part in previous committees and commissions regarding legal capacity, guardianship and advocacy services.[13] In 1986, these three organizations joined forces to form the Ontario Advocacy Coalition (OAC) to campaign, alongside Concerned Friends, for a province-wide non-legal advocacy system. According to Boyce et al. (2001), intellectual disability advocates had been pushing the government to develop a user-led advocacy system since the mid-1970s when the Developmental Services Act formally signaled the beginning of community-based services for PLWID. Now they had allies outside the intellectual disability community.

Eventually, the OAC would bring together over forty disability groups to work towards independent advocacy services. Boyce et al. (2001) point out that the leading organizations all had close ties with the OACL and PFO. In other words, the main thrust for a non-legal advocacy system came from people who had worked alongside people with intellectual disabilities or who were labelled themselves. According to Orville Endicott, Co-Chair of the OAC alongside Patrick Worth, then president of PFO, the establishment of a province-wide non-legal and publicly funded advocacy system would amplify the voices of those seldom heard (“Advocates from within,” 1992). Referring to a man who had passed away because he had refused to go to the hospital, Patrick Worth believed that advocates could save lives: “it seemed to me as if nobody tried hard enough to find out why he didn't want to go (to the hospital)” (Fine, 1986, p. A17).

Broadly, Ontario’s new non-legal advocacy system would “(a) contribute to the empowerment of vulnerable persons and (…) promote respect for their rights, freedoms, autonomy and dignity” (*Advocacy Act, 1992*, p.2). The Minister of Citizenship saw the “bill as a vehicle for an advocate, not to make decisions, but to be able to explain to vulnerable adults the choices that they have and to be able to express and carry out those choices for them” (“Advocates from within,” 1992, p. C5).

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[13] For example, the Fram Committee and the O’Sullivan Commission (Boyce et al. 2001).

The Act established an Advocacy Commission to provide advocacy services directly to individuals or through non-profit community programs. The commission was comprised of people with physical disabilities and illnesses, invisible disabilities, Ontarians over age 65, people with psychiatric and neurological disabilities as well as patients' rights organizations. Advocates were given the authority to meet with the person in need of advocacy support, to enter group homes, long-term care facilities, prisons as well as retirement homes and other unlicensed housing facilities. Advocates had the authority to access, with the person's consent, their records (Spindel, 1992). At the time, it was estimated that "600,000 adults in the province with moderate to severe mental and physical disabilities encounter[ed] difficulty advocating on their own behalf" ("Advocates from within," 1992). As of 1992, forty rights advisors had been hired by the province of Ontario.

Even though the *Advocacy Act, 1992* was dismantled[14] a few years later, it remains an incredible achievement for these mostly grassroots disability organizations. In their analysis, Boyce et al. (2001) conclude that disability advocacy organizations, comprised primarily of groups and leaders from the intellectual disability community, were the motivating force behind the *Advocacy Act,1992*. They also made important contributions to its related legislation regarding capacity and consent to treatment.

Tableau #5 – The Controversial Issue of Who Decides?

In the previous tableau, I omitted an important event that took place in the final hours of the development of the *Advocacy Act,1992* and the associated reforms to laws concerning mental capacity and consent to treatment. However, it is a moment in intellectual disability advocacy that is worth describing because it touches upon the controversial issue of capacity and the right

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[14] For a very good analysis of the reasons for the repealing of the *Advocacy Act, 1992,* see Boyce et al. (2001), *A Seat at the Table. Persons with Disabilities and Policymakin*g.

of PLWID to make their own decisions with the supports they need. As the legislative package was finalized, activist, mother and Community Living member Audrey Cole and People First member and institutional survivor Pat Worth, introduced the idea of supportive decision-making as an alternative to guardianship. Cole had independently studied supported decision-making (Panitch, 2008) and became a recognized expert on the topic. She was also the chair of CACL's National Task Force on Alternatives to Guardianship since 1991. Cole and Worth demanded that "supportive decision making" replace substitute decision-making in the *Substitute Decisions Act* (SDA). They argued that everyone should have the right to legal capacity, regardless of mental capacity and that appointing a substitute decision-maker would be a rights violation. According to Stainton (2016), alternative approaches to substitute decision-making in Canada in both practice and law such as those proposed by Audrey Cole and Pat Worth date back to the 1970s.

According to Boyce et al. (2001), the introduction of this alternative model of decision making at such a late stage in the development of the legislation and the lack of support from other disability organizations members of the OAC harmed the Coalition's image (p. 102). It exposed disagreement within the OAC on a fundamental issue: the right to retain legal capacity regardless of mental capacity. It was a thorny issue that had been sidestepped during the E. (Mrs.) v. Eve case since forced sterilization was prohibited regardless of mental capacity and in the Clark v. Clark case since Justin Clark successfully convinced the judge that he was mentally capable of making his own decisions. Although the cases exposed the risks of guardianship, neither case questioned its legitimacy or desirability. However, that was exactly what Audrey Cole and Pat Worth did with their proposal.

In 1992, People First of Ontario, People First of Canada, Community Living Ontario, and the Canadian Association for Community Living formed the Coalition on Alternatives to

Guardianship when Ontario was reviewing the *Substitute Decisions Act*. They argued that guardianship imposed on persons considered mentally incompetent violated their right to autonomy and self-determination. Again, according to the Coalition, this was a clear case of discrimination on the basis of mental disability which was prohibited under the Canadian Charter of Rights and Freedoms.

Faced with resistance from within the OAC and without, People First Ontario and People First of Canada published a press release announcing that they would be protesting in front of the Attorney General's office (Boyce et al., 2001; Coalition on Alternatives to Guardianship, 2014). In the release, they stated that they would remain there until their demands were heeded to review what they considered to be an "archaic piece of legislation that in effect strips the rights of those deemed incapable of speaking for themselves" (Coalition on Alternatives to Guardianship, 2014, p. 8). The press release quoted Denis Laroche, President of People First of Canada:

> We must make sure that people have support in making decisions from "partners" they know and trust. These partners then would interpret their needs and desires to others. Decision making must occur within trusting relationships and it is essential that proposed legislation reflect the fact that we all make decisions with the help of others. (Coalition on Alternatives to Guardianship, 2014, p. 8)

The tactic paid off because, within a few hours, the Attorney General's office contacted the People First groups with a commitment to finding a solution (Coalition on Alternatives to Guardianship, 2014). According to Boyce et al. (2001), this action by People First members was one of the most important political events that took place concerning the Substitute Decisions

Act because it led to tangible changes in the legislation. An alternative course of action (ACA) was added to Ontario's *Substitute Decisions Act*. The ACA introduced a prohibition on guardianship where practical arrangements could be made to enable a person to make their own decisions thus avoiding a loss of legal capacity (Coalition on Alternatives to Guardianship, 2014).

At the time, Ontario's Attorney General had expressed a commitment to implementing supported decision-making as part of the ACA (Coalition on Alternatives to Guardianship, 2014). This was not implemented even though different forms of supported decision-making were recognized in other Canadian jurisdictions (Coalition on Alternatives to Guardianship, 2014). The ACA amendment was welcomed but as Bach and Kerzner (2010) point out, in the end, the decision is made by the guardian or the person's attorney. Moreover, no details are given regarding the best way to foster autonomy and support the person in making their own decisions.

The Bloomfield family from Guelph Ontario has done considerable work on supported decision-making. Andrew Bloomfield[15] is an artist who lives with complex autism and communicates using Supported Typing. He is also a pioneer as the first to incorporate an entity of support to help him with decision-making and to continue his good life. Inspired by work led by the Wetherows[16] in Manitoba, Andrew and his parents incorporated a non-profit entity of support they named Friends of Andrew Bloomfield (FAB). The legal entity, commonly known as a microboard, was legally incorporated in 2001, to support Andrew to direct his own life, maintain and develop relationships, make decisions and, more generally, to live a good life.

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[15] See: FAB: Friends of Andrew Bloomfield, Label Free Channel, 2016 dec 5, 10:30 https://youtu.be/_BKu6POLiv8

[16] Inspired by the work of David and Faye Wetherow on microboards. For more information, see: https://www.communityworks.info/articles/microboard.htm.

Microboards have three primary functions “Nuture Freely Given Relationships,” “Offer Support with Decision-making” and, “Maintain Formal, Legal Governance and Accountability Structures” (Microboards Ontario, 2022). Microboards consist of a minimum of five co-directors, including the person with a disability, committed to ensuring “that the person with a disability has ways to understand options and make decisions about her/his life” (Bloomfield & Bloomfield, 2012, p. 45). In Andrew’s words: “I want to say that it is essential to hear my voice, no decisions are made about me without me” (Label Free Channel, 2016, 10:30). In summary, Microboards provide a formal structure for receiving support with decision-making despite the lack of recognition of this decision-making alternative by Ontario courts.

Despite the failure to achieve recognition of supported decision-making in Ontario, social services ministers of all levels of government agreed that people with disabilities, including those with intellectual disabilities, were citizens who should have control over their lives. This official recognition was laid out in the 1998 agreement *In Unison: A Canadian Approach to Disability Issues* (Government of Canada, 1998). Furthermore, in Ontario, at least some community-based services were available in many parts of the province. Following the closure of five institutions for children (Yoshida, 2015, p. 186) and much advocacy on behalf of parents, individualized funding options such as Special Services at Home (SSAH) became available through MCSS. SSAH set a precedent for future individualized funding programs in Ontario such as the Direct Funding scheme for Ontarians with physical disabilities (Yoshida, 2015). With SSAH, parents could now hire support workers to work with their children. Individualized funding was later extended to adults. Many things had changed but the province had yet to close its last three largest institutions and commit fully to a community-based and decentralized approach to providing supports and services. PLWID. To complete this shift, MCSS engaged in a process it named “Transformation,” the topic of Tableau 6.

Tableau #6 – Advising the Ministry on Transforming Developmental Services

In this final tableau, I discuss MCSS’s process of transforming Ontario’s services for PLWID alongside the results of the focus group held in Ottawa. This tableau focuses on the advisory role played by parents and self-advocates during Transformation. Although these mothers commented on the visual historical timeline I had produced to initiate our discussion about intellectual disability history, they were most interested in talking about the recent process of Transformation. Three mothers took part in the consultation process and all have been active in advocacy, some since the 1970s when their sons and daughters were born, others as siblings.

Between 2004 and 2009, family and self-advocate representatives took part in a consultation process regarding the transformation of the province’s services and supports for PLWID. Hickey (2012) points out that this process was the result of successful advocacy on behalf of advocates to close institutions and to end decades-long policies of segregation (as cited in Borbasi et al., 2008 and Lord & Hutchison, 2007). A provincial-level Joint Developmental Services Sector Partnership Table was created by MCSS and included ten representatives from family groups and networks, six from agencies, four from the ministries of social services and children and youth. No self-advocate representatives were invited to take part in the Partnership Table. Two representatives from People First Ontario were finally included but only after Family Alliance Ontario other family groups advocated for their presence. These two self-advocates then requested additional representation and, with the support of the family group representatives, two more were eventually invited to the Table.

According to the Terms of Reference, these representatives were invited to provide "input, advice and expertise" for transformation (Terms of Reference, 2008). At the regional levels, Passport committees and Transition committees were also established to advise respectively on the new individualized funding program and transitions from high school to adult services. In its documents, the Ministry emphasized its intention to work with all stakeholders and to pay particular attention to the advice of individuals and families (MCSS, 2006) to choose the best way to implement its new policy focus. It is difficult to imagine how the Ministry intended to uphold its vision of "Persons with disabilities participate as full citizens in all aspects of Canadian society" (Joint Developmental Services Sector Partnership Table, 2004, p.8) without the direct involvement of those most concerned.

This overarching vision for the Transformation of Ontario's developmental services was first presented in Partnership Table's Preliminary Discussion Paper (2004). It was informed by *In Unison* (Government of Canada, 1998) wherein the idea of citizenship and the importance of having control over one's life was recognized by Social Services Ministers at Federal/Provincial and Territorial levels (Joint Developmental Services Sector Partnership Table, 2004). MCSS and Partnership Table documents emphasized a new direction for a system of community-based supports and services that would be accessible, equitable, fair, and sustainable and that would promote "full participation," "self-reliance" and "living as independently as possible" (MCSS, 2006).

In addition to the Joint Partnership Table and its Preliminary Discussion Paper, the Ministry held public consultations across the province with a variety of stakeholders to comment on the Discussion Paper and the final stages of policy development. In response to this invitation, four organizations representing people with intellectual disabilities and families collaborated to articulate a Common Vision for the transformation of developmental services. People First of Ontario, the Family Alliance Ontario (FAO), the Individualized Funding Coalition for Ontario, and the Special Services at Home Provincial Coalition saw Transformation as an opportunity to end paternalism, discrimination, and exclusion by supporting “self-determination and citizenship” (FAO et al., 2005b). These groups also pointed to the *In Unison* (Government of Canada, 1998) agreement to remind the Ministry of its commitment to “individualized disability supports, controlled by the person and their family” (FAO et al., 2005a, p. 2). Their Common Vision documents highlight the following as essential to Transformation: independent planning and facilitation, portability of the person’s funding, simplicity, transparency, accountability, support for creative support arrangements, an independent review and appeal mechanism, and participation of People First groups and autonomous family networks “in system planning, community priority setting evaluation and quality assurance” (FAO et al., 2005b, p. 8). By 2007, the Ministry reiterated its commitment to supporting citizenship self-determination and full participation and incorporated portability and accountability into its principles (MCSS, 2007).

When I met with the mothers to discuss intellectual disability advocacy, my goal was to ask them to identify and comment on specific events and moments that they thought were important for other self-advocates and advocates to know about. After a brief review of the visual timeline designed to spark discussion, it became apparent that their involvement in the Transformation of developmental services via the Partnership Table was what they most wanted to discuss. In light of what I presented above, there seemed to be many similarities among the priorities of the various stakeholders regarding Transformation. In the following section, I present the mothers’ experiences of advising the Ministry on Transformation and their understanding of the priorities.

Members of the Partnership Table, the Common Vision groups and the mothers who took part in the focus group valued fairness and equity. Independent facilitation was considered an essential component to creating a fair and equitable system for all. For as long as publicly funded services for PLWID had existed in Ontario, PLWID with parents who had superior advocacy skills and the right connections had greater success in accessing supports and services. For this reason, it was imperative to find ways to compensate for the disadvantage experienced by PLWID whose families could not adequately assist them with advocacy or advocate on their behalf. The role of independent facilitators would be to assist individuals and families to plan and to advocate for access to supports and services based on their priorities and needs.

Nancy explained,

> "We wanted to make sure that families with less education, who were on the lower-income scale, who didn't have time or that it was not in their personality, or skills… [would have access to an independent facilitator]. The facilitator would have been the catalyst to help those families to get what they needed."

As the mothers connected with families in their respective advocacy groups, they recognized that many needed help. Marian remembered, "…we recognized that when we met in groups with other families (some) didn't have the ability to advocate…or to navigate systems." The mothers talked about the role of independent facilitators as a practical and concrete approach to increasing equity and fairness. They explained how facilitators would listen to the person and their family and act as an intermediary between them and the system.

Nancy was especially worried about families who had a son or daughter with a severe disability and who had become less involved in their child's education and supports. Their isolation and lack of adequate supports had contributed to lowering their expectations for their son or daughter's future. "They had been told by professionals that they would take care of everything and not to worry about attending their son or daughter's individualized planning (IP) meetings because 'that would be too much work for you Mrs. Smith… we're doing a good job.' [These parents] trusted the system" Nancy explained, and "as late as 1989, I was told to put my daughter in Rideau Regional…those who did trust the system, they all went to Rideau Regional from my area…I know Justin [Clark] and the gal who was with him."

Nancy remembered that some parents, who she had come to know during her years of advocacy in rural areas, just hoped that their son or daughter would receive basic care.

> "'…just care for them, feed them, sing to them…change their diaper,' that's all they were asking…so, those were the families that I was the most scared for when it came to Passport [individualized funding] when I found out that the facilitators were not going to be involved...those were the families that I fought for because I knew they wouldn't have a chance."

During the discussion, there was much focus on the role of independent facilitation in promoting fairness. It was also identified as a priority for the Common Vision groups, however, as they said, "[the Ministry] pulled that [facilitation] out. For these mothers, the decision to leave independent facilitation behind meant that fairness could not be achieved. According to these mothers, supports and services are still not provided "according to the level of need of the individual" (Nancy), instead, they continue to hinge on a family member's capacity to advocate.

In Nancy's words, "We were promised that the government was thinking about and looking at the facilitator role of a non-partisan facilitator."

"Yes," agreed Marian.

"That got pulled out at the end. That was a tease!" said Nancy.

“That was one thing we all agreed on” Marian.

“All of us were adamant…So that took away…equality across the Province. [The government] took it away...this whole equality goal has never been followed through.” Nancy.

One of the self-advocates who took part in the Partnership Table, confirms “Independent facilitation was huge, it was important to avoid conflict of interest and not everyone wants to be with an agency” (Personal communication, May 31, 2018). Furthermore, no appeal process was implemented. “What parents…should be the most upset about is that they don't have an appeal process…this whole process…is still subjective,” said Nancy about the assessment process to determine the level of developmental services. “Yes, it is subjective because they [DSO SIS assessors] are telling people don't put that down because you won't get it so...so that's totally not what it's supposed to be like” agreed Marian. The lack of information about the possibilities of supports beyond group homes and home shares, for example, made it difficult for families to request alternatives to these dominant models of residential support for PLWID.

Advocates wanted agencies independent of service-providing agencies to be created in all regions to provide publicly-funded facilitation services to PLWID and their families prior to assessment and beyond. According to Nancy, the idea was that

> “You could ask for a facilitator which is paid by the Ministry so that person would sit with you as a family and talk to you before your loved one left school. and for things like about hopes and dreams for example and if you never even thought about your son or daughter being a volunteer or having goals individually they would help you go through a process … It was free and then they would help you so you prepared really for… the SIS assessment process to make sure that if you got nervous as a parent or a loved one, a sibling, they would …make sure that the plan that you had

> created in a comfortable environment was going to play out with the SIS assessment…because it was a very clinical tick the box, so this was to give equality and as a result of not being [implemented], the SIS assessment did not provide equality across this province."

The independent facilitator could advocate for a review of the assessment if it did not adequately reflect people's needs. This was similar to the role of advocates proposed in the early 1990s under the *Advocacy Act, 1992*.

Although the Ministry stated that the process of Transformation was about fairness, it failed to invite PLWID, those who would be most affected by the changes in policy. Luckily, family group representatives did not accept to move forward with the Partnership Table without representation by self-advocates. Fairness was understood by these mothers and others representing family groups and self-advocates as ensuring that everyone, regardless of socio-economic status, would have access to supports and services on an equal basis with others. A key component of ensuring fairness and equity was the introduction of independent facilitation services to families and self-advocates who needed additional support.

The introduction of Passport, the new individualized funding program, was one way for the Ministry to implement its main principle of promoting a citizenship agenda. Passport funding would allow for greater self-determination and control by PLWID and families. However, Marian worried about families having the capacity to manage the funding for their sons and daughters, "Families are overloaded…Some don't have a clue how to do that!... There is no infrastructure for families…accounting and someone…to guide you through the process." In the absence of adequate support to assist individuals and their families to manage and spend individualized funding, the funds are given to service-providing agencies who charge a fee to manage the funds. As the mothers pointed out, that means that individualized budgets made available through the Passport program to increase participation and self-determination return to service providers. Managing Passport funding places service providers in direct conflict of interest since they provide assistance on how to spend the funds. Although individualized funding such as the Passport program introduced flexibility and increased the potential for control over supports and services for some families, Transformation did not include the creation of the necessary infrastructure or 'institutional scaffolding' (Mackenzie, 2014) to enable all PLWID and families to exercise greater control. Some of that infrastructure could have included independent facilitation services but also support with managing a personal budget, hiring support workers, providing guidance, doing the payroll and other common activities conducted by employers.

Although ongoing and regular participation in the "planning, community priority setting evaluation and quality assurance" (Common Vision) of supports and services for PLWID had been identified as a priority by the Common Vision groups, it did not materialize. The mothers remembered that when the regional DSO agencies began operating, the Ministry "pulled all the committees away. The Transition and the Passport committees…so we as parents no longer had a voice representing our regions" remembered Nancy. Communication between the Ministry, agencies, families, and self-advocates diminished after the implementation of the DSO agencies.

There was noticeable disappointment about the outcome of the Partnership Table discussions. Although the Partnership Table and regional committees had created spaces for the various actors to meet and to discuss how to implement the vision of Transformation, these mothers felt that, in the end, their advice was not taken into account. Marian wondered, "If parents were part of it, and agencies were part of it, how much do they listen in the end?"

“They didn't!” answered Nancy.

Mary shared a similar experience as a participant on an advisory committee for a local agency. “We advise [the agency] all the time, they don’t listen!”

Marian explained, “At the end of the day, we could advise as much as we wanted and at the end of the day...the budget that MCSS got and what they did with that money for example...let's say that the DSO cost more money to set up in the end, then they said facilitation is gone. Like the IT alone, remember Emma those meetings, the IT, because they had to have a separate location so they went downstairs from Service Coordination, so there would be a different identity or the IT for the SIS assessment to get online was phenomenal, millions! Across this province for 10 locations and then into the Ministry office. So, at the end of the day, they listened to us and they decided at a provincial level, what was the priority.”

Looking back on her experience, Emma saw it as “a bureaucratic setup from the very beginning.”

Marian agreed “That's right.”

Emma continued, “They sucked the life out of all the parents, they sucked the life out of all of us sitting at the Tables, running around taking care of our kids and all the other things that went with that…and in the end, where are we?”

Nancy nodded as she listened to Emma and added, “Then [the ministry] could state very clearly that parents were involved and had a voice in the process so they can…say: We listened to you, we heard you and we developed this and you agreed to it. We didn't agree to it! We just didn't know how to fight them anymore.”

The discussion continued as Nancy expressed her frustration with the outcome of the process. “We had an advisory type of role but they didn't take any advice.”

“No!” Emma agreed emphatically.

“I have come to realize that this is how the Ministry operates, even today, they'll say they took advice…from advisory and family reps and all that and they just go on…,” said Marian. According to her, the Partnership Table was discontinued because the Ministry did not appreciate family input. “They knew if they didn’t do [what we asked], when we got back to the Partnership Table, we would embarrass them. That’s why they got rid of it”

On a separate occasion, a self-advocate representative, who had taken part in the Partnership Table, expressed similar disappointment about the process, “We screamed and hollered but it didn’t feel like our voices were heard” (Personal communication, May 31, 2018).

In summary, far from transforming developmental services “based on the advice of individuals and families,” participants felt that the decisions made by the Ministry did not reflect their priorities. As a result of these experiences, the mothers felt that families and self-advocates must get organized. Marian explained how she had been trying to connect groups, “I think the movement has to be big, that's why I was saying all the time family networks have to get together, everyone has to work together.” Despite their agreement on the need for a strong Province-wide network, they struggled to bring groups together, as Marian continued, “…so I try to get other family groups to connect with one another, but they say no, we have our own vision.”

To this, Nancy responded emphatically, “There it is again… families against families!”

Marian asked the others, “How could we, you know, have a family network strong enough around the province, get the networks working together and come in with a big advocacy campaign?”

Marian’s question brings the discussion back full circle to the very beginnings of grassroots intellectual disability advocacy and Arendt’s (1970) description of power as a property belonging to and dependent upon a group’s existence. In the past, many factors contributed to the development of the parent-led intellectual disability movement as well as the self-advocacy movement. Family advocates and self-advocates sometimes disagreed on important questions such as decision-making and approaches to advocacy, but they agreed about the necessity to close institutions in favour of community-based supports and opportunities. What is the vision for the next seventy years of community-based supports and services in Ontario? Although the province’s last large institutions were closed in 2009 and much work has been done, families and especially, PLWID continue to be excluded from decision-making processes that directly affect them.

Discussion

The purpose of this chapter is to document and analyze the history of intellectual disability advocacy in Ontario. My goal is also to make visible struggles and contributions by advocates. The participation of people with intellectual disabilities and their allies in grassroots advocacy and public policy discussions has contributed in important ways to change social expectations for people with intellectual disabilities.

To limit the scope of this study, I focused on six significant events in intellectual disability advocacy in Ontario. The focus group session helped identify significant events for inclusion. In six tableaux, I shared stories about: (1) grassroots organizing by parents; (2) organizing by self-advocates; (3) Justin Clark’s fight to leave the Rideau Regional Centre; (4) Ontario’s Advocacy Act; (5) the struggle for an alternative to substitute decision-making and (6) family and self-advocates’ involvement in Ministry consultations to transform Ontario’s developmental services system.

Since the first efforts to organize, an important shift from highly centralized and isolated anti-supports to comparatively decentralized and dispersed supports and services across the province has occurred. Furthermore, there is recognition, at least in print, that people with intellectual and developmental disabilities should have opportunities to full and meaningful participation as citizens of Ontario. However, the lack of meaningful involvement of PLWID and their families in the design and decision-making process of policies that affect them continues to plague the system created to support them. Fifty years ago, Welch (1973) recognized that a "major fault of the present system of care is [that]…its use is generally not controlled by that person, his family or his guardian" (p. 9).

A recurring and overarching theme is the lack of direct involvement of PLWID in questions that concern them. Although things have changed since Justin Clark's struggle for freedom, people with intellectual disabilities continue to have little say in shaping the services and supports meant to promote full participation. Whereas parents advocated for their children in the early days of advocacy, the Eve Decision regarding reproductive rights exposed the strengths of collaboration but also the limits of exclusively parent-led advocacy. People First Ontario, Justin Clark, the struggle for non-legal advocacy services and an alternative to substitute decision-making touch upon the importance of voice and the opportunity to make one's own decisions. Nonetheless, as late as 2004, the ministry did not initially invite PLWID to take part in the Transformation of developmental services. Family representatives had to advocate for their inclusion in a process that most directly impacts them. In other words, self-determination, choice, and independence are recognized as important but the supports and structures that would enable PLWID to practice them have not followed.

In addition to these selected stories of advocacy, theories and frameworks outlining elements of a good life recognize the value of self-determination and control over one's life. For example, Verdugo et al.'s (2012) quality of life framework identifies it as one of the eight domains of life, Runswick-Cole and Goodley's (2013) Network of Resilience found that "control over one's life" was a valuable resource for resilience, Nussbaum's (2006) Central Human Capabilities recognizes the importance of having control over one's life including "having the right of political participation" and "Being able to hold property" (p.77). Finally, the CRPD proposes that signatory States support the active participation of people with disabilities in policy development "persons with disabilities should have the opportunity to be actively involved in decision-making processes about policies and programmes, including those directly concerning them" (United Nations, 2006, Preamble (o)). The Convention clearly states that countries are expected:

> To promote actively an environment in which persons with disabilities can effectively and fully participate in the conduct of public affairs, without discrimination and on an equal basis with others, and encourage their participation in public affairs, including:
>
> (ii) Forming and joining organizations of persons with disabilities to represent persons with disabilities at international, national, regional and local levels (United Nations, CRPD, 2006, art. 29b).

Currently, services and supports are being reformed by the Ontario government. Families and self-advocates were given very little time to provide feedback on proposed principles and to respond to a questionnaire regarding services and supports. Despite the lack of time, self-advocates through Respecting Rights, a self-advocacy group supported by the ARCH Disability Law Centre that includes People First founding member Peter Park have shared their priorities and principles for a system of supports and services. For example, Respecting Rights (2021) has proposed:

> People's Voices Need to Be Heard. The government should learn from self-advocates by having regular accessible and supported meetings with them. Self-Advocates must be part of helping to make developmental services better.

An Ottawa-based ad-hoc coalition of six family and self-advocacy groups has also proposed that the Ministry engage in: "Meaningful and regular dialogue with a wide range of stakeholders, including self-advocates, families and service agencies" (Disability Advocacy Network of Eastern Ontario, Letter to Rupert Gordon, 2021, 26 January) to achieve the overall proposed vision of empowerment and inclusion of PLWID. Meaningful participation, inclusion, and control over one's life for PLWID requires, as is evident in the tableaux, additional supports to facilitate information gathering, communication, and decision-making. The tableaux also reveal that direct and meaningful involvement in the design, monitoring, and evaluation of supports and services is key. To correct this major fault in the system, a formal and accessible process and structure should be reinstated. The structure, which could resemble the Partnership Table model or adopt other forms which I will discuss in the last chapter, must enable direct participation by PLWID, not just as advisors but as equal partners. Designing new models of participation will depend heavily on the ability of government representatives, self-advocates and family members and allies to imagine feasible and accessible forms of citizen participation.

In addition to experimenting with and formalizing such structures, individualized supports for PLWID to facilitate participation and advocacy for oneself or on behalf of a family member are necessary. Although the need for individualized supports has long been recognized (O’Sullivan, 1987, Potter, 1988, Lord & Hutchison, 2003, CRPD, 2006, Art. 19, Verdugo et al. 2012), it has yet to be implemented. As I reviewed the advocacy efforts of the past, it was interesting to notice the similarities among the roles of People First advisors, advocates under the *Advocacy Act, 1992,* supportive decision-makers in the alternatives to substitute decision-making and independent facilitators proposed by family and self-advocate representatives during Transformation of developmental services. In Table 1, below, I summarize the roles, qualities and conditions identified as important for advisors, advocates, decision-making partners, and facilitators.

Table 1

Advisors, advocates, decision-making partners, and independent facilitators

	Advisors	Advocates	Decision-making partners	Independent facilitators
Role	The role of advisors is to “support decision-making with encouragement, empowerment, genuine desire to listen carefully, respect, dignity…The role of the advisor is to empower” (Worrell, 1988, p. 40)	An advocate is directed by the client. Advocacy is "instruction-based": the actions of an advocate must be guided by the instructions of a client and the advocate must serve the client on a voluntary and consensual basis”	A decision-making partner supports decision-making. They are people who have gained the trust of the PLWID and knows them well. “…it is essential that proposed legislation reflect the fact that we all	The role of a facilitator is to “increase the odds that a person will live in a way that reflects her interests and preferences…help the person gain more control over their lives.” (O’Brien, 2014, p. 15). A facilitator develops a relationship of trust, supports,

		(O’Sullivan, 1987, p. 121). “An advocate does not decide what is in the best interest of the client, but instead, acts on the client's instructions. (“Advocates from within,” 1992).	make decisions with the help of others.” (Coalition on Alternatives to Guardianship, 2014, p. 8)	and promotes the person’s views and interests, assists with planning, establishing priorities, follow-through, promotes self-determination
Qualities	An advisor is a good listener. They are understanding, respectful and sensitive.	Advocates are good listeners, caring, respectful, persistent, and compassionate.	Decision-making partners listen to the person (Bloomfield & Bloomfield, 2012).	Independent facilitators are good listeners and good communicators (Able 2, n.d.).
Conditions	Advisors are free of conflict and are aware of power imbalance with self-advocates.	“Advocates must be independent and free of any actual or perceived conflict of interest” (O’Sullivan, 1987, p. 121) Advocacy services should be accessible to all persons in vulnerable situations.	Decision-making partners are free of any conflict of interest (Bloomfield & Bloomfield, 2012).	Independent facilitators work independently from direct service providers.

To ensure full and effective participation of PLWID in all spheres of life, there is a need for facilitation, decision-making and advocacy supports. This position is strongly supported by the work of philosophers Silvers and Francis (2009) who, as I mentioned in Chapter 1, have sketched out a theory of trusteeship that explains how PLWID and others with cognitive and communicative disabilities may be assisted to formulate and to articulate their own conceptions of the good. Accepting that the practice of autonomy is relational, they compare the process of aiding with thinking to prosthetic cognition. Like any other prosthesis, prosthetic cognition varies in extent and duration according to the characteristics of the user and the prosthetic itself (Silvers & Francis, 2009), which in this case would be human. According to them, to act as a trustee is “no casual occupation” (p. 493) and, like a prosthesis, assistive thinking and articulation should aim “amplifying the functioning of the subject” (p. 487). One supporter in Browning’s (2018) research echoed this idea:

> I like the idea of the prosthesis where you are just an extension, you are kind of an accommodation to someone in the same way a wheelchair or a crutch would be used to help someone physically (p. 134).

A trustee requires various skills such as building and maintaining a relationship of trust,[17] assisting the person to evaluate the feasibility of their idea of the good. This can be done through a process of assisted “cognitive probing” using words or other non-verbal communicative strategies to identify and evaluate goals and to assist with other cognitive tasks such as “calculation, reflection, extrapolation, focus” (Silvers & Francis, 2009, p. 490) as needed. Trustees, they suggest, should be aware of and differentiate between the thwarting of goals due to ableism and goals that are unrealistic. Silvers and Francis (2009) suggest that the trustee’s role is to propose and explore feasible alternatives while carefully avoiding ableist biases that limit possibilities. Again, according to them, good trusteeship involves focused attention on the person being assisted as the sole source of inspiration for the ideas generated as part of the process,

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[17] As opposed to the Rawlsian criteria of having the ability to reciprocate, which according to Silvers and Francis (2009), is a poor explanation for what motivates human cooperation.

specific to the person. Trusteeship requires attentiveness, insight and “imagination to see how to alter the world so the subject will flourish” (Silvers & Francis, 2009, p. 493). My overall recommendation would be to provide some form of independent facilitation services to each child and adult who requires cognitive and communication assistance until such services are no longer needed. I will share more details about this recommendation in the overall discussion of my dissertation.

Until profound structural changes have been made to the ‘social, and institutional scaffolding’ necessary for people with intellectual disabilities to access information, communication and accomplish what they judge to be valuable, direct, and on-going human assistance will be needed to ensure they have an opportunity, on an equal basis with others, to exercise autonomy and to contribute meaningfully to shaping their own lives. Additionally, individualized funding programmes such as Passport require management skills that are often beyond the ability of PLWID as well as many parents. Independent facilitation services may be part of the solution for ensuring supported and autonomous decision-making or, at least, decision-making that is solely inspired by the PLWID. Independent facilitators could work with people labelled with an intellectual disability and their families from an early age and could remain assigned to them for as long as possible and as desired by both parties. This could be similar to what is proposed by Malhotra and Rowe (2014), who recommend that educational assistants be assigned to a student to facilitate their educational experience from primary to post-secondary. Long-term relationships would establish trust and the development of a deep knowledge of the person. Instead of assuming that a person with an intellectual disability can depend on a family member, most likely their mother, to take on such a role, a facilitator would work on their behalf to support them when needed to research, to make decisions and to advocate for the supports and services they want and need to live a good life. This individualized and ongoing facilitation could include supportive family members and friends. Facilitation, decision-making and advocacy supports need not be limited to PLWID. The story of the *Advocacy Act, 1992* illustrates the need for such supports by other Ontarians who are in positions of disadvantage due to cognitive or communication impairment, psychiatric disabilities and social isolation and institutionalization.

Implementing both a system-level structure and independent facilitation services to individuals and their families would represent a modest step toward ensuring that the law governing developmental services in Ontario respects the overarching principles of the CRPD that include, among others, the respect for autonomy (United Nations, CRPD, 2006, arti. 3a) and accessible information and communication (United Nations, CRPD, 2006, Preamble (v)).

Conclusion

Self-advocates, family members and allies have worked tirelessly for better supports that would allow them to live well and thrive in the community and for the right to make their own decisions. Significant gains have been made in education, in the discourse on the delivery of supports from a custodial approach to person-centered and individualized approaches. However, Ontarians with intellectual disabilities continue to be excluded from important conversations regarding the system of supports meant to facilitate their full and meaningful participation in all aspects of life. Groups such as People First have gained considerable experience in advocacy, nonetheless, the voices of family members continue to overshadow the voices of self-advocates. New groups are emerging and doing important work. One such group is Respecting Rights. It was founded by self-advocates and the ARCH Disability Law Centre. Respecting Rights, which includes self-advocates such as Peter Park, social workers, and lawyers, is currently developing a charter of rights for developmental services, facilitating advocacy workshops, and developing an accessible complaints process for those using developmental services.

PLWID and their families have contributed in important ways to our understanding of disability and to shaping the supports and services that currently exist. The advocacy stories included in this chapter illustrate the importance of supporting PLWID to raise their voices and to include them in policy development and in research to continue shaping our evolving understanding of disability. In the next chapter, I present a participatory study I conducted with PLWID who face barriers to communication wherein the elements of a good life were explored using audio/visual methods.

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Chapter 4 – Using Audio/Visual Methods to Explore a Good Life with People Labelled with an Intellectual Disability

Relationship of Manuscript 2 to the Dissertation

Having outlined the general literature and theoretical perspective informing my overall topic of a good life and narrated six stories of intellectual disability history in Ontario, I now present the participatory study conducted with five PLWID from the Ottawa area to explore the perspectives of a good life. The purpose of this chapter is to share the findings and implications of this exploration. Participants self-identified or their primary support person identified them as having an intellectual or developmental disability and as facing barriers to communication. I met with participants and their primary supports in a workshop format five times and individually on multiple occasions. Overall, audio/visual results reveal that participation and relationships are an important aspect of participants' view of a good life. I discuss the possibilities of participatory audiovisual methods for articulating these perspectives. Using audio/visual methods to facilitate the process of exploration and articulation of participant's perspectives proved valuable.

Abstract

Purpose and objectives: There is much agreement on the various aspects that contribute to a good life. The ability to practice self-determination, to participate in and contribute to society, meaningful relationships, and opportunities for self-development as well as physical, emotional, and financial health and security, are recognized as essential. The purpose of this study was to learn from PLWID who face significant barriers to communication about what they most value as part of a good life.

Methods: Using audio/visual methods and approaches drawn from supported decision-making and AAC, I facilitated a series of five workshops to five participants labelled as having an intellectual or developmental disability and facing significant barriers to communication and six supporters living in the Ottawa Region. During the workshops, participants received support to think about what was most important to them as part of a good life. Their ideas about a good life were presented in the form of collaboratively produced video vignettes (34 in total).

Results: Participants' video vignettes show that participation in artistic and sports activities as well as relationships with friends and family are important aspects of a good life. Existing relationships facilitated participation in meaningful activities and provided opportunities to maintain and develop ones.

Conclusion and implications: The findings of this study may impact policy and practice, suggesting that closer attention be paid to relationships and their connection with participation.

Disability Studies Quarterly (DSQ), 8000-12,000 words.

Current: 11, 489 words.

There is much agreement regarding the various elements that contribute to a good life. Some of these elements are referred to as capabilities (Nussbaum, 2006), resources Runswick-Cole & Goodley, 2013), good things (Wolfensberger et al., 1996), valued experiences (O’Brien, 1989), life domains (Schalock et al. 2008) or rights (United Nations, CRPD, 2006). Regardless of the differences in conceptual categories, these frameworks recognize self-determination, participation and contribution, physical and emotional health, financial security, meaningful relationships and occupations and opportunities for self-development as important aspects of a good life. Genuine opportunities to experience these good things in life have been limited for PLWID. In the introductory chapter, I described a coercive environment that limits PLWID in their attempts to live a good life based on their own values and priorities. In Chapter 3, I shared stories about parents, and later PLWID, who advocated for community-based supports and services to enable them to make their own decisions and to have opportunities to participate in and contribute to their communities. In this study, I use participatory audio/visual methods to explore a good life with PLWID who face significant barriers to communication to learn about their ideas of the good. PLWID continue to demand to take part in discussions about policies that directly affect them. As mentioned in Chapters 1 and 3, advocacy groups such as Respecting Rights represent important opportunities for PLWID to engage with policy makers. However, participation in such discussions continues to be limited, especially for those who face greater barriers to cognition and communication.

Unless the perspectives of PLWID, including those who face significant barriers to communication, are known and considered when designing policies and programs, supports and services risk failing to support a good life. Rather, these supports maintain the status quo; PLWID continue to be deprived of genuine opportunities to thrive. For this reason, I was motivated to design a study that would allow me to learn from PLWID who face barriers to communication about what they consider important to a good life. As researchers, it is essential that we search for ways to engage with PLWID who face barriers to communication and to listen to what they have to say. Trusted family members, friends and staff are helpful communication partners in some circumstances. However, depending exclusively on others to learn about the priorities of PLWID is simply not good enough. Caregivers may have different priorities (McIntyre et al., 2004). And, very importantly, PLWID have the right to be accommodated to take part in all spheres of life, including research and policy development (United Nations, CRPD, 2006). Thus, every effort must be made to engage with the person to gain an understanding of their perspective. According to Brown, Hatton, and Emerson (2013):

> The overall issue [for research] is how to hear the voice of people with intellectual disabilities, and especially those with severe intellectual disabilities who cannot communicate their quality of life ideas in ways that we can readily understand...major challenges remain and much more sophisticated ways of allowing the voices of people with intellectual disabilities to be “heard” as valid by researchers need to be developed (p. 321).

Sheridan et al. (2019) point out that valuable knowledge is lost when the perspectives of PLWID are excluded from research on QoL. Hu et al. (2011) identified the exclusion of PLWID from studies on family quality of life as a ‘major methodological’ flaw. Correia et al. (2017) remark that the reliance on mothers as the sole respondent is an obvious limitation and that it is imperative to include the perspectives of PLWID since “the contribution of people with ID to research remains untapped” (p. 60). This is especially true for those who face significant barriers to communication since traditional qualitative research methods such as interviews, questionnaires and focus groups, unless adapted, tend to exclude them. Finally, Verdugo et al. (2010) observed differences between results obtained through external observation and proxy responses compared with the perspectives of PLWID via self-reports of quality of life.

In the next section, I present the theories and frameworks used to explore a good life with research participants. In the methodology section, I detail the participatory process of producing video vignettes. Then, I present and discuss a selection of the vignettes. Each video vignette reflects an aspect that is valued by participants as part of a good life. Finally, I present implications of the central findings on a good life and its characteristics for researchers, PLWID, families, support workers, agencies, and policymakers.

A Good Life

Many frameworks and theories describe the elements and conditions for a good life. The capabilities approach (Nussbaum, 2006), network of resources Runswick-Cole and Goodley, 2013), good things in life (Wolfensberger, et al. 1996), valued experiences (O'Brien, 1989) and the Convention on the Rights of Persons with Disabilities (CRPD) (United Nations, CRPD, 2006) propose aspects deemed essential to a good life or a life that is worth living. To facilitate the exploration of a good life with participants, I chose Verdugo et al.'s (2012) quality of life framework with eight life domains linked to clusters of CRPD articles. The eight quality of life domains (Schalock et al., 2008) are: 1) personal development and 2) self-determination both of which are categorized under Independence, 3) interpersonal relationships, 4) social inclusion (I use participation) and 5) rights are included in the broader category of social participation, and finally, 6) emotional well-being, 7) physical well-being and 8) material well-being are grouped under well-being.

The QoL framework with its eight domains was well suited to support an exploration of a good life with participants. The framework included the most commonly recurring elements found in other theories and frameworks regarding a good life and it was more accessible than working with the lengthy Convention. The link between CRPD articles and QoL life domains (Verdugo et al., 2012), provided me with rights-based examples of each domain. As mentioned in Chapter 1, an important motivation to use the QoL framework was its increasing use in the developmental services sector as a tool to evaluate and monitor services.

Many aspects of a good life are experiences imagined impossible for PLWID (Johnson et al., 2010; Elks, 2019). Low expectations for PLWID, according to Johnson et al. (2010), have limited policy and program development. Instead of aiming for a good life, they observe that UK policy has focused on achieving an “ordinary life.” Elks (2019) wonders if the focus been on supporting better lives or good lives. The difference is significant considering the social history of PLWID, in other words he remarks, better does not necessarily mean good. If these domains of life reflect elements of a good life and can meaningfully be linked to the CRPD, an important international convention written by people with disabilities, including Canadians, one must question whether the policy in Ontario reflects these ideas and aspirations? In Chapter 1, I briefly reviewed the Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act 2008 (herein referred to as the *Social Inclusion Act*, *2008*), in light of the frameworks regarding a good life for PLWID and to situate my study in the province of Ontario. I mentioned how key concepts included in the Act such as social inclusion, independence, choice, rights and well-being overlap with elements present in frameworks and theories about a good life. However, the *Social Inclusion Act, 2008* fails to define these concepts and to provide guidance regarding their implementation. Despite claiming to promote social inclusion, the Act lacks a vision since it remains unclear what is meant by social inclusion and how to achieve it. I also pointed out how the medical model perspective of intellectual and developmental disability as well as a narrow liberal understanding of independence continue to shape the *Social Inclusion Act, 2008*. In my opinion, the Act suffers from a lack of meaningful participation and contribution by those most concerned by it. I will come back to this topic later to discuss the study's results considering the results of exploring a good life with research participants. In the following section, I present the theoretical frameworks that informed the design and conduct of this study.

Theoretical Considerations

In the previous section, I briefly summarized literature relevant to understanding the concept of a good life. In this section, I discuss the frameworks and concepts that guided the design of my study. I begin with a discussion of the social model of disability, followed by a QoL framework and the Convention and finally, I explain how a relational approach contributed to the study.

My research is situated in a social model approach to disability focuses attention on the environmental factors that interact with individual impairment to create disadvantage. The model stems from disability rights movements and was developed by people with disabilities. The social model of disability informed the design of this research by maintaining my attention on the various conditions that could facilitate the participation of PLWID in the study. Maintaining this standpoint helped me to learn about a good life from PLWID who face barriers to communication.

The exploration of a good life was informed by a quality of life (QoL) framework linked to the Convention. In this study, I used the QoL framework as a springboard for discussion. As mentioned earlier, I chose the QoL framework because its eight domains of life made it accessible and helped us to begin our exploration with a broad view that included many facets of life recognized as core to a good life in many countries (Bigby et al., 2014). Knowing that the QoL framework is being used in Canada by policymakers and service providers to evaluate and monitor developmental services also motivated my choice. And although the practice of peer administered QoL questionnaires in some provinces (e.g., Alberta and British Columbia) is a step in the right direction, much more can be done to increase the participation of those with a greater need for cognitive and communication assistance and to move beyond reliance on knowledge that is shared via text and words.

Although I appreciated the simplicity of the QoL framework and its history in developmental services, I also wanted the study to maintain a close relationship to disability human rights. The Convention is the first international legal framework created by people with disabilities and included strong participation by PLWID. By ratifying the Convention in 2010 and the Optional Protocol in 2018, Canada agreed to bring its internal laws up to CRPD standards which include many obligations to ensure the full participation of people with disabilities in all spheres of life. My approach to ethics for this study was informed by relational ethics (Bergum & Dosseter, 2005) wherein the consequences of disclosure must be considered considering the impact they may have on participants' existing and potential relationships. In short, a relational approach informed the methodology and methods for this research.

Methodology and Methods

The overarching methodological approach to this study was guided by inclusive research methods with people labelled with an intellectual disability as outlined by Walmsley and

Johnson (2003, p. 64). I now describe how the five principles of inclusive research methods informed this study:

1. The research problem must be one that is owned (not necessarily initiated) by disabled people.

   I chose to explore a good life with participants to keep the study as broad as possible to give participants the opportunity to choose what was most important to them. In this sense, participants chose the focus of the study.

2. It should further the interests of disabled people; non-disabled researchers should be on the side of people with learning disabilities.

   By learning about past advocacy efforts, how to facilitate meaningful participation, and learning about participants' priorities for a good life, this research contributes to knowledge regarding want PLWID value most and creative ways to learn from them.

3. It should be collaborative – people with learning disabilities should be involved in the process of doing the research.

   Participants were involved in data collection and analysis. Like Photovoice where analysis begins the moment participants decide which images to take and to include. Even though participants did not take the photos or video themselves, their priorities directed the process. I worked collaboratively with participants in the sense that we used our respective strengths and skills to explore a good life. This approach reflects Walmsley and Johnson's (2003) 'team approach' when working with PLWID.

4. People with learning disabilities should be able to exert some control over process and outcomes.

   Participants had control over which images and words were included in their video vignettes.

They also had and continue to have control over the results via the Google website I created for each participant and to which they have, with the help of their supporter, control of the username and the password.

5. The research question, process and reports must be accessible to people with learning disabilities.

I chose the concept of a good life because it was more accessible than other phrases such as social inclusion or quality of life. Taken separately, the words ‘good life’ are easier to understand, “What is good in your life?” What is important for your good life?” I also asked participants “What is most important in your life?” In French, it translated to ‘bonne vie’ and I asked participants questions such as “Qu’est-ce qui est bon dans ta vie?”, “Qu’est-ce qui est le plus important dans ta vie?” and, “Qu’est-ce qui est important pour une bonne vie?” I also chose such an open question because I wanted participants to choose the focus of the study.

Visual tools such as the pictogram sheets, the Good Life Wheel and the ‘*Yes, No, don’t know*’ decision-making visual facilitated communication and I describe other strategies in greater detail in the methodology section. We used visual methods to make the data collection process more meaningful to participants but also to ensure that the results would be accessible. The exploration of a good life with participants was also guided by a synthesis of theories and models regarding a good life for PLWID which was illustrated by the *Good Life Wheel* which I now present in greater detail.

As mentioned in Chapter 2 on methodology, I chose audio/visual methods as a data collection tool for a variety of reasons but primarily to increase communicative access (Simmons-Mackie et al., 2007). And, to use Haw and Hadfield’s (2011) terminology, I used audio/visual methods in a modality of articulation to assist participants “voice their opinions and communicate" (p. 2) their perspective of a good life. Cluley (2016) states that "The reality is that some people with learning disabilities require alternative approaches to research to facilitate their inclusion and to hear their voice/see their world" (p. 44). I now describe the research process with attention to the ways I used visual methods to increase communicative access and to support participants voicing their perspectives on a good life.

A Story of The Research Process

Prior to participant recruitment, I obtained ethical approval for this study from the University of Ottawa. Consent forms were designed using an easy read format[18] (see Appendix G) and consent was an on-going and layered process (Pink, as cited in Cox et al., 2014) that was repeated as needed during the study period (Frauenberger, 2015). This step-by-step approach to consent is common practice in the context of studies using visual methods within a participatory framework.

To launch the study, I invited participants who self-identified or whose main supporter identified the participant as someone who has been labelled with an intellectual or developmental disability and as facing daily barriers to communication. Two women and three men took part in the study (see Chapter 2 on methodology for more details). Participants and I completed five workshops including one session to view and analyze the final results. Additionally, I met with participants individually on average six times each for individual data collection sessions and informal interviews over the course of the study. The overall goal of the workshops was to share a common starting point to explore a good life and to listen to other participants' experiences and perspectives to expand one's own ideas. Briefly, here is the goal of each workshop:

Workshop 1: Get to know one another, review the research process, and get thinking

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[18] I also prepared a conventional text-based consent form for supporters taking part studies 2 & 3 (see Appendix H).

about a good life.

Workshop 2: Share and discuss first data collection experience and continue developing storyboard.

Workshop 3: Begin editing process

Workshop 4: Finalize editing decisions for each audio/visual story

Workshop 5: Last Video Analysis Session (optional)

Place and research context is important to doing research with PLWID. For the workshops, we met at the*Space* Ottawa, an independent media arts studio for adults with autism and other developmental disabilities. I chose this location because of its centrality, main floor access and the possibility for weekend bookings. I conducted individual data collection sessions with participants between workshops in various locations across the city and beyond. Sometimes, supporters and participants collected audio/visual data independently. I designed this study as a series of four workshops with the possibility of an additional workshop if needed.

Six supporters (three mothers, one sister, one female support worker, one female neighbor, one father helped with data collection) played important roles in this study. The work they did included establishing initial contact with me about the study, facilitating meetings communication and transportation in many cases. Supporters also provided contact information for activities, people or places identified by participants and facilitated the completion of third-party consent forms. Finally, they took part in data collection which I describe later.

A few potential participants were excluded since communication was not a significant daily barrier. Another interested participant could not take part in the research due to a lack of appropriate supports. I briefly describe this situation. Over a month-period, I interacted with a local day program staff regarding an interested participant. The staff had received my poster via their agency. In total, the staff person sent me twelve emails to support one of their program participants to take part in the studies. The staff shared their concerns about the need to travel to a different location for the study since they supported a total of eight people. The staff person described the interested participant as non-verbal but as very determined to communicate. They also explained that the person used gestures and some American Sign Language (ASL) and thought that I would find this person a pleasure to work with.

Since the study might take place during the weekend or evenings, the staff shared the recruitment poster with the group home staff where the potential participant lived and requested that they contact me to learn about the study and next steps. The day program staff then took the time to read the easy read consent form with the interested person. They admitted that it was difficult to know if the individual understood all the details of the study, especially the information about publishing in scholarly journals or sharing results at academic or advocacy conferences. However, the staff person assured me that the person was keen to take part and was excited to meet with me about the study. The staff also offered to investigate whether the individual had a legal guardian that should be contacted.

Despite the expressed interest by the woman attending the day program and the efforts made by the staff to support her, I was never contacted by the group home, nor did I could meet with that person alongside a support staff to discuss adjustments that would be necessary to make participation possible. Between these two settings designed specifically to support PLWID, there was insufficient individualized support and communication. I stopped recruiting for this study once I reached the maximum of five participants.

Although I made earnest efforts to be accessible by creating text and video-based recruitment materials as well as offering to meet with people in person, many PLWID nonetheless required active and direct communication support to learn about the possibility to take part in the study and to facilitate their participation in research. Family members, paid support staff and a friend played an essential role as facilitators in sharing information, establishing initial contact, and maintaining on-going participation. All five participants who took part in this study had at least one supportive person with whom I could communicate via telephone and email to share information, arrange individual meetings, and assist with communication during most encounters. I relied on the support of willing and available supporters to provide personal assistance to participants. In addition to engaging the participants' supporters, I developed various materials to assist with data collection. In the next section, I describe the materials to support communication and how I used them in the context of this study.

Accommodations to Increase Communicative Access

Since participatory research is, to a great extent, dependent upon dialogue, I incorporated a variety of AAC strategies into the research process (Boxall & Ralph, 2009, p. 48). As suggested by Boxall and Ralph (2009), supported decision-making (SDM) approaches were used to support participants' exploration of a good life. Beyond individual AAC approaches, participants and I used a variety of strategies such as active listening skills, gestures, the use of personal photographs, pictograms, writing and video to facilitate communication and increase understanding. Using public domain images found on the Internet, I created a simple 'Yes, No, I don't know' decision-making support (see Figure 1) to assist with decision-making and facilitate mutual understanding. This tool was inspired by Teachman's (2016) Visual Consent Display (p. 206) which invited further clarification when participants pointed to 'I don't know'. These were part of what I called my 'bag of tools' inspired by Munford et al. (2008).

Figure 1

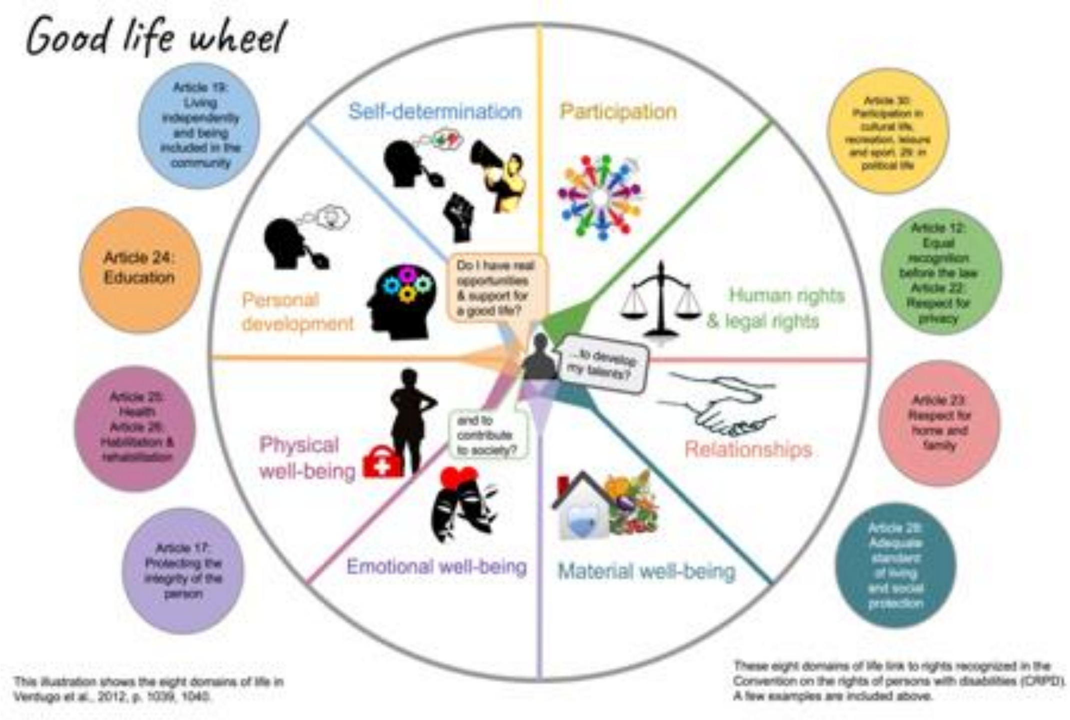
'Yes, No, I don't know' decision-making support

To facilitate an exploration of a good life, I designed an illustration of the eight domains of life that included CRPD articles (see Figure 2) using Google Slides. Verdugo et al. (2012) link clusters of CRPD articles to the eight domains of QoL. As mentioned above, these domains are personal development, self-determination, interpersonal relationships, social Inclusion (I use participation), rights, emotional well-being, physical well-being, and material well-being. I then assembled sheets of pictograms (see Figure 3) to provide visual examples of the eight QoL domains and associated CRPD Articles.

Figure 2 pictured below is a circle divided into eight equal parts, like a pie. Each piece represents a QoL domain and has a colour and simple image assigned to it. Next to the life domain, an associated CRPD article is presented in a bubble in the colour corresponding to the domain.

Figure 2

Good life wheel



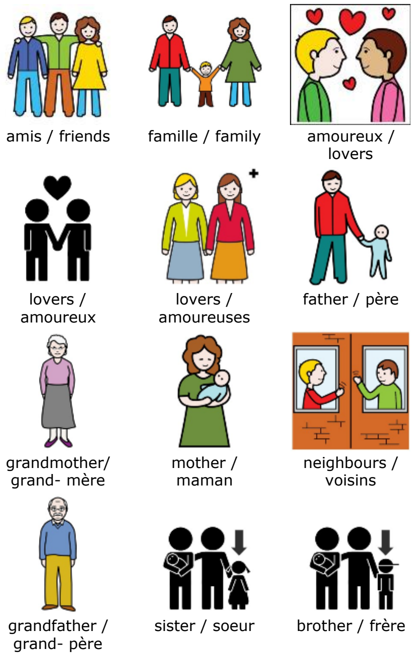
This illustration shows the eight domains of life in Verdugo et al., 2012, p. 1039, 1040.

These eight domains of life link to rights recognized in the Convention on the rights of persons with disabilities (CRPD). A few examples are included above.

Figure 3

Interpersonal relationships pictosheet

Interpersonal relationships / Relations interpersonnelles



Pictogrammes: ARASAAC (http://www.arasaac.org) Sclera (http://www.Sclera.be) Imprimé par Picto-Selector (http://www.PictoSelector.eu)

These pictogram sheets (see Figure 3) were an invaluable support to communication. Although the sheets could not cover all possibilities, they did serve as a starting point for discussion. I describe in greater detail how pictograms were used to facilitate communication in the next chapter. To further support thinking about a good life and taking notes, I created a workbook entitled *Exploring my good life* (see Appendix I). Inspired from Verdugo et al.'s (2012) descriptions, questions found in quality of life questionnaires and CRPD language, I described each of the eight life domains as the following: 1) personal development is about having genuine opportunities to access quality education, to develop my talents, to explore my identity and sense of self and to develop my creativity and spirituality; 2) self-determination is about having genuine opportunities to choose where and with whom I live, which activities I engage in, what clothes I wear and how I spend my money. It depends on having opportunities to communicate in ways that I prefer and make sense to me; 3) participation is about having genuine opportunities to belong and/or to contribute to one or multiple communities; 4) human rights and legal rights are about having genuine opportunities and support to exercise my right to equal treatment, privacy, to supported decision making and to dignity among many others; 5) Relationships is about having genuine opportunities to have meaningful relationships as well as encounters; 6) material well-being is about having genuine opportunities and support to live in a safe and comfortable home, to access healthy foods, clothing and other basic needs; 7) emotional well-being is about having genuine opportunities to live in an emotionally safe environment and to set my own boundaries; and 8) physical well-being is about having genuine opportunities to be healthy and feel good physically. Participants are prompted to share stories related to each life domain. The *Exploring my good life* workbook was used by one parent and myself as a support for keeping notes throughout the process. As mentioned earlier, the questions I asked participants during the workshops and individual sessions were "What is good in your life?" What is important for your good life?" "What is most important in your life?"

In some cases, I video documented participants doing what they had identified as meaningful. In other cases, mothers, support workers and fathers video recorded. All five participants actively took part in deciding what was important and even essential to a good life for them, they reviewed, commented, and made decisions about which images to include. Participants guided and directed the selection and production of audio/visual material. However, none of the participants took pictures or video themselves. Instead, they featured in their photographs and videos, something also observed by Overmars-Marx et al. (2018). I was surprised by this outcome as I had imagined that some participants would want to take pictures or video. Perhaps it was the fact that participants mostly valued activities and relationships in which they enthusiastically took part, something I will discuss in greater detail in the results section.

Supporters took on various roles to support data collection. Some supporters took on the role of taking video and photographs (support worker, mother, father). Some actively searched for photographs in family archives (mothers, sister, father, support worker) to help illustrate some of the ideas identified by their son, daughter, sister, or service user. Sometimes, we found no images to support what a participant had identified as important. Nor could we produce the image because of distance or the inability to obtain consent from friends or family members living far away. In those situations, I met with participants to help them search the Internet for public domain images to evoke or illustrate their idea.

As a result of our team-based approach to data collection and analysis, a total of 34 video vignettes were created. Each participant has between 4-8 videos expressing essential elements of a good life. To facilitate sharing video vignettes with family, agencies, and support workers, I created a Google website for each participant's video vignettes. Philippe and his parents preferred that I embed the video vignettes in a PowerPoint presentation[19] that they could share with others.

Editing/Montage Process

The process of creating the video vignettes began when participants expressed what they considered to be most important to a good life. This process involved various stages of back-and-forth discussion using a combination of the pictograms, their own pictures, and discussions with supporters. Once the images had been collected, I imported them into Final Cut Pro X, a professional video editing software and created short sequences. During the workshops, we watched and talked about the sequences. Sometimes, our discussion led to identifying other aspects of a good life. After each viewing, I took note of the participant's and the supporter's feedback. I adjusted by adding, deleting, or changing the images. We watched the sequences as a group and, in some cases, individually, until participants requested no further adjustments.

During our last workshop, we spent just over an hour categorizing all video vignettes according the QoL domains illustrated in the *Good Life Wheel*. Assigning the video vignettes with participants[20] and supporters to specific life domains was challenging. The vignettes related to many domains at once illustrating the interdependence of opportunities for personal development, self-determination, participation, rights, relationships, material, emotional and physical well-being. Julia and Rick pointed to aspects of the vignettes that linked to participation and relationships whereas the mothers linked most of the content of the video vignettes with

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[19] Philippe's presentation includes additional information about the way he communicates, Things or situations that can trigger anxiety or frustration, Signs that Philippe has become frustrated, What do avoid and What to do to help since this information was key to supporting his good life.

emotional well-being. For example, a discussion of Julia's gymnastics vignette allowed the group to acknowledge that it fit into participation as well as having an important relational aspect since Julia mentions her best friend. For participants and supporters, the vignette also connected to emotional and physical well-being. Further, the mothers suggested that having opportunities to do and to be what one finds meaningful results in overall emotional well-being. Finally, one mother remarked while pointing to the giant wheel on the table "We need all of these things to have a good life."

Results

In this section, I present the overall results of our exploration of a good life. I then introduce each participant and their perspective on a good life. I have embedded one video vignette per participant to facilitate viewing. Participation and relationships stand out as the good life priorities for the research participants. Table 1 presents the QoL domains and the corresponding video vignettes.

Table 1

Video vignettes categorized by life domain

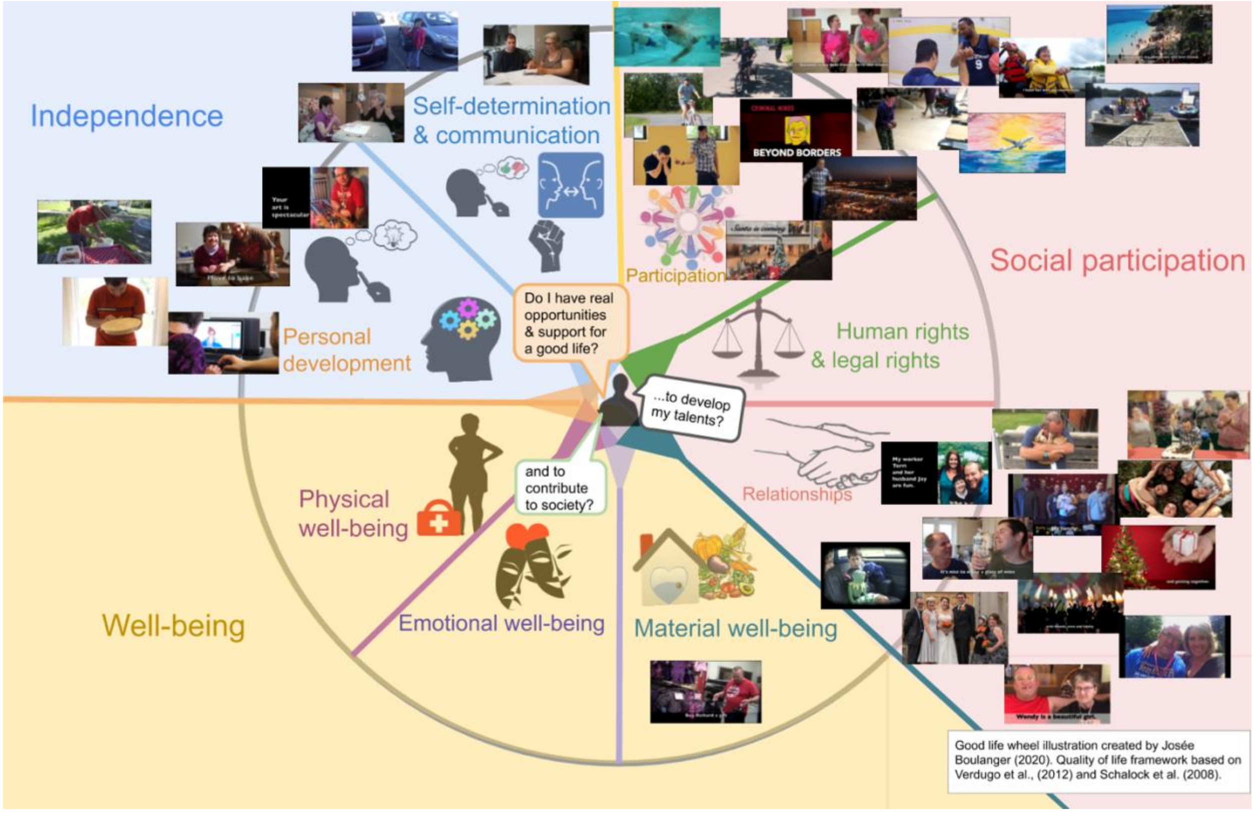
Quality of life domains	Julia	Rick	Philippe	Maggie	Ilyasse	Total
1. Participation	4/6	3/8	2/8	2/7	3/5	14/34
2. Human rights & legal rights						0/34
3. Relationships	1/6	3/8	3/8	2/7	2/5	11/34
4. Material well-being		1/8				1/34
5. Emotional well-being						0/34
6. Physical well-being						0/34
7. Personal development	1/6	1/8	2/8	1/7		5/34

8. Self-determination			1/8	2/7		3/34
Total	6	8	8	7	5	34/34

All participants had at least two vignettes directly related to both participation and relationships and many more featured important relationships or showed the relational aspect of their activities. As can be seen in Figure 4, most of the vignettes are situated in the overarching category of social participation and more specifically the life domains of Participation and Relationships. In the *Exploring my good life workbook*, I described participation as having genuine opportunities to belong and/or to contribute to one or multiple communities. Participation for Julia, Philippe, Ilyasse, Maggie and Rick included taking part in artistic activities (e.g., dance, media arts, visual, textile arts and culinary arts), sports (e.g., cycling, swimming, bowling, rowing, basketball, gymnastics), travel (e.g., international travel, summer camp, family trips), and passive leisure activities (e.g., watching televised series, watching videos on a tablet, lounging). Video vignettes linked to participation revealed important relational aspects. In the *Exploring my good life workbook*, I described the life domain of Relationships as “having genuine opportunities to have meaningful relationships as well as encounters.” Julia, Philippe, Ilyasse, Maggie and Rick chose to show or to mention relationships with friends, parents, siblings, cousins, teammates, mentors, coaches, an intimate partner, a pet, and paid support workers. Overall, the results show that participation and relationships but those related to personal development also closely relate to participation and relationships.

Figure 4

Good life wheel including video stills of video vignettes



Good life wheel illustration created by Josée Boulanger (2020). Quality of life framework based on Verdugo et al., (2012) and Schalock et al. (2008).

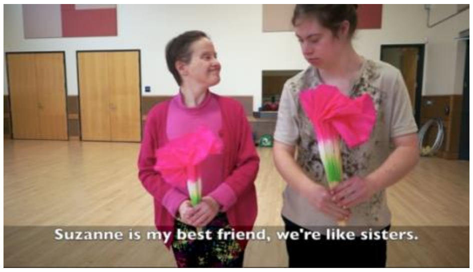
I now introduce each participant, their supporter, whether they attend a day program and receive individualized funding from MCCSS. I then share what they chose to show about a good life.

About Julia

Julia's sister had received one of my recruitment posters through a local family advocacy network. When I met Julia about the study, she was in her fifties. She is a noticeably quiet person. As I got to know her, I learned that a highly active, smart, and competitive woman hid behind her unassuming appearance. Julia had been living with her sister and brother-in-law for many years. She had previously been married and her husband had also lived with them, but he had passed away from cancer. Her sister had always been on the lookout for opportunities for her and she had supported both Julia and her husband throughout his battle with cancer. Julia had worked as a clerk at the House of Commons and at the CRTC. She was one of the founding members of the Special Olympics gymnasts in Ottawa and had travelled extensively with her sister. It was clear that her sister played a key role in facilitating Julia's good life. Her sister managed her Passport individualized funding and used it primarily to cover the costs of Julia's media arts classes at the*Space* Ottawa. Over the years, her sister had regularly organized parties for Julia and her friends. However, in the past few years, her sister worried that she had not had so much time for Julia since she was caring for her husband who was terminally ill.

What Do We Learn About a Good Life from Julia?

Video vignette 1*: I am a gymnast*



Click on the image above or follow this link to watch the vignette: https://youtu.be/5RXPqJlh9sk

In both *I am a gymnast*, and *I am a Dragon Boat racer*, we learn that Julia enjoys competition, she enjoys a physical challenge, and sharing her passion with teammates, sister, and best friend. In *I am a Dragon Boat* racer, we see Julia smiling and enjoying herself as she paddles hard says how fun it is to go fast. We get the sense that she is proud of her sister who is also a dragon boat racer and a firefighter. The vignette I am an artist showcases Julia's artwork. We see her extremely focused facial expression as she works on a digital drawing. She says that she likes to learn new skills and we hear her media arts instructor provide tips and guidance.

In getting together with friends and family, she shows and tells us that she enjoys going to the cinema with friends, celebrating special events with others, giving, and receiving presents and staying up late for New Year's. In Travelling is one of my passions Julia says that the best part of travelling is "staying with my roommate and best friend." For Julia, challenging oneself physically and creatively, learning new skills and measuring one's skills against others are important to a good life. Equally important to Julia is camaraderie and sharing one's passions with people she cares about. To view all video vignettes made with Julia's guidance, follow this link: https://sites.google.com/view/julia-tuschak/home

About Ilyasse

Ilyasse joined the study after his neighbour contacted me after seeing my recruitment poster and video at the day program for people with developmental disabilities where she worked. Ilyasse is a quiet and shy man in his early twenties. At the time of the study, Ilyasse was living at home with his mother and sister. Ilyasse's mother managed his Passport individualized funding and spent it mostly on a day program run by the city which he attended four days a week. On Fridays, he stayed home with his mother and attended his local mosque. His mother told me how much he loved to stand at the entrance to welcome the men. Despite his shyness, he enjoyed greeting people at the mosque and to be with people he knew.

As I got to know him, I noticed that he often wondered about a friend or family member. Where were they? What were they doing? When would he see them? From the beginning, it was clear that Ilyasse's priority was spending time with friends and family. His mother said that Ilyasse asked about his friends and family members every day but that it was not always possible to see them. She explained that Ilyasse often felt lonely at home, especially on weekends but she found it difficult to find more opportunities for him since so many services and programs were offered only in English, which she did not speak, and little was left of his Passport funding once his day program was paid. While some services are offered in French in the Ottawa region, they are quite limited. Thus, communication was also a barrier for Ilyasse's main support.

What Do We Learn About a Good Life from Ilyasse?

Video Vignette 2: *Je suis un athlète*

Click on the image above or follow this link to watch the vignette: https://youtu.be/gDI9QyIDHuY

Through Ilyasse's vignettes *J'adore danser* (*I love dancing*) and *Je suis un athlète* (*I am an athlete*) both linked to the life domain of participation, we learn that he enjoys dancing, basketball, and soccer. In both vignettes, we see that Ilyasse is shy and hesitant but with encouragement and support from his good friend Gaël, he dances away to the music and skillfully throws the basketball and handles the soccer ball. Gaël gives a high-five and says "Bravo!" and "Encore Ilyasse!" Ilyasse appears to like the encouragement and the activities as he keeps smiling throughout. The relationship between Ilysasse and his friend is central to his participation in these activities. Outside the frame, the day program staff facilitates the activity by *J'aimerais voyager au Maroc* (*I would like to travel to Morocco*) is also linked to participation but Ilyasse has not yet had the opportunity to go to Morocco to visit extended family.

The vignettes *Je vous aime* (*I love you*) and *J'aime les célébrations* (*I love celebrations*) link directly to the life domain of relationships. In the first one, Ilyasse names important people in his life as images appear on the screen. I helped Ilyasse select public domain images from the Internet to illustrate the importance of friendship and family. In the vignette about celebrations, Ilyasse is smiling as he is surrounded by his friends at the municipal day program he attends. As Gaël did with sports and dance, his friends encourage him, cheering him on "Ilyasse! Ilyasse!" to blow the candles and once he succeeds, the clap their hands, laugh and cheer. Through Ilyasse's vignettes, we learn that he is a creative and athletic guy. The importance of expressing oneself creatively, to perfect one's skills, to have friends that know how to encourage you. Staying connected with friends and family is also very important to Ilyasse as part of a good life. To view all video vignettes made with Ilyasse’s guidance, follow this link: https://sites.google.com/view/ilyasseyoussoufi/home

About Rick

Rick is a talkative and often humorous man. When I first met him and his main support worker, I immediately noticed his stylish yellow eyeglass frames and the giant papier mâché ketchup bottle in his apartment. At the time of the study, he was in his late 40s and was living in a bachelor pad located in the basement of a group home. Sheri-Lynne, Rick’s main Passport worker, contacted me about the study. His Passport funding is managed by the agency that also manages the home and daily supports where with he lives.

What Do We Learn About a Good Life from Rick?

Video vignette 3: My girlfriend *Wendy*

Click on the image above or follow this link to watch the vignette: https://youtu.be/SJl5Ll4DIys

Three of Rick’s video vignettes relate directly to relationships *Wendy is a beautiful girl*, People who are important to me and *I love my cat Peaches*. In Wendy is a beautiful girl, we see Rick and Wendy talking and enjoying a coffee at Tim Horton’s coffee shop. In another scene, they sit next to each other. Rick has his arm around Wendy as they patiently answer questions asked by Rick’s support worker. We learn that Rick would like to marry Wendy someday. In *I love my cat Peaches,* we see Rick lovingly hold his cat and kiss him. For Rick, an intimate relationship, caring for a pet, having a fun support worker, friends and family are important to his good life. Other vignettes such as *I am an artist*, *My new bike,* and *A job that pays* contain important relational aspects such as Rick’s relationship with his support worker, his desire to save money to buy give gifts for those he cares for, to get married and to travel. *I love Christmas* and *California dreaming*, tell us that celebration, travel, and play are also important to Rick's good life. To view all of video vignettes made with Rick's guidance, follow this link: https://sites.google.com/view/rick-prophet/accueil

About Philippe

Philippe is a man in his early thirties. His mother, who had hired me years ago to provide personal assistance to Philippe for gardening, contacted me about the study. I remembered Philippe as a hard worker. I had always enjoyed his happy humming as he worked doing what he liked. Although Philippe did not speak, I remembered him as a very expressive and communicative in non-verbal ways. By observing his body language and listening to the pitch of his humming, it was quite easy to know whether he was happy with a situation.

At the time of the study, Philippe spent five days per week volunteering at a program managed by a local service provider funded by MCCSS. His mother drove him to most of his activities, but other times, his father did. His mother managed the individualized funding he received from MCCSS using it to cover a portion of the day program. His parents paid for the rest of his supports out of pocket. An increase in the cost of the day program was imminent and Philippe's mother was concerned since the family could not afford to cover the additional and exceptionally large amount for full-time one-on-one support. She worried about the impact on his emotional well-being because she knew how much Philippe liked to keep busy or, in his own words "I hate to do nothing."

To talk about the study, I met Philippe and his mother in their home. After his day program, Philippe liked to relax on the living room couch to watch Youtube.com videos. His mother and I sat at the kitchen table to discuss the project. His mother invited him to join us when I had questions for him about the study. Philippe did supported typing with his mother and preferred to answer no more than two or three questions in one sitting. She explained that I should get straight to the point to keep Philippe engaged as he preferred short conversations.

What Do We Learn About a Good Life from Philippe?

Video vignette 4: ***Working at the farm***

Click on the image above or follow this link to watch the vignette: https://youtu.be/a7NkqOgcN5o

His vignette *Working on the farm* fits most closely to the life domain of personal development, but it hints at the way Philippe likes to be supported. Philippe expressed during our individual meetings that he preferred to be with people who know him well. In this vignette, we see how the support worker takes a very hands-off approach to supporting Philippe in his work at the farm. She provides short words of encouragement and direction, similar to the way his mother interacts with him in the vignette *Great to cook*.

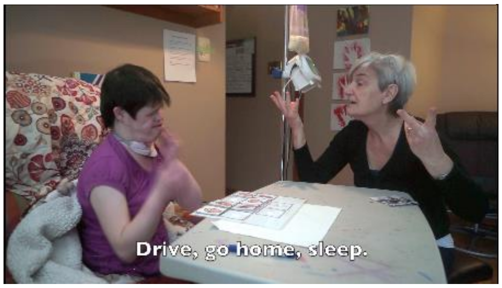
Although these two vignettes relate mostly to personal development, supportive relationships facilitate Philippe's volunteer work and his contribution to a family meal. Through the vignettes *My home*, *People who are important to me*, *Having fun with my siblings*, *Cycling with dad* and *I love water* Philippe communicates that spending time with family, doing physical activities indoors and outdoors and being playful with family members is important to him. The archival footage provided by his parents allow us to understand that swimming and cycling have been important to Philippe since his childhood and that his parents are an integral part of these activities. Through Supported typing, we learn that Philippe shares his thoughts and opinions using a small keyboard and receives support from his mother to do so. A good life includes being able to communicate and being understood.

About Maggie

I had met Maggie a few times before when she had attended meetings of a local advocacy group with her mother. Maggie is a small woman in her early thirties but she looks much younger than her age. Maggie may be small, but she does not go unnoticed with her generous smile and assertive way of signing ASL. At the time of the study, Maggie was living in her own house, a house that her parents had bought for her. Her house was sunny, and artwork beautifully adorned the walls. I also noticed lots of visual lists and calendars to help Maggie, her roommates and support staff know what needed to get done. The house was big enough for Maggie, a few roommates, guests and potentially a live-in support person. Decisions were made by talking things through as a group. Maggie's mother managed her Passport funding and as well as Family-Managed Care Home and Community Care Support Services.[20] When Maggie was ready for her mother to leave her house, she would sign and wave insistently "Mom, I love you, bye!"

What Do We Learn About a Good Life from Maggie?

Video vignette 5: *Communicating with me*



Click on the image above or follow this link to watch the vignette: https://youtu.be/GEnjSULY4Nk

Maggie's video vignette Communicating with me relates to the domain of Self-determination. Maggie's mother explained how important it was for Maggie to communicate with others in sign language. This is also expressed in the vignette *Everyone can sign at summer camp, I love it!* Maggie's mother explained how Maggie loves going to summer camp and going for a boat ride but the aspect that stands out the most is the pleasure of

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[20] Home and Community Care Support Services is funded by Ontario's Ministry of Health's via its new Crown agency, Ontario Health. It was formerly known as the Locally Integrated Health Network (LIHN).

communicating with and being understood by others. Listening to Maggie and being able to understand her is essential to Maggie's good life. Her mother explained that when someone Maggie loves is no longer in her life; she thinks that they have passed away and becomes very distraught. Although Maggie uses sign, paying attention to her body language and asking many questions are important: "Maggie doesn't have the words to express her emotions so it can come out as self-abuse" A bit of detective work is necessary. "We have to ask her, is it because Janet is gone? Once we know what is causing her to harm herself, then we can begin to help her through it." Shared language, an interest in understanding and a willingness to respect Maggie are key to her ability to exercise her autonomy as we see in the vignette when she points to the 'Happy' and pushes the sheet away with a big smile. Maggie has a direct but diplomatic and positive approach to making herself understood.

In *I know my routine at my day program*, Maggie shows that although it is unusual for her to be followed by a video camera, she knows what she is doing at her day program. Maggie's mother explained that it is important to Maggie that others recognize that she is capable and knows what she is doing. In the vignettes *I love bowling* and *I love to bake!* Maggie shows that she enjoys a physical challenge and being creative in the kitchen with a friend that makes her feel loved. Maggie is known for being generous with her cookies, giving them away to friends and acquaintances. To view all video vignettes made with Maggie's guidance, follow this link: https://sites.google.com/view/maggie-hart/accueil

In summary, the results show that participation and relationships are key to a good life for all five participants. Opportunities for personal development and autonomy are also important. Significantly, many vignettes show the importance of relationships regardless of the life domain to which they directly connect. How can these findings inform policy and support a good life?

Discussion

The objective of this study was to explore a good life from the perspective of PLWID using participatory audio/visual methods. I now present implications of the central findings on a good life and its characteristics for researchers, PLWID, families, support workers, agencies, and policymakers. The results show a close connection between participation and relationships.

Participation and Contribution

In the first chapter of the dissertation, I discussed participation in relation to contribution. I explained that I prefer the concept of contribution, which is a synonym for participation, because it focuses attention on the active role one plays in co-creating or shaping an experience. From that perspective, participation means having opportunities to produce or to achieve something with others and to help make it successful (Cambridge University Press, 2021). As I mentioned before, what constitutes a significant contribution may fall outside conventional ideas. Etmanski (2000) advocates for a society wherein the presence, participation, and unique contributions of PLWID are recognized and valued. When asked ‘What is a good life to you?” or “What is the most important thing in life for you?” participants’ show in their video vignettes that taking part in artistic activities (e.g. dance, media arts, visual, textile arts and culinary arts), sports (e.g. cycling, swimming, bowling, rowing, basketball, gymnastics), international travel, Summer camp and family trips, as well as passive leisure activities such as watching their favourite television series, videos on a tablet and relaxing at home is important. Participants chose to show these activities because they enjoyed them. They represented opportunities to learn and to develop various skills, to relax and have fun, to creatively express themselves and to test their abilities against those of others. In other words, participants benefited personally from taking part in meaningful activities. Equally important however is recognizing how their participation allowed them to add to the lives of others. Julia makes valuable contributions as a teammate in her Dragon Boat racing team and her Special Olympics gymnastics team. As an artist, she shares her creative interpretation of the world and lived experiences thus adding beauty. Ilyasse contributes as a caring and fun member of his day program who loves to dance and has impressive athletic skills. He also contributes by creating opportunities for his best friend Gaël to develop his coaching skills as a caring and supportive friend. Philippe contributes to the functioning of the farm and care of the animals. He provides meaningful employment for the farm staff who respects Philippe's autonomy. He also gives a helping hand to his parents in the kitchen with dinner preparations and bakes beautiful pies. As an avid swimmer and water aficionado, Philippe creates opportunities for others to enjoy the water. Rick contributes to the well-being of his girlfriend as a caring partner and to his cat Peaches as an affectionate pet owner. As an artist, he shares his unique impression of the world (e.g., the giant papier-mâché ketchup bottle and the Kiss on the lips painting) and creates beautiful and wearable art pieces (e.g., silk scarves). Rick also provides meaningful employment opportunities for his primary support worker who visibly enjoys assisting Rick in all aspects of his life. Maggie contributes as a friend and as a roommate who loves to laugh and have fun. She also contributes as a friend to Jay who enjoys spending time with her to bake cookies and to go on outings. The video vignettes reveal how research participants contribute to the well-being of other humans and animals. They also show how they add beauty and their unique perspectives through visual art and dance and how they contribute to the success of sports teams, day program experiences, to employment experiences and relationships.

Relationships

Although the video vignettes show the importance of participation and opportunities for self-development, many also reveal their deeply relational aspects. These results are consistent with Johnson et al. (2010) and Gladstone's (2014) suggestion that relationships play an essential role in supporting a good life for PLWID. The results also reflect prior research that revealed the importance relationships with family (Correia et al., 2017), as a vehicle for inclusion (Lord and Hutchison, 2007), as a resource that contributes to resilience (Runswick-Cole & Goodley, 2013) and as a dimension of life that is valued above employment (Johnson et al., 2010, Gladstone, 2014). Literature by families (Community Living British Columbia, 2011, Etmanski, 2000) and PLWID also points to relationships as essential to a good life. PLWID demand a right to relationships (Ignagni et al., 2016). In a recent video, a Respecting Rights (2021) self-advocate states "I have the right to choose to be in a relationship. Whether we are gay, lesbian, trans. We want you to accept us" (04:23). Others, like Andrew Bloomfield, claim that connection is the reason for being (Bloomfield, 2010).

The CRPD refers to relationships only once in Article 23. Respect for home and the family placing greater emphasis on opportunities for full, equal, and effective participation in all spheres of life. Verdugo et al. (2012) link the life domain relationships directly to Article 23 - Respect for home and family. So do Fulford and Cobigo (2018). Ignagni et al. (2016) interpret Article 23 as the right to sexual identity and expression, friendship, marriage, and parenthood. However, other rights scattered throughout the Convention are identified as supporting relationships: 1) Article 3 - General principles such as the right to autonomy, choice, and independence (Fulford & Cobigo, 2018), 2) Article 19 - Living independently and being included in the community (Fulford & Cobigo (2018) and specifically the right to co-habitate with persons of one’s choice (Ignagni et al. 2016); 3) Article 20 - Personal mobility, 4) Article 22 - Respect for privacy (Fulford and Cobigo, 2018), 5) Article 24 - Education and more specifically the right to peer support (Fulford and Cobigo, 2018), 6) Article 28 - Adequate standard of living and social protection. Access to money and funding (Fulford and Cobigo, 2018) facilitates relationships, and 7) Article 30 - Participation in cultural life, recreation, leisure, and sport is also indirectly linked the life domain of relationships for Verdugo et al. (2012). I would also point to the importance of section 4 of Article 30, the right to ones “cultural and linguistic identity, includ[ing] sign language and deaf culture” as essential to the development of relationships. Being a member of a linguistic minority like Maggie and Ilyasse represents an additional barrier to finding meaningful opportunities for participation and relationships.

Julia devotes one vignette specifically to relationships *Getting together with friends and family* in which she tells us that she loves to go out with friends, to give and receive gifts during special occasions. However, relational aspects are present in four other vignettes (e.g., gymnastics, travel, art, and rowing). Philippe devotes three video vignettes to relationships (e.g., *My home*, *People who are important to me* and *Having fun with my siblings*). Five other video vignettes show the relational aspects of participation (e.g., *I love water* and *Cycling with dad*), self-development (e.g., *Great to cook* and *Working at the farm*) wherein gentle encouragement is key to Philippe’s success. Ilyasse dedicates two video vignettes to relationships (e.g., *Je vous aime* and *J’aime les célébrations*). His three other vignettes also represent important relational aspects like his desire to visit family in Morocco (*J’aimerais voyager au Maroc*) and his friendship with Gaël (e.g., *Je suis un athlete* and *J’adore danser!*). Direct encouragement (e.g., to blow out the candles on his birthday cake in *J’aime les célébrations*) from friends is also very important to Ilyasse’s participation in activities he visibly enjoys. Maggie has three video vignettes that signal the importance of relationships (e.g., *Meet my roommates, friends and staff* and *I love my family*). The vignette *Everyone can sign at summer camp, I love it!* Maggie is at camp where others also communicate in ASL and *I love to bake!* with someone she loves to be with. Finally, in *Communicating with me*, Maggie's communication abilities are evident when she is with someone who is familiar with ASL and her communication style.

Rick has three vignettes directly showing the importance of relationships (e.g., *My cat Peaches*, *My girlfriend Wendy* and *People who are important to me*). In the vignettes *I am an artist* and *My new bike*, we see the special relationship between Rick and Sheri-Lynne, his Passport support worker. In his vignette *A job that pays*, Rick says that he wants to "make money and get married to Wendy," go on a holiday, buy a new cat tree and gifts for those he cares about. He also wonders what he will do once his volunteer placement is over because he says he does not want to be bored, echoing Philippe's "Hate when I do nothing."

Looking Outside the Frame

What remains outside the frame are the relational aspects that enable Maggie, Ilyasse, Julia, Philippe, and Rick to take part in activities that are meaningful to them and to maintain valued relationships. The following are some of the tasks done by a supporter: research opportunities, share information in an accessible manner, provide support to make choices, organise personal assistance to take part in the activity if necessary or provide personal assistance directly, manage individualized funding (e.g., Passport funding). PLWID currently do not receive assistance to manage their individualized funding. Parents or siblings take on this work which entails finding, hiring, training, paying direct support workers or day programs with Passport funding. The Passport program exists on a tacit assumption that someone, such as parent or sibling, will be available to manage the funds (Saaltink & Ouellette-Kuntz, 2014, p.

52). When no family member is available, service providers can manage individualized funding for a fee. However, these two situations may not optimal due the widely varying abilities of family members to conduct these tasks and the potential conflicts of interests on the part of service providers. My research therefore supports prior research (Sheridan et al., 2019) which indicates that participation and relationships may be inextricably linked. Maggie's opportunity to lives in a with roommates is dependent upon her mother's ability to manage the house and the supports. Rick has his own apartment within a group home.

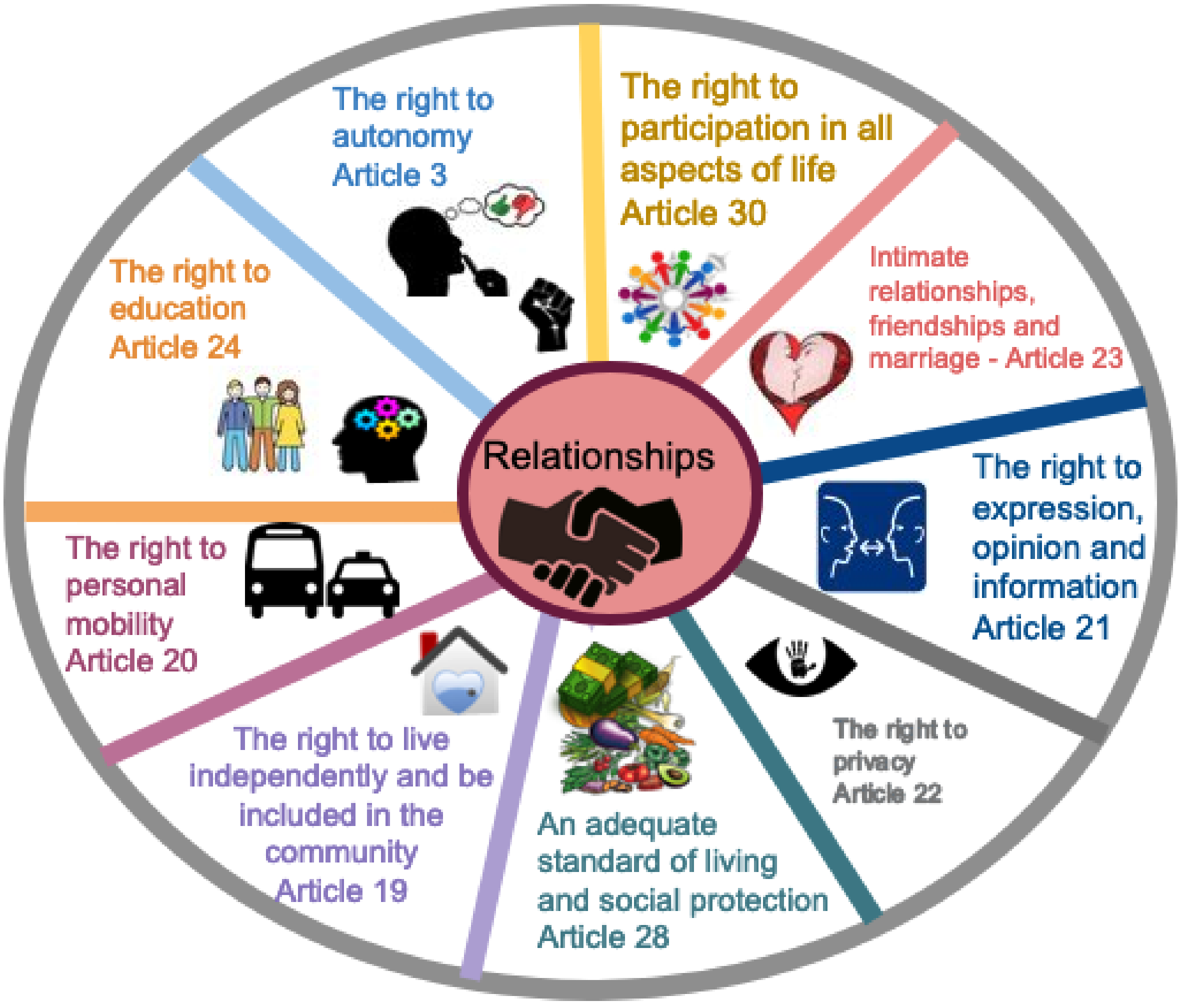
Video vignettes show Julia, Ilyasse, Philippe and Maggie taking part in disability-specific activities (e.g., Special Olympics, rowing, media arts classes, city day program and MCCSS-funded day programs). Participation in disability-specific activities is sometimes viewed as a less valuable than activities available to the general public. Article 30 of the CRPD recognizes the value of participation in both mainstream and disability-specific activities. Citing the literature, Gilmore & Cuskelly, (2014, p. 194) explain that "many individuals with intellectual disability felt that friendships, particularly best friendships, could occur only with another person with intellectual disability. This preference was explained by the importance of equality in friendship and the desire to avoid exclusion and controlling behaviour in mainstream contexts (Gilmore & Cuskelly, 2014). Although it is important to avoid devaluing disability-specific activities, it is equally important to question whether PLWID have the necessary supports to take part in mainstream activities and whether buildings, policies and staff adequately accommodate individuals.

Centering Relationships and Opportunities for Contribution?

Based on the importance of relationships uncovered in my own research and in previous research, I recommend an explicit focus on relationships when designing supports and services with and for PLWID. Further, when service providers are faced with making decisions regarding housing and supports for those they serve, they should pay close attention to the potential impacts of these decisions on existing relationships. Decisions to change support staff and housing arrangements should be guided by a relational framework. Through *Figure 5* presented below, I show CRPD articles identified as supporting relationships. I then propose a list of questions related to each CRPD as a starting point to facilitate a discussion with PLWID regarding relationships. A conversation to think about relationships could be facilitated using similar individualized approaches and a CRPD framework adopted to explore a good life (e.g., visual supports, supported decision-making and various AAC strategies) in the context of this study.

Figure 5

CRPD rights in support of relationships



Article 3 - General Principles (Respect for inherent dignity, individual autonomy)

- Who currently helps me to make decisions?
- Who else could help me?
- What is working well/or not so well?
- What other kinds of support would help me to make my own decisions?

Article 19 - Living independently and being included in the community

- How do my supports help me live more autonomously?
- Did I choose my living arrangement?
- Can I invite friends, family, or an intimate partner to my home?
- What other kinds of support do I need to help me shape the way I live?

Article 20 - Personal mobility

- Do I have access to transportation to meet with people who are important to me and to take part in meaningful activities?
- How can my supports facilitate transportation?
- How can various levels of government work with PLWID to ensure appropriate and adequate transportation?

Article 21- Freedom of expression and opinion, and access to information

- Is information presented to me in ways that I can understand?
- Do I have access to technology or other supports for alternative and augmentative forms of communication?
- How can my supports help me facilitate communication, self-expression, and access to information?

Article 22 - Respect for privacy

- Do I have enough privacy to engage in relationships of my choosing, including intimate relationships?
- What would need to change so that I could have more privacy?

Article 23 - Respect for home and the family

- How do my supports help protect and maintain relationships that I value?
- How do my supports help me development new relationships of my choice?
- What other kinds of support do I need to strengthen current relationships or develop new ones?

Article 24 - Education

- Do I have opportunities to learn in settings such as college, university, or workshops?
- Do I have access to adult continuing education opportunities?
- What kinds of support would help increase my opportunities for learning?

Article 28 - Adequate standard of living and social protection

- Do I have enough money to socialize with friends and family outside of my home?
- Is my home safe and welcoming for my friends, family and intimate partners?
- What kinds of supports or opportunities could help me have enough money to participate in socializing and other aspects of relationships like buying gifts on special occasions?

Article 30 - Participation in cultural life, recreation, leisure and sport

- Do I have opportunities to take part in activities that I enjoy?
- Do I have a choice between taking part in disability-specific activities and activities for the general public?
- What kinds of support could increase my opportunities to take part in activities that are meaningful to me?

To summarize, the CRPD articles related to the life domain of relationships promote and protect autonomy, living independently and being included in the community, communication, mobility, privacy, family, friendship and intimate relationships, educational opportunities, an adequate standard of living and participation. This research suggests that a focus on relationships supports participation and autonomy. The CRPD rights shown in the visual and the questions listed above assist with thinking about essential rights that must be respected to support the maintenance existing relationships and the development of new ones. Further participatory research that takes relationships and participation as its starting point is needed to continue exploring with PLWID, including those who face significant barriers to communication.

Implications

Regarding the research implications of my work, there is a need to further explore the perspectives of PLWID who face significant barriers to communication. With respect to researching relationships, there is also more to be done. The complexity of relationships is underexplored and there is not a great deal of research with PLWID who face significant barriers to communication. My own research suggests that the connections between participation and relationships also deserve further exploration. In all cases, researchers would benefit from utilizing inclusive methods and methodological paradigms to learn more about what is valued and prioritized by PLWID themselves.

This study also has implications for healthcare and personal support workers. Direct support work and planning should facilitate opportunities to maintain and deepen existing ties with family members, friends and other valued relationships (e.g., intimate relationships, pets, colleagues and other peers). Direct support should also look for opportunities to develop new relationships. Such opportunities can be fostered by facilitating participation in activities identified as meaningful to the person for example, various arts and sport activities (Article 30) and learning opportunities (Article 24 – Education). Professionals providing assistance with planning and direct support can use a process similar to the one used in throughout this study to become acquainted with the person's interests and priorities for a good life. As suggested above, the CRPD rights that support relationships (Articles 3, 19, 20, 21, 22, 23, 24, 28 and 30) can serve as a guide for healthcare and personal support workers wanting to facilitate connection. They may also assist PLWID and their families to think about the ways in which various types of relationships can be better protected and facilitated.

Lastly, policy governing supports and services for PLWID should reflect priorities identified by PLWID regarding a good life, including this study. The literature on a good life, the good life wheel and the results of this study serve as examples of inclusive approaches to sparking dialogue regarding policy priorities and collectively re-writing the *Social Inclusion Act, 2008*. This entails a commitment to reimagining the policy development process with PLWID. In other words, a good life for PLWID begins with a commitment to listening and learning from them.

Conclusion

In this study, I adopted participatory audio/visual methods to explore a good life from the perspectives of people labelled with an intellectual disability who face barriers to communication. Through video footage, photographs new and old as well as images found on the

Internet, participants expressed what was most important to them. Their resulting video vignettes show that they value participation and relationships as essential to their good life.

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Chapter 5 – Decisions, Decisions, Decisions! Supporting Decision-Making in Audiovisual Participatory Research with People Labelled with an Intellectual Disability

Relationship of Manuscript 3 to the Dissertation

Communication and decision-making are at the heart of participatory research. In this chapter, I explore my efforts to facilitate thinking, decision-making and articulation of ideas about a good life by PLWID who face significant barriers to communication. This study is based on documentation of the participatory study described in the previous chapter in which I facilitated the exploration of a good life with PLWID using audio/visual research methods. Providing assistance with exposure to and exploration of ideas, choosing and ways of communicating were key elements to meaningful engagement in research about a good life. In this chapter, I examine how decisions were made regarding participants' views about what they most value in a good life. My objectives are to better identify these factors and to make them visible to researchers, self-advocates, family member and allies to demystify the collaborative process and to critically reflect on the significance of process and methodology in the context of research and advocacy.

Abstract

Purpose and objective: The objective of this third study was to document and analyse the conditions enabling PLWID to meaningfully take part in research.

Methods: I documented the process of exploring a good life with five participants labelled with an intellectual disability from the Ottawa area using a combination of video, photography, observational notes of workshops and individual meetings, telephone calls and email communication. Using a narrative approach, I describe specific decision-making moments during the study and discuss the strategies, relationships and tools used to facilitate decisions and contributed to participation.

Results: The results of this study reveal that audio/visual research methods tailored to each participant's needs and integrated at each step of the research process, facilitated decision-making and enabled participants to take part in the research process and to communicate their ideas about a good life. They also reveal important relational aspects of decision-making.

Conclusion and implications: Recognition of the relational quality of decision-making has implications for policy and practice with PLWID and others facing barriers to cognition and communication.

The International Journal of Social Research Methodology, 8000 words.

Current: 7438 words

Every day we are faced with decisions, from choosing what to wear, to eat, when to sleep or the kinds of activities in which we wish to engage or the people with whom we like to spend time -- these moments contribute to creating our distinctive life paths (Welch, 2013). The right to make one's own decisions has been at the heart of much controversy when it comes to PLWID and many are still denied the opportunity to make their own decisions. Advocacy stories shared in Chapter 3, described ways that disability advocates fought for the right to make choices with the support they need. Chapter 4, focused on participants' ideas of a good life. The objective of this third study was to document and analyse the conditions enabling PLWID to meaningfully take part in research and to share their perspectives. To reach this objective, I describe decisional moments that took place as part of the research process of exploring a good life with participants. I also discuss the strategies, relationships and tools that facilitated decision-making. According to Welch (2013), each person has the potential to contribute to the development of society in unique and unexpected ways when they have opportunities and appropriate supports to exercise their autonomy. Research by Lachapelle et al. (2005) reveals that increased opportunities to exercise self-determination results in a higher quality of life for PLWID. And, the more PLWID practice self-determination, the more they develop their decision-making skills (Wehmeyer, 2000). As mentioned in Chapter 1, Silvers and Francis (2009), point out that the more extensive need for cognitive assistance has excluded PLWID and others with cognitive disabilities from theories of justice. This different way of processing information, remembering, communicating, and making decisions is rarely accommodated. By describing the different ways participants made decisions and communicated their choices throughout the study, I hope to contribute to understanding regarding relational approaches to decision-making in a research context and beyond. Through short narratives, I discuss the factors that contributed to the process of making decisions.

Throughout the study, participants were invited to make decisions about participating in the research process, about what they wanted to share with others, how they wanted to participate, whether to reveal their identity and what was most important to them as part of a good life. What conditions enabled the research participants to share their perspectives on a good life? How can this knowledge be helpful to other researchers and policymakers interested in learning from and working alongside PLWID who face significant barriers to communication? In what follows, I summarize the participatory research study I undertook, I discuss decision-making and briefly review literature about supported decision-making. I then describe my methods before presenting short narratives of decisional moments that took place in the context of an exploration of a good life. I end this chapter with a discussion of the implications of the results for research and policy.

I begin this chapter with a summary of the previous study. I follow with a presentation of literature on decision-making and the theoretical frameworks informing this study. I then describe moments wherein decisions were made in the context of the participatory study on a good life. I end this chapter with a discussion of the results and recommendations.

In the first manuscript, I created a table (see Table 1 in Chapter 3) to compare various roles in support of autonomy and decision-making. Table 1 showed the many similarities among the roles of advisors, advocates, decision-making partners, independent facilitators, and trustees in terms of the skills, tasks, and conditions necessary for helping with thinking, decision-making and communicating process. Supported decision-making (SDM) is an approach introduced by advocates and self-advocates from Ontario to enable equal recognition before the law. Although Ontario does not recognize SDM (Law Commission of Ontario, 2017), PLWID with their families, support workers and friends practice making decisions with supports in the course of daily interactions. Some, like Andrew Bloomfield and others who have incorporated their own microboards, may use supported decision-making agreements to help guide those providing assistance. Approaches to SDM and are as diverse as the people who engage with them both formally and informally. Individuals' cognitive abilities can be more or less "abstract or concrete, coherent or disconnected, informed or naïve" (Silvers & Francis, 2009, p. 476) and these varying abilities interact with the attitudes, beliefs, and abilities of those available to facilitate decision-making. Browning (2018) identified five factors that influenced the interaction "the experiences and attributes the person and their supporter brought to the process; the quality of their relationship; the environment in which decision making occurred and the nature and consequences of the decision" (p. 173). Thus, the abilities, expectations, beliefs, and skill level held by parents, siblings, friends, support workers, researchers, health professionals and educators can both facilitate or hinder decision-making.

Background

To provide context, I now briefly summarize the participatory research study about a good life. Five participants from the Ottawa area took part in a series of five workshops and individual sessions (average of six sessions and informal interviews per participant) to think about and what a good life looks like to them and to share their perspective using audio/visual methods. All five participants were accompanied by a supportive family member, staff person or friend who knew them very well. Supporters and I assisted participants to make decisions about what participants wished to include as important to a good life and how they would like to show these activities, people, or places. The results revealed participation as important to a good life, especially being active in sports and in artistic and cultural activities. Results also show that participants highly value relationships with family members, friends, an intimate partner, and support workers.

Literature Review

The purpose of this literature review is to clarify my understanding of decision-making, the roots and prevalence of supported decision-making. Before discussing the literature on decision-making, I look at the origins of the word decision and to decide. The Latin root of the verb to decide stems from “decidere meaning to determine, or “literally "to cut off,"” (Online etymology dictionary, 2021) or to take this path and not that one. To determine is from the Latin determinare “to enclose, bound, set limits to.” Making decisions seems to be about choosing to take one path and leaving another behind. It is also a process through which one can express one’s boundaries. Whereas deciding connotes finality, the verb to choose which is related to the Old English ceosan and means “...to test, taste, try” points to the temporary or revocable nature of decisions. The root of the word to choose is a reminder of the temporary nature of decisions and the freedom to explore and the authority to decide if and when to push one’s boundaries. Harding and Tascıoglu (2018) classify decisions into three broad categories “everyday preferences, life choices, and difficult decisions” (p. 25). Whether we choose which clothes to wear, which activity to engage in, the support worker we prefer, where we want to live and with whom, decisions are made in a specific place and time. A multitude of cultural, economic, and social factors interact to influence our decisions and sometimes in fact, leaving us with no choice to be made. For PLWID and others who face similar barriers to cognition and communication, the absence of decision-making supports increases exponentially the situations wherein they are effectively left with no choice. Making and revising decisions takes place at an individual level such as changing one’s mind about which shirt to wear in the morning or moving away from the parental home. Other decisions such as amending policies that govern services and supports for citizens to revising a nation's constitution, impact many lives. In both cases, deciding to test one path over another represents opportunity to express one's values, preferences, and beliefs as an individual and as a society.

All frameworks and theories regarding a good life presented in Chapter 1 acknowledge the importance of autonomy. For example, autonomy is referred to as voice and choice (Elks, 2019), self-determination (Verdugo et al. 2012), control over one's environment (Nussbaum, 2000), and power and control (Runswick-Cole & Goodley, 2013). Autonomy also figures prominently in the CRDP. Specifically, the Convention recognizes independence and the freedom to make one's own choices (United Nations, CRPD, 2006, Preamble (n)). The Convention stipulates "that persons with disabilities should have the opportunity to be actively involved in decision-making processes about policies and programmes, including those directly concerning them" (United Nations, CRPD, 2006, Preamble (o)). PLWID and their supporters were instrumental to the development of the Convention's Article 12 regarding equal recognition before the law that requires signatory states to "take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity" (United Nations, CRPD, 2006, art. 12, sec. 3). This need for direct support, as Silvers and Francis (2009), point out has been used as a justification for denying the right to equal recognition before the law. However, they also note that, from a relational perspective, everyone would have to be excluded from recognition since no one makes decisions independently (p. 487).

In Ontario, as early as 1973, a report by Welch to the Ministry of Social Services recognized the importance of supporting the autonomy of PLWID. The opportunity to make one's decisions was, according to Welch's report, a precondition to what he called a "life of normalcy" (p.9). He also attributed much of the system's disfunction to this very lack of control on behalf of the person, their family, or their guardian. Self-advocates and allies fought for the right of PLWID to make their own decisions and proposed the idea of supportive decision-making over 50 years ago (Stainton, 2016). In People First groups, support was provided by advisors who were expected to respect decisions made by members and support their leadership abilities (Worrell, 1988). Justin Clark's struggle to leave the Rideau Regional Centre was a battle for his right to choose where to live and with whom, and to gain greater control over his life generally (The Ottawa Citizen, 1991). Support for decision-making and implementation was at the heart of the work to create Ontario's first Advocacy Commission back in the early 1990s to provide non-legal advocacy services to citizens in vulnerable situations (O'Sullivan, 1987). Supportive or supported decision-making was introduced as an approach by mother and advocate Audrey Cole while she led the Coalition on Alternatives to Guardianship. To this day, the Coalition on Alternatives to Guardianship reunites self-advocates and allies from across Canada to advocate for the right of PLWID to legal capacity for all regardless of cognitive abilities (Coalition on Alternatives to Guardianship, 2014). In Ontario, the Bloomfield family has worked consistently since the early 2000s to create, maintain and promote legally incorporated entities such as Arohas and Microboards that support self-determination and decision-making for PLWID.

Supporting decision-making is a process through which a person experiencing barriers to cognition and communication receives assistance allowing them to make choices and practice autonomy. This process can include providing accessible information via alternative formats such as easy read format, verbal or non-verbal communication such as in-person demonstrations or re-enactments, visual supports such as photographs, pictograms, drawings, and video. Many PLWID and others who face similar barriers employ Augmentative and Alternative Communication (AAC). AAC includes using gestures, vocalizations, body language, including facial expressions, pictures, and symbols. AAC also includes using software (e.g., GoTalk Now or and hardware (e.g., dynavox or tablet) to support and augment one's potential for communication. Communicative accessibility is an important aspect of supportive decision-making and can be compared to creating cognitive and communicative ramps. Communicative accessibility is a concept developed by aphasia researchers (Simmons-Mackie, Kagan et al., 2007) that describes an environment that is highly adapted to the conversational, information and expressive needs of people with aphasia and include acknowledging one's own communicative limitations. Simmons-Mackie et al. (2007) "define communicative access ... in terms of participation in communicative events, giving and getting information, and making informed decisions...often...requir[ing] accommodations or adaptations" (p. 41). It includes Supported Conversation for Adults with Aphasia (SCA™) (Aphasia Institute) described as a method that includes various techniques (e.g., short sentences, observing non-verbal cues, gestures, pausing, drawings, keywords, pictographs) to facilitate communication (Aphasia Institute). Verifying understanding is an important step and can be done by repeating in one's own words, expanding on what one thinks one understood and summarizing longer conversations. When I first learned of SCA™, I was struck by the similarities with approaches to supporting communication with PLWID. These were approaches that, as a sibling, I had used regularly when communicating with my brother and others who face barriers to verbal communication. I especially appreciated the stated goals of SCA™ as being "1. Acknowledge the competence of the adult with aphasia. 2. Help the adult with aphasia to reveal his or her competence" (Aphasia Institute) and thought that these should be part of the goals of all types of supports for communication and decision-making.

As mentioned in Chapter 3, Silvers and Francis (2009) propose a theory of trusteeship. They propose that the trustee providing cognitive assistance must focus attention on and draw their inspiration exclusively from the person. In other words, Silvers and Francis (2009) urge that all aspects of the idea regarding what is good be specific to the person and devoid of the priorities and interests of the person in a trustee role. and should not limited to one person. A person with a cognitive disability may engage in such a process with different people. Silvers and Francis (2009) also urge trustees to look beyond stereotypes when providing cognitive assistance, use their imagination, attention, and insight. According to them (Silvers and Francis, 2009) the role of trustee is 'no casual occupation.' The Coalition on Alternatives to Guardianship (2014) suggests that, when in doubt, the process and result of an assisted decision-making process should be tested for the "'best interpretation of will and preferences' rather than 'best interests'" (p. 4). Many PLWID and their close supporters practice SDM informally. Their intimate and tacit knowledge of one another facilitates and expediates decision-making. Silvers and Francis (2009) suggest that the roles of trustee may not be compatible with the role of caregiver as it may be difficult to separate one's own interests from the person being supported. In Chapter 3, I showed the importance of acknowledging power imbalances (Worrell, 1988) and avoiding potential conflicts of interests (O'Sullivan, 1987, Bloomfield & Bloomfield, 2012) when taking on a role such as an advisor, advocate, decision-making partner or independent facilitator. However, in practice, family members, paid support workers and peers do provide support with decision-making for the practical reason that the social circle of PLWID is often very limited (Araten-Bergman & Bigby, 2021). Citing the literature, Araten-Bergman and Bigby,

(2021) mention that "social networks of people with intellectual disabilities averaged 3.1 members with at least one of those a paid staff member" (p.1). In addition to a limited social network, the lack of access to communication supports and services for PLWID add to the barriers to decision-making. For example, the Augmentative Communication and Writing Service (ACWS) at The Ottawa Hospital Rehabilitation Centre offers AAC services to adults with physical disabilities but not to those with developmental or intellectual disability.[21] The lack of access to AAC devices, supports and services as adults leaves many PLWID dependent upon their limited circle of close supports to assist with interpretation and decision-making. When assistance with communication and interpretation is limited to one support person, the lack of external and independent support increases vulnerability to interpersonal coercion.

Currently, Ontario has a formal discourse promoting "social inclusion, individual choice, independence and rights" and the right to make "informed decisions" (*Social Inclusion Act, 2008*, Reg. 299/10, PART II, s. 4). However, little guidance is available to community agencies funded by the province to provide supports and services to citizens with developmental and intellectual disabilities. The Act provides a hint about its interpretation of independence in its definition of adaptive functioning defined as "a person's capacity to gain personal independence, based on the person's ability to learn and apply conceptual, social, and practical skills in his or her everyday life (*Social Inclusion Act, 2008*, 2(1)). In other words, independence is understood as the result of the individual capacity to adapt to the demands of everyday life. As McCauley and Matheson (2016) and Carey et al. (2012) and have also remarked that, instead of working towards structural changes to increase access to the good things in life, the role of service

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[21] When I contacted the Augmentative Communication and Writing Service (ACWS) to request services for my brother, I was told that the root cause of his communication difficulties must be physical. As a child, he had access to speech therapy in an attempt to correct or ameliorate his speech but as an adult, he did not qualify for services that would facilitate communication.

providers is to assist individuals to adapt to society for successful integration. The Act also fails to explain how to promote and support individual choice. This is surprising given that decision-making and who has the right to do it, has been an ongoing topic of controversy and advocacy in intellectual disability history.

In this section, I clarified the meaning of decision-making and highlighted its relationship to autonomy. I briefly reviewed the importance of decision-making and autonomy to a good life. I also situated decision-making in light of the CRPD, described various supported decision-making approaches and briefly situated SDM in the context of Ontario. In summary, there are many creative ways to support PLWID who face barriers to communication to make decisions allowing them to create their unique life paths. By documenting the process of exploring a good life using participatory visual methods, I hope this study will contribute to a better understanding of SDM.

Theoretical Framework

In this section, I describe the theoretical framework that informs my understanding of decision-making, capacity and autonomy. I also briefly discuss the concept of Amartya Sen's concept of adaptive preferences as they relate to decision making. Following the CRPD, I see decision-making as a right that all persons, regardless of cognitive or communicative abilities, should have the opportunity to practice. Supporting each individual's autonomy is good because all persons are intrinsically valuable. Supporting the highest forms of autonomy for all citizens is also valuable at a societal level because each individual is unique as a complex and unlikely encounter of biological, social and ecological factors. As such, everyone has the potential to set things in motion in unexpected ways, which, according to Arendt (1998), is the reason we are born.

Following Kong (2017), I understand decision-making as an interpersonal process that is impacted by a variety of external pressures. This perspective is in contrast with a liberal perspective that conceptualizes mental capacity and decision-making as a process that takes place "within an individual's mind, in relative isolation from others" (MCA, S. 1(3) in Kong 2017, p. 21). Instead, from a relational (Kong, 2017) and social construction perspective, competence, capacity, and decision-making processes are to be examined in social relations (Rapley, 2004). For Silvers and Francis (2009), coaching or otherwise assisting people with cognitive disabilities in forming their notions of the good becomes simply a more extensive and enduring version of commonplace conceptual midwifery" (p. 487). If a strict liberal definition of capacity were to be enforced, they argue, all citizens would have to be excluded from consideration. Kong (2017) suggests that the CRPD itself represents a critique to an atomistic view of autonomy, mental capacity, and decision-making. She points to the fact that the CRPD regards the concept of 'mental capacity' and the tools, such as mental capacity assessments, as discriminatory since this idea and the practices that exist to bring it into being deny fundamental rights to persons with disabilities. Silvers and Francis (2009) take a practical approach "how to build justice in the circumstances of the actual world, taking individuals as they are in all their variety" (Silvers and Francis, 2009, p. 495). Justice, according to them, is achieved by implementing small progressive steps.

Disagreement and controversy about decision-making, and capacity often relates to decisions of a medical (for ex.: The Eve Decision, 1986) or financial nature because such decisions can have immediate life altering effects. Although protecting the well-being of the person is at the heart of this debate, liability and minimising risk for professionals, financial institutions, agencies, and government also motivate the desire to maintain the status quo of substitute decision-making. Since supported decision-making is not yet recognized in Ontario, it is important to pay attention to the diverse ways of facilitating choice for PLWID in different contexts. To focus exclusively on these one-off high stakes decision-making situations obscures the equally important practice of daily micro decisions that, when added together, shape a person's life. The chronic lack of opportunities to practice making one's decisions, however small, thwarts autonomy. It is a subtle form of daily violence experienced by PLWID often left unreported and remains 'under the radar' (Crawford, 2007) because it is not of a criminal nature. It is my hope that by paying attention to decision-making in contexts such as participatory research can contribute to understanding the relational nature of decision-making. It is also my hope that to pay attention to the various supports needed for decision-making contributes to harm reduction towards PLWID and all others who require similar supports. In the next section, I discuss the methods used to document the participatory exploration of a good life with PLWID.

Methods

Data Collection

To collect data for this study, I combined video and photo documentation and observational notes based on workshops, individual meetings, telephone calls and email communication. To document the workshops, I mounted a video camera (using a wide-angle lens and external microphone) onto a tripod to record each workshop. At the beginning of each workshop, I flipped the camera viewfinder toward the participants and reminded them that we were being filmed and that we could watch some of the footage if they wanted to or if we had time at the end of the workshop. In addition to video documenting the workshops, I photo documented one individual data collection session per participant. I documented this process myself to avoid adding another layer of work for supporters already providing essential support.

Most of the images used to create the video vignettes and to document the process were either produced by myself or a supporter. The remainder of the images used in the video vignettes were found images (e.g., personal or family archives, public domain images) or, in Julia and Rick's case, artwork they had previously created. All images, regardless of origin, were included in the video vignettes based on decisions made by participants. In this sense, participants played a directorial role.

After each workshop, I imported the footage into FinalCutProX, a professional video editing software package. Title slates were inserted to assist in identifying various stages of the workshop such as Introduction, Round table sharing, and so on. I identified segments by cutting sequences into individual clips and naming them descriptively. I then recorded comments directly onto the footage using the titles tool in FinalCutProX. Comments were added directly to the video footage by using FinalCutProX's title tool. The initial rationale for choosing this approach was to allow us to examine the footage within a one-hour time limit. I viewed and examined the video footage myself.[22]

Ethical Considerations

Participants were given the choice to preserve their anonymity during the data collection process. They could opt out of documenting their individual data collection process. I also explained that I could use selective framing, blurring or other image filters to preserve their anonymity and avoid using the video documentation in publications. All participants, including supporters, chose to reveal their identity.

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[22] As mentioned in Chapter 2 on methodology and in Manuscript 2, the duration of the workshops was shortened to accommodate participants' preference for a shorter session. This left us with no time to collectively review video documentation of the workshop.

Results

This section focuses on decision-making moments throughout the research process. I describe specific moments during the study and discuss the way decisions were made, as well as the types of supports and strategies that were used to assist with decision-making. In the past, I have worked with groups who knew each other before engaging in a storytelling/sharing process. The experience of working with a group that does not share a shared experience or history such as members of an advocacy group added a layer of challenge. Although SDM approaches were used throughout the study, including recruitment, I have chosen to focus on the workshops and individual sessions. I included a short narrative description of the recruitment process in Manuscript 2 and the consequences of a lack of support for an interested participant. First, I briefly describe the workshops, individual data collection sessions and the good life workbook. I then describe decision-making situations. I also discuss the role of the researcher and the support person in these decision-making situations.

Workshops

The goal of the workshops was to share the good life framework with all participants and supporters present to generate and share ideas. During the workshops, I introduced the Good life wheel illustration (see Appendix E) and we brainstormed examples from participants' lives. We watched examples of stories told by/with and for people who face significant barriers to communication. Participants shared photographs and meaningful objects to get to know one another and to learn about what and who they valued. Some of the objects and photographs may be misleading when supporters made the choices for participants. This was discovered farther along during the research process.

During the first workshop, I gave participants and their supporters a notebook, pens, storyboard templates, the illustration of the *Good life wheel*, a copy of the *Exploring my good life workbook*, tips on how to take pictures and video, copies of third party release forms (see Appendix J), a list of local free mental health and legal resources. I also created an easy read handout clarifying the roles for them, their supporters and myself in the research context:

Roles for family members, staff, or friends

- My wishes or thoughts about a good life likely differ from the wishes and thoughts of the participant I am accompanying.
- Ask myself: "Is this what I would like for him/her? Or is it what s/he would like?" "How do I know that?"
- I can facilitate communication and understanding between the participant and others.
- I can be a good listener.
- I can support the participant to make their own decisions.
- I avoid making decisions for them.
- I can help the participant to take pictures and/or video or to find images.

Roles for the researcher

- I make sure that the space is accessible and comfortable for everyone.
- I make sure that information about the research project is easy to understand.
- I make sure that participants have access to what they need to take pictures and video and to participate actively in the research project.
- I support participants and family members, staff, or friends in their respective roles.
- I am available to answer questions or provide support throughout the research process.

Individual Sessions

Working with participants to articulate ideas about a good life was different for each person. During individual sessions, I used a variety of supports to facilitate our conversations. With some participants, I relied heavily on the visual supports I had created for the study. These included remarkably simple tools such as the *Yes/No/I don't know* visual, a visual scale as well as pages of pictograms illustrating examples of life domains and rights. With others, communication was facilitated by their mother via supported typing or ASL.

Pictograms

Participants pointed to images that they found meaningful (see Figure 3 in Chapter 4). Once I asked questions about the image and by combining other AAC approaches as well as checking with supporters, I felt confident that I understood participants. I then drew simple line drawings to illustrate a sequence of actions or activities based on my understanding. I showed the sketch to the participant and asked them if we should take pictures or video. If I remained unsure, supporters confirmed whether this was indeed something the participant would include as part of their good life. Trustworthiness of the results was achieved by reviewing the content several times and asking the same questions at separate times during the research process with both the participant and checking with the supporter if needed.

The Workbook

I initially created a guidebook to provide additional details about each quality of life domain and associated CRPD article, central human capabilities, and resource identified in the network of resilience. However, during the research process, it evolved into a workbook where supporters could record ideas (see Appendix I).

Deciding What to Share with the Group

Herein, I use a narrative approach to provide illustrative stories of research process moments that serve to illustrate shared decision-making in the context of my research.

The very first decisions regarding what was important to the participants were made at home with the help of supporters and in some cases by supporters. During my first meeting with participants and supporters and before our first workshop, I requested that participants bring pictures and/or meaningful objects to help us to get to know one another other and to learn a bit about what was important to them.

Figure 1

Sharing photographs and meaningful objects during the first workshop

Following sharing meaningful objects and photographs with the group, we began working individually. I worked one-on-one with Julia. I then worked with Sheri-Lynne and Rick. To accommodate Ilyasse in terms of language, we experimented with a first separate workshop in French. We also thought a first individualized workshop would be beneficial for Ilyasse since he was not a fan of jumping into new social situations. Therefore, I worked with Ilyasse, his neighbour who also worked as a support worker and his mother during that first workshop. We sketched on the storyboard template and took notes. Philippe’s mother attended the first workshop alone to see the venue, to evaluate, based on her knowledge of her son, if she thought that he would feel comfortable attending a workshop. During this first workshop, I learned about the many ways that participants preferred to work (e.g., that Julia likes to write things down). I now describe how decisions were made in the context of exploring a good life with each participant.

Making Decisions with Philippe

I initially met with Philippe's mother once to discuss the research. I gave her a consent form to read and asked her about his schedule: when would be a good time to meet?
She talked about the fact that Philippe has many idiosyncrasies and that knowing them and accommodating them makes his life run more smoothly. I asked her if she thought that Philippe would like it if others knew about his idiosyncrasies and she responded, “oh yes!” I suggested that that might be part of Philippe's vision of a good life for himself (Journal notes).

I depended on Philippe’s mother to confirm that he would like to share information with others. Based on our previous relationship, the information that Philippe’s mother gave me to facilitate supporting him was always helpful. She knew his likes and dislikes. She also asked Philippe directly what he thought about new people supporting him and activities. Philippe was very straightforward in his answers and did not hesitate to tell his mother when he did not appreciate someone’s behaviour or a situation. Most of our direct communication happened through supported typing which Philippe only does with his mother. I asked him questions and he would type answers with his mother providing gentle support to his forearm and reading the typed answers aloud.

Figure 2

Philippe and his mother doing supported typing during an individual data collection session

Based on what he said during one of these facilitated conversations, Philippe's mother had chosen pictures and shared them with me. I assembled the images as a video vignette. Philippe then watched it and said that there were two pictures he was not happy about. I changed the pictures with ones that he had approved. While his mother played an especially vital role in facilitating the process, he clearly knew what he liked and agreed with and what he wanted people to see and what he did not. I suggested that we could add a computer-generated voice to some of Philippe's words. To help Philippe decide if he agreed with my suggestion, I created a draft video for him to watch and to provide feedback. Without seeing what it might look like in context, it would have been difficult for Philippe to decide whether he liked it or not. Had he said no, his mother could have asked him if he did not like the sound of the voice or, if he did not like having a voice at all. Faced with the latter, I would have had to present alternative choices to give him the opportunity to decide which one he preferred. In this case, he liked it and his mother said that it resembled a computer-generated voice they had used in the past.

For the second workshop, Philippe joined the group for the first twelve minutes. We watched video clips of Philippe, looked at his pictures.

I ask Philippe, “what is your talent?”

Mom takes out his writer, looks at him and repeats “What is your talent?”

He responds “I love to be home”

His mother says “Well, that’s not your talent. You want to leave now?”

“No”

His mother reads the text aloud “He says I love to be home, it’s true, it is fun at home”

I ask differently “What are you very good at?”

Philip responds “Hate when I do nothing”

His mother agrees “Yeah, you like keeping busy?”

Rick contributes to the conversation “Me like keeping busy too.”

Philippe’s mother asks him “What else do you want to say?”

He responds “Very great lunch”

“Ah, ok, that’s what I thought…”

“I want to go home” Philippe continues

His mother asks “So, were you happy to come here today?”

“yes” he replies “Real nice to meet everyone”

“Ok, let’s go, he wants to go home” his mother says looking at us.

Although Philippe did not want to spend much time with the group in a workshop setting, he was given the chance to make that decision himself. His preference to only take part in individual data collection sessions did not exclude him from participating in the study. Philippe's participation illustrates the result of a flexible research design and allowing participants to choose their level of participation, to maintain control over the parts they want to participate in and those they do not. A flexible approach avoided excluding Philippe by design.

Making Decisions with Julia

When I first met Julia and her sister at a Tim Horton's to talk about potentially taking part in the study, she was getting ready to go to one of her media arts workshops at the*Space*. I explained the study and asked Julia if she thought she might like to take part. She whispered in her sister's ear. Her sister encouraged her to speak directly to me, but Julia was not so interested in doing this. However, she was interested in participating in the study.

Julia's sister very much encouraged us to communicate directly without depending on her. After the initial visit with Julia, the first workshop and a data collection session, Julia and I were able to communicate directly without needing interpretation by her sister. During the first workshop, I learned that Julia liked to write in the little notebook I had provided for the study.

Nonetheless, her sister played a key role in facilitating her participation in the research. She helped to find pictures, to confirm my understanding of Julia, to provide contact information to film Julia doing things that she had mentioned were very important to her and occasional transportation to or from the workshop.

Our individual data collection meetings took place at the house Julia shared with her sister. During our first individual meeting, I asked Julia questions about what was important to her. I showed her pages of pictograms I had put together and categorized according to the eight life domains of participation, self-determination, material well-being, emotional well-being, physical well-being, human rights, personal development, and relationships. We examined each page carefully. When an image caught her attention, she pointed to the pictogram. I then asked her what I thought the image could mean to her and she responded in writing in a notebook I had given her for the purpose of the study. Julia pointed to an image of friends celebrating. When I asked her about it, she wrote in her notebook that she liked getting together with friends. Her sister, who overheard us, confirmed that Julia had always liked having friends over and organizing parties.

As mentioned in the previous chapter, I learned that friendship, sports, arts and travelling figure prominently for her. As we went through the pages of pictograms, her sister was busy preparing a meal but occasionally took part in the conversation:

“Julia has played lots of sports, she is very competitive, she loves to win!”

I learned from her sister that Julia was part of a rowing club for people with disabilities. I asked Julia if it would be a good place to start collecting images. She agreed and her sister provided me with the contact name and information of the Rowing Club to set up a date.

During the second workshop, we watched everyone’s pictures and video clips. As I played the video footage of Julia and her sister rowing in a dragon boat, I looked at Julia and said “So here Julia, I’m hoping I’ll be able to record you talking a little bit about paddling with your sister. So, we’ll see. And Krysia [her sister] said you love competing and winning!” (Video notes from 2nd Workshop).

Figure 3

Watching and discussing vignettes

During a second meeting at Julia's, her sister shared pictures she found in family albums of parties they have hosted over the years. When I showed them to Julia, she frowned and did not appear to be interested in including these in her video vignette.

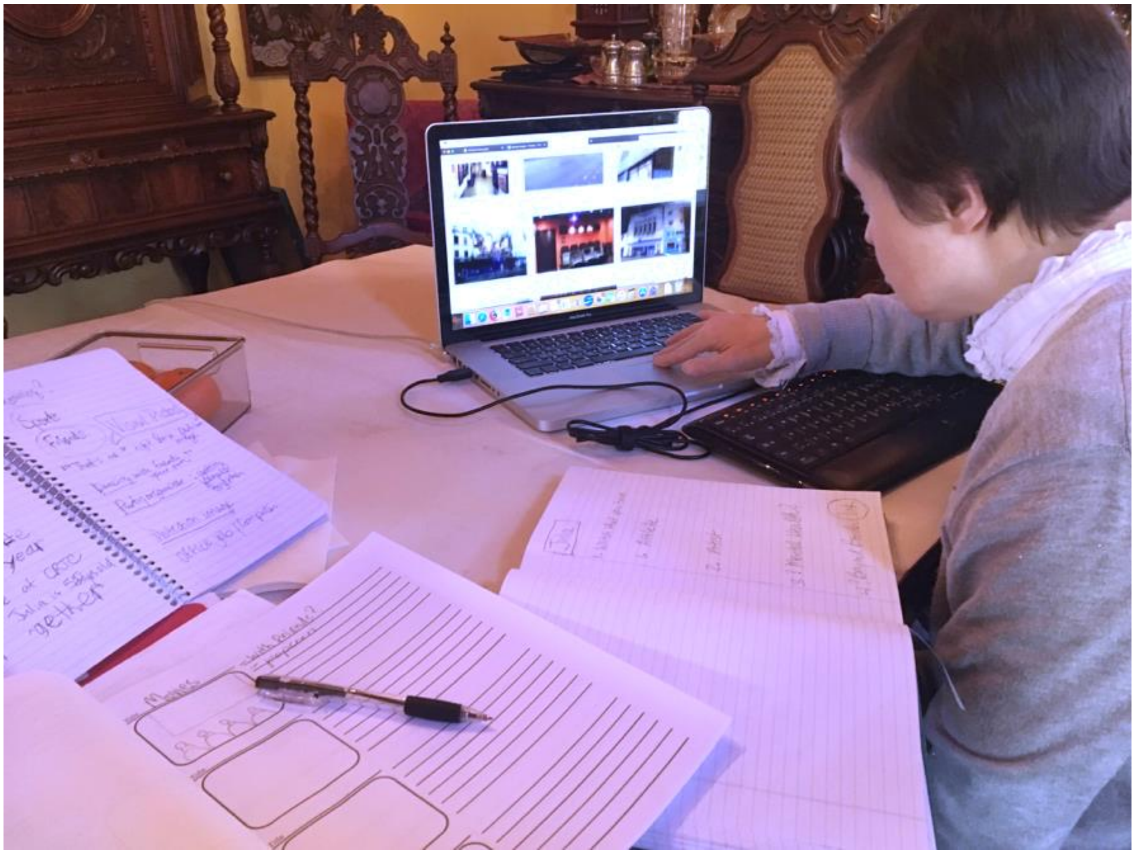
"So, you don't want us to use these pictures?"

"No, was a long time ago" Julia whispered.

In the picture below, Julia is exerting her preference. She is looking for public domain images to use to illustrate this element of what she considers part of a good life. The researcher and filmmaker in me preferred the pictures found by Julia's sister but I refrained from mentioning this to Julia and instead helped her to search for public domain images that she would like.

Figure 4

Julia looks for images about celebrating



Julia was clear about what she wanted to show and what she did not want to show in her video clips. The pictograms were especially useful in sparking initial discussions and for making plans about what should be included. When Julia disagreed with a suggestion made by me or her sister, she communicated with a frown or whispered a few words.

It was interesting to see the differences of opinion concerning what her sister thought she would like to include and what Julia herself wanted to include in her video vignettes about a good life. Her sister wanted to show Julia's past life experiences since she was proud of these accomplishments and had been key to her good life in the past. Julia however saw the past as, well, the past. It was over and she had no interest in including it as part of her current vision of a good life.

At the time of our sessions, art was very important to Julia, and we agreed that documenting her practicing her art would be a good idea. After filming Julia at her media art workshop, I spoke with her media arts teacher who informed me that Julia had written short pieces for the newsletter. I asked him to describe their writing process, and this is what he wrote:

> I've known Julia for just over a year through her involvement at the*Space*. When introduced, her sister had mentioned she was an accomplished painter and enjoyed writing and I have since come to know a lot about her. Though each project and workshop typically introduce new elements or steps, our communication and process has stayed the same.
>
> When doing work that is more story driven, such as writing dialogue or an article for the paper, I will prepare questionnaires and frame questions on paper for her to fill out in pencil as she seems most comfortable adding details than if typed on a keyboard. I will then consult her on her answers and point to areas where more detail can be added. When writing longer pieces, I will often suggest two or three words and she will type the one she wishes to use. When reading out loud and making edits I will ask her if changing this would be okay and will only proceed if given a smile and a nod of agreement
> (Rian Alston).

Since Julia had written about so many of the elements that she had identified as important to her, I asked both Julia and Ryan if parts of the writing could be included in her vignettes and they agreed. During one of our individual sessions, I discovered that when prompted, Julia enjoyed reading aloud for the video camera. Hearing Julia’s voice narrating her video vignettes came as a wonderful surprise to her sister and me.

Making Decisions with Maggie

Figure 5

An individual data collection session at Maggie's

During one of our individual meetings, I sat with Maggie, her mother, and her primary support worker. Using their knowledge of Maggie and the pictogram sheets I prepared, they asked her questions. I took notes. I also drew the ideas on the storyboard template as a visual to help plan the next steps. Based on these notes, Maggie’s mother chose to do most of the video recording herself. She had wanted to video record some of Maggie’s life for some time and she saw the study as a good opportunity to get started. Based on the notes we took, her mother video recorded events and found pictures that illustrated Maggie's priorities for a good life. Once I received the material from her mother, I edited it into short vignettes. I would then go back to Maggie's house to show her the result as we watched the video vignettes on her tablet, Maggie responded with a big smile.

During a subsequent workshop at the*Space*, we watched Maggie's video vignettes with the group. I read the subtitles aloud for Maggie's mother and looked to her for feedback, "So that's [the video vignettes] based on our conversations."

"Yeah" Maggie's mother responds.

Philippe's mother reads the subtitle "My mom is filming me"

Maggie's mother comments on the video vignette of Maggie at her day program "She stops! You can't talk and hold the camera at the same time!"

I say "Yeah, 'cause you have to sign!"

Maggie's mother responds "Yeah, I am trying to sign" Then comments "She's thinking 'what are you doing mother?'"

"I turned down the sound [in Maggie's video vignettes] because that's what Maggie hears. I'm curious to know what everybody thinks"

Philippe's mother "Yeah, that's how she communicates"

Rick asks looking at Maggie's vignette of the day program "Is this her work?"

"This is Day program" Maggie's mom answers.

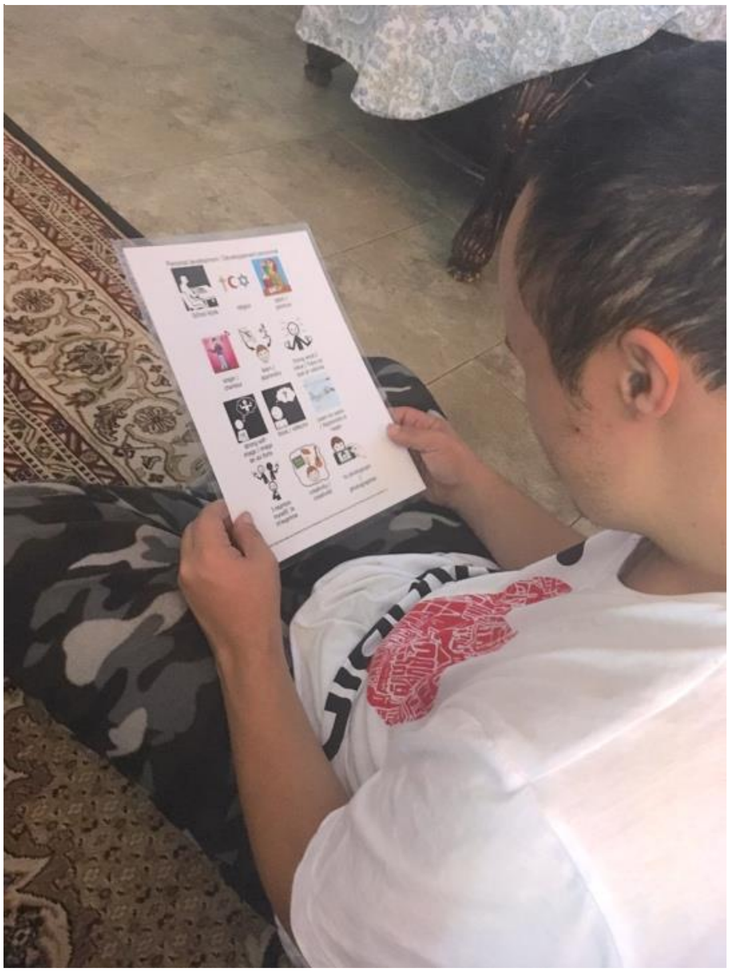
Rick repeats "Day program. What Day program her go?"

Maggie’s mother responds “CAFA” and continues to comment the video “She [Maggie] won’t go in, ‘What are you doing mom?’ her mother says aloud as she interprets Maggie’s posture and look. Body language, all body language, this is Deaf culture, stop, look.”

To illustrate Maggie’s capacity to choose and to identify those she trusts, her mother shared an example about the process of obtaining a power of attorney. Decision-making with Maggie, as her mother explains, is built on the notion of trust - and is based on her family doctor's knowledge of Maggie but also of her relationship with her mother, her father, and sisters: “As a non-verbal person, it was important for us to get an ‘independent’ assessment from her [Maggie’s doctor . . . as assessment that our lawyer, who was a disability law expert, relied on to accept Maggie's signature [for a power of attorney] as coming from a competent individual who could indicate who she trusted to help her make decisions, or to step in when she could not make those decisions.” Maggie’s family doctors willingness to recognize her ability to identify those she trusts, allowed her to formally name her family members as those she trusts to act as her attorneys if and when needed.

Figure 6

I share pictogram sheets with Ilyasse to spark discussion



Making Decisions with Ilyasse

During our first meeting in their home, I spent some time talking with Ilyasse’s mother in the living room. As I explain the study, she tells me that Ilyasse loves to watch videos on Youtube.com and to take pictures and video with his cellphone. She invites Ilyasse to join us. He smiles but appears to be very shy. It is difficult for me to tell what Ilyasse can and cannot understand but his mother reassures me that he does understand everything, he just does not like talk very much, she says. I explain to Ilyasse that I would like to know what is important to him and would he like to take pictures of people, places, things, and situations that help to make his life good. I use my *Yes/No/I Don’t Know* visual to help Ilyasse communicate whether he would like to try it out. Using body language (e.g., thumbs down and a frown to signify not being happy), I reassure them both that Ilyasse can end his participation in the study at any time. Throughout our conversation, he is smiling and when I ask him if he would like to participate, he whispers yes and points to the big green thumbs up/oui.

During the individual meetings, Ilyasse’s mother encouraged Ilyasse to speak but he rarely did. She explained that he does speak to her when they are alone but generally does not speak to anyone else. He sometimes whispered to his mother but rarely spoke to me directly. Hoping that Ilyasse might communicate more directly with me, his mother sometimes went to the kitchen leaving us in the living room to chat on our own. With the help of pictograms and searching for images on the internet, we were able to communicate. Occasionally, he whispered a word or two, but we mostly communicated using gestures and pointing to objects and images, including the pictogram sheets I had prepared for the study. It was important that I pay attention to his body language and facial expressions as well as check in with his mother if I was unsure about my interpretation. Through conversations with his mother, by pointing to pictograms, and through conversations with the neighbor who introduced me to Ilyasse and his mother, he made it clear that people are the most important in his life. Spending time with friends and family was what he enjoyed and wanted most. However, it was difficult for his neighbour to coordinate times to assist him to take pictures with the people he cared about. After various failed attempts over the course of a few months, I met with Ilyasse in his home to suggest that we search for images on the Internet to express his desire to stay connected with friends and family. We sat in the living room with my laptop, I searched for public domain images of friends and showed them to Ilyasse. I saved the images that he liked.

To create the video vignette about friends and family, I suggested to Ilyasse that he 'talk into the video camera' to tell us who he cares about, who he loves explaining that I would put his words and the images together. As he mentioned someone, I repeated the name to confirm that I had understood properly and then I would add including the previous name "Alain, et qui d'autre? Hmmm…qui d'autre?" (Alain, and who else? Hmmm...who else?)

Making Decisions with Rick

As Rick and I chatted over a pizza lunch (Rick’s favourite), I took notes using a storyboard template (see Figure 7). Pointing to my sketches and repeating what Rick says in my own words, I checked to make sure that I understood what he told me. When I was unsure, I repeated what I thought I had heard. If my guess was wrong, I asked Rick to repeat. If I remained unsure, I verified with Sheri-Lynne, his support worker and she was generally able to confirm or to clarify. Another support worker hired with Rick’s individualized funding observed: “I often tell Rick how patient he is with me.” I agreed with her, Rick was very generous and willing to patiently repeat to help us understand. Rick loved to talk and share stories about what was happening in his life and his plans for the future. Although close staff and friends generally understood him, as a newcomer, I sometimes needed assistance.

Rick wanted to keep the messaging in his video vignette positive, so he decided to refrain from saying that he would move out if he could not have his cat with him. After some consideration, he felt that it would be better to simply let people know how much he cared about Peaches. The advocate in me thought it would send a stronger message to say that he would move out if Peaches could not stay with him but Rick preferred a more diplomatic approach. His final video vignette *My cat Peaches* reflects his decision to focus on the positive. Accommodating Rick’s communication style involved mostly repeating what I thought I had understood to give him an opportunity to correct me when I was wrong.

Figure 7

Using a storyboard template to make decisions with Rick

Title Rick Prophet

Scene ______

I am happy in my appartment

" If I couldn't have my cat I would move away."

If I had more money, I would go to California

Making silk scarves + ties

My tricycle!

Having my own money

Choosing Which Life Domain Connects Most with Each Video Vignette

Figure 8

Assigning video vignettes to QoL domains

During the fourth workshop, I asked participants if they would like to meet one last time as a group. We met for a fifth and final workshop shortly before Christmas. To experiment with this group process of assigning all video vignettes to specific QoL domains, I decided to reproduce a tabletop version of the *Good Life Wheel* (see Figure 8). At first, we began watching each video vignette individually, but we soon realized that it was not necessary since we had watched them many times during previous workshops and individual sessions. Luckily, I had taken a screenshot of all 34 video vignettes, printed, and laminated them to look like postcards. To prompt discussion, I held up each card, briefly described the video vignette. I then gestured to the giant *Good life wheel* on the table and asked “So, where should this one go?” and pointing to each domain “Do you think it is mostly about relationships, participation, learning new things?” and so on. As I mentioned in Chapter 4, the task of deciding which life domain best corresponded to each video vignette was a challenge. However, the process was worth the experiment, and I discuss this further in the next section.

Discussion

I now present implications of the findings of this study. Both quality of life studies reviewed by Sheridan et al. (2019) included PLWID who took part in focus group discussions and individual interviews without additional cognitive or communication accommodations. Similarly, participants who took part in Correia et al.'s study (2017) were selected based on their ability to communicate verbally. This was seen by staff, who were responsible for identifying participants, as an essential requirement for successful participation. My own experience of community-based video making with PLWID also reflected the assumption that only those with verbal communication capacities can participate in video projects. Unless an explicit invitation is offered to those who do not communicate primarily using words, these potential participants are often not considered by staff or family members as suitable candidates since 'they won't be able to *say* anything.'

In contrast, the results of this study show that it is possible to learn about a good life PLWID who face significant barriers to communication when attention is paid to each participant's communication needs. It is imperative to include the perspectives of PLWID when inquiring about quality of life because their point of view "appears to be a somewhat unique—and probably critical—source of information" (Correia et al. 2017, p. 60). Importantly, differences exist between results obtained through external observation and proxy responses compared with the perspectives of PLWID via self-reports (Verdugo et al. 2011, Verdugo, Gómez, Arias, Schalock, 2010).

Citing the literature, Browning (2018) describes SDM as a process that supports autonomy, is interdependent and focused on the person. Interdependence was expressed through the study design; tools and strategies were used to facilitate participation and support cognitive processes. The design of the study was flexible to allow participants to choose when and how they wanted to take part. For example, Philippe's preference to avoid group sessions did not exclude him from the study. Instead, as an accommodation, his mother attended the group sessions, took notes and then discussed them with Philippe at home at their own convenience. More specifically, I provided 'assistive thinking' (Silvers and Francis, 2009) to support communicative access in the broader context of decision-making and participation in exploring a good life. For example, I researched and shared examples of stories told by others who communicate in a variety of non-verbal ways. To facilitate decision-making, I proposed different options, I supported communication and decision-making using approaches included in SCA^{TM} such as drawings and pictures, repeating and verifying. Based on their intimate knowledge of participants' communication style, supporters also used these strategies to facilitate participation.

Implications for Researchers

Researchers must continue to explore and experiment with various approaches to increase the participation of those with a greater need for cognitive and communication assistance. This is important because many perspectives are absent from current understandings about a good life. Taking into consideration perspectives previously excluded from research will ensure a richer understanding on this topic and many more. The creative incorporation of visual methods in all steps of the research process not only facilitates more equitable access to sharing one's knowledge through research but also helps researchers to move beyond reliance on knowledge that is shared via text and words. This study demonstrates that no additional specialized software or expensive tools are necessary to include people who face barriers to communication. Visual supports were easy to create using public domain images, a printer, and a basic laminating machine. To reduce reliance on family members as supporters in the research process, researchers may assign funds that would allow PLWID and others needing similar supports, to hire personal assistants to facilitate participation in research.

Implications for Post-Secondary Institutions

To normalise participation in research of PLWID and others who face significant barriers to communication, postsecondary institutions must ensure that methodology courses discuss approaches and tools such as presented in this study that may increase access. This will contribute to the inclusion of the perspectives of those traditionally excluded from research. Like the concept of Indigenizing education and research that value “Indigenous ways of knowing, thinking, feeling and being... [and include] Indigenous ways of teaching and learning to form and create pedagogical approaches” (Queen’s University, 2022), postsecondary institutions must centre the diverse ways of knowing, thinking, feeling and being of those labelled as having an intellectual, developmental, or cognitive disability and facing barriers to communication. By promoting ‘methodological abundance’ (Hannula et al., 2014) and flexibility minimally through its methods courses, postsecondary institutions may contribute to fostering studies that more accurately reflect the diversity of human experience.

Implications for Personal Assistants

Personal assistants can and do play a significant role in supporting service users to take part in research. In this study, Rick’s support worker played a key role in facilitating his participation. She provided transportation, coordinated meetings, supported data collection, she helped Rick to search for pictures of important people in his life, she facilitated communication and generally supported his participation in the study. Personal assistants can facilitate participation by sharing recruitment material with those they support and suggesting to support them to take part in the study.

Implications for Policymakers

Access to individualized assistance for PLWID to take part in all spheres of life, including research, is essential. Artificial caps on individualized funding programs such as Passport must be reviewed to reflect the real support needs of PLWID. Furthermore, individualized funding programs should not exclude those who require assistance with managing funds (e.g., Direct Funding) nor should they be designed based on assumptions that family members will be capable and available to manage them (e.g., Passport). PLWID and others who face similar barriers, must have their unique cognitive and communicative abilities and styles accommodated.

Conclusion

In conclusion, this study allowed me to explore, document and analyze conditions in which PLWID made decisions in the context of a participatory research study using visual methods. My research supports the results of previous studies that show that PLWID can and do make meaningful decisions for themselves (Bonham et al., 2004) despite what family members and support workers initially thought about participants' abilities. For those who require more extensive direct support, the results of this study suggest that creative approaches facilitate both understanding and communication thus questioning the practice of relying exclusively on responses by proxies such as parents, siblings, support workers and others closest to the person. More broadly, this study problematizes the narrow conceptualizations of cognitive and adaptive functioning as defined in Ontario's *Social Inclusion Act, 2008*. Cognitive processes and participation are seen to be deeply relational. Facilitating a good life and greater justice for PLWID includes recognition of widely diverse ways of arriving at ideas of the good.

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Chapter 6 – Overall Discussion

> “We are not actually talking about tinkering around at the edges of society to let people in. For disabled people to play a full part in…society, this society will have to change fundamentally” (Michael Oliver in Taylor, 2004).

This research points to some of the changes in policy, research, and supports that have occurred in Ontario, but also fundamental changes that have yet to happen. To this end, my main research objective was to gain a better understanding of a good life from the perspectives of PLWID, to learn from past advocacy events and to generate knowledge about the conditions that make it possible for PLWID to articulate their vision. My research was situated within the sociohistorical context of the province of Ontario. To address the overarching objective of my dissertation, I drew from multiple sources, including historical news articles, legal documents, audio/visual data, my research notes, the perspectives of PLWID, parents, a sibling, a support worker, and a friend. Together, my research findings present a rich picture of the research problem and provide insight into a good life from the perspectives of PLWID who face barriers to communication. They also point to various pathways to support autonomy and decision-making, something I explore in greater detail in this chapter.

In this chapter, I summarize the findings of my research, I evaluate the findings using criteria from creative analytical practice ethnography (CAP). Next, I discuss the results describing in greater detail ways forward for supporting the autonomy of PLWID and enabling opportunities for contribution and relationships. I then use the idea of a spectrum to share my recommendations for implementing fundamental social changes that I believe would reduce barriers to a good life and contribute to greater social justice for PLWID.

Potential Contribution of this Research

It is my hope that this dissertation may assist researchers and supporters gain a better understanding of a good life from the perspectives of PLWID, the use of AAC and supported decision-making approaches in research, as well as some of the possibilities of audio/visual methods for engaging with people who face barriers to cognition and communication. It is also my hope that this research supports and adds to the many calls for recognition and respect of alternative ways of processing information, making decisions and articulating one’s ideas. Following Boxall and Ralph (2011), I believe that “Creative approaches to involvement in research [may] also have wider application in relation to advocacy, an area from which people with profound and multiple learning disabilities have so far largely been excluded” (p. 178). An important undercurrent to this dissertation is my understanding of autonomy and individuality as both radically specific and inescapably relational. By providing an opportunity for participants to share their views on a good life, a platform for stories of advocacy events in Ontario and an exploration of decision-making in the context of participatory research, I hope my work reduces a knowledge deficit caused by the exclusion of PLWID. Instead of disbelief or skepticism towards uncommon ways of thinking and communicating, I encourage an attitude of curiosity and humility to learn more from those seldom heard. Our collective ability to understand the world and to learn how to live good lives together depends on it.

My research also suggests that we need innovation in rehabilitation and health professions and a move away from biomedical understandings of intellectual disability. Favoring egalitarian relationships and new understandings of disability and ability is supported by critical scholars in rehabilitation working across disciplines (Gibson, 2005, Turcotte & Holmes, 2021). Increasingly, researchers recognize the urgency to work in collaboration with those who suffer and resist the consequences of exclusionary conceptions and practices (Turcotte & Holmes, 2021). This includes embracing expansive understandings that acknowledge many correct ways to practice autonomy and diverse ways to think about and articulate one's idea of the good (Silvers and Francis, 2009).

Summary of Dissertation Findings

In Chapter 1, I presented the theoretical perspectives that underpinned and informed my dissertation. I adopted a relational and radical individualist perspective as my overall theoretical standpoint and described how it informed my ontological understanding of the nature of being as radically specific and simultaneously intricately socially embedded. This standpoint also informed the way I understand the human way of knowing. From a relational and radically individualist standpoint and agreeing with Silvers and Francis (2009), there are multiple ways of knowing, and more specifically in the context of this study, of thinking and arriving at ideas about a good life.

My literature review demonstrated that researchers, self-advocates, families, and legal frameworks recognize similar elements necessary for a good life. Essential elements include autonomy, participation, contribution, relationships, self-development, emotional, physical, and material well-being, and rights. In this dissertation, I paid particular attention to three elements of a good life: autonomy, contribution, and relationships. To situate my study in the province of Ontario, I briefly presented the state-funded system of supports and services designed for PLWID and a critique of the *Social Inclusion Act, 2008* that governs them. In Chapter 2, I detailed the methodological approaches adopted to conduct the three studies in this dissertation by articles.

To answer my specific research question “What can we learn from past advocacy efforts?” I presented in Chapter 3, six tableaux recounting stories of intellectual disability advocacy in Ontario. The objective was to document and to analyze intellectual disability advocacy in Ontario. Remembering advocacy actions of the past contributes to understanding the common threads that underly advocacy efforts throughout the years. By looking back, we learn that PLWID have fought for the right to make their own decisions and the supports required to do so. The tableaux revealed that the exercise of autonomy is deeply dependent upon the support received by the person. For example, Justin Clark’s story illustrates how, even in an environment where he experienced extreme environmental coercion, his relationships with staff who became friends, an opportunity to learn Blissymbolics, the support of lawyers from the ARCH disability law clinic enabled him to exercise his autonomy and free himself from the Rideau Regional Centre. The People First self-advocacy movement fought for independence from parent-led movements such as the Community Living movement which initiated the fight for supports and services based in one’s community. The tableau about the *Advocacy Act,1992*, briefly recounts Ontario’s short-lived but trailblazing non-legal advocacy system. The Act and the Advocacy Commission was the result of years of collaboration among organizations of persons with disabilities and older adults across the province to demand individual advocacy services for citizens who required supports due to cognitive and communication barriers. We also saw how advocates in intellectual disability led the battle for the extension of the right to legal capacity and supports for decision-making to all citizens regardless of mental capacity.

During the process of MCCSS’s transformation of supports and services for PLWID, policymakers consulted with families and, with PLWID at the request of families through the structure of a provincial Partnership Table. However, the changes made to developmental services and supports failed to reflect their priorities and aspirations. The Transformation process did not change the on-going structural problem of inadequate funding and interminable waitlists (Auditor General, 2014, Ombudsman, 2016) nor did it translate into fostering practices that enable a good life.

To answer my specific research question “What is a good life from the perspectives of PLWID who use various forms of augmentative and alternative forms of communication (AAC), I collaborated with five participants and their supporters from the Ottawa area. I was informed by social model approach to disability and by the *Convention on the Rights of Persons with Disabilities (CRPD)*. My methodology was informed by Walmsley and Johnson’s (2003) inclusive research methods with people with intellectual disabilities. Participants were diverse in terms of mother tongue, as well as their use of alternative and augmentative strategies for communication. To present the results, I wrote short narratives to introduce each participant. I then embedded five collaboratively created video vignettes that visually communicates one of their priorities regarding a good life.

Participants’ video vignettes show that participation (14 vignettes) and relationships (11 vignettes) are most important to a good life. In other words, part of a good life for participants was doing activities they enjoyed with friends and family. For example, Julia talked about travelling and doing gymnastics with her best friend, Philippe swimming and cycling with his father, Rick spending time with his girlfriend, cat, and support worker, Ilyasse dancing and playing basketball with his friend Gaël, and Maggie baking cookies with Jay and going out with her roommates. Some video vignettes focused primarily on relationships such as Philippe’s *People who are important to me* or Rick’s *My girlfriend Wendy*. Other vignettes related to participation such as Ilyasse’s *Je suis un athlete* and Julia’s vignette about gymnastics, and

Rick’s new bike. Still others related to opportunities for personal development (5 vignettes) like Rick’s *I am an artist* (5 vignettes) or self-determination like Maggie’s *Communicating with me* (3 vignettes). Regardless, all 34 vignettes short of Julia’s vignette *My favourite show,* featured important relational elements. The relational aspects are visible, for example, Julia’s friendship with Suzanne, her teammates and her sister, Rick’s support worker cycling with him, Philippe’s parents swimming with him, Maggie, and her friend Jay baking together and Ilyasse’s friendship with Gaël and the others at the day program). The video vignettes suggest that there is an important relationship between opportunities for participation (CRPD Article 30 - Participation in cultural life, recreation, leisure, and sport), self-development (CRPD Article 24 – Education) and self-determination (CRPD Article 3 - General Principles, e.g., Respect for inherent dignity, individual autonomy) and relationships. In the vignettes, relationships are seen to support and facilitate participation and to contribute to the enjoyment activities such as visual and culinary arts, dance, recreational and competitive sport. Thus, relationships can facilitate participation in activities that are meaningful to participants and, render these activities more engaging and fun. The value of participation is recognized in the CRPD and, in an albeit limited way in, Ontario’s *Social Inclusion Act, 2008.* The unspoken omnipresence of the role of relationships in all life domains and articles of the CRPD, needs to be made explicit.

To address my research question “What are the possibilities and limitations offered by participatory audio/visual methods for enabling PLWID to articulate their vision of a good life?”, I described and discussed decision-making moments that took place during the study including the types of material supports and strategies used to facilitate participation in the exploration of a good life. The findings reveal that participatory audio/visual methods used in combination with strategies that drawn from supported decision-making, Supported Conversation for Adults With

Aphasia (SCA™), AAC approaches play a key role in facilitating participation in the research process. By drawing from and adapting these approaches to accommodate the communication and cognitive style of each participant, they were able to share their ideas. In other words, I did not use one method to facilitate participation and support decision-making throughout the research process. Rather, I combined many approaches, tools, and strategies to accommodate each participant.

Based on this research experience, helping with decision-making involves conducting specific tasks such as planning, establishing priorities and a schedule, helping with reflection, imagination, focus and implementation. For example, I assisted participants in thinking about a good life by showing the *Good Life Wheel*, explaining each of the eight life domains with concrete examples supported by the pictogram sheets. The pictograms were not exhaustive, but they provided a useful starting point for thinking about what was important for a good life.

Supporting decision-making also involved using a variety of strategies such as asking questions with words or non-verbal cues, taking visual notes, making suggestions, and presenting concrete examples to participants as options. It was also important to observe facial expressions such as smiles and frowns, body language, tone, and pitch of voice to increase my ability to understand participants. It was also important to check my understanding with supporters.

Many skills are required to facilitate and support communication and articulation including listening skills, focused attention, and creative problem-solving skills to find ways to generate ideas and find solutions unique to each participant. Further, communication skills such as explaining ideas in clear and simple terms was essential and so was the ability to interact with supporters according to their preference (e.g., in person, audio call, email, text) since their assistance was key to ensuring meaningful participation. Supporters played a variety of roles including providing transportation to and from workshops, communicating via telephone, email and in person with me to organize meetings and data collection sessions, some searched family photographic archives for images that reflected elements of a good life mentioned by participants, some took part in data collection by recording video and taking pictures of events, people and places important to participants, all facilitated communication between participants and me.

In line with the results of the first study which revealed that personal assistance should be free of conflict of interest, it was important to ensure that the participant was our only source of inspiration (as Silvers and Francis would put it) when assisting them with thinking about a good life. For example, Philippe's mother took the time to watch video vignette drafts with him and to listen to his critiques. She then shared his feedback with me via email, including direct quotes from their conversation. I made changes based on that feedback. Respecting Julia's choice to exclude pictures of past life experiences perhaps led to visual results that were less compelling since we used images from the Internet. Although the images her sister had selected would have been more visually compelling since they told a story about Julia's marriage and her travels with her husband, it would not have reflected her wish to focus on more current relationships and activities.

This last study allowed me to pay attention to relational elements that support autonomy and decision-making but remain outside the frame of the video vignettes. These "invisible" supports include proposing the activities, accessing, organizing transportation, and facilitating the activity. This logistical support was necessary for participants to meaningfully take part in the study and the activities they valued as part of a good life. Examples of MacKenzie's (2014) 'social scaffolding' such as accessible public transportation, personal assistance, individualized funding, and income security also impacted participants opportunities to take part in the research and activities.

Overall, the results of this study reveal that when assistance was adapted to the individual, participants could and did make many decisions and thus could participate meaningfully in the research process. The belief that the only correct way to make decisions is to do it independently of others does not reflect reality and worse, it excludes and discriminates against those who cannot hide their need for assistance. By denying the relational nature of reasoning and decision-making, it positions PLWID and others with cognitive and communication impairments as unfortunate exceptions that can be excluded from discussions about the good (Silvers & Francis, 2009). In summary, the results of my dissertation research contribute to a better understanding of the perspectives of PLWID on a good life and the conditions that make it possible for them to participate in knowledge production.

Evaluating the Research Results Using Creative Analytical Practice Ethnography

In this section, I use Richardson's (2000) criteria to discuss the value of my studies. Concepts such as reliability and validity do not translate easily to arts-based methodologies such as narrative approaches and audio/visual methods and for this reason, I refer to her evaluative questions. The goal of my research was not to measure a good life nor to provide step-by-step instructions for the conditions for meaningful participation. Instead, my goal was to gain a better understanding of good life from the perspective of the research participants. I also aimed to learn about PLWID's contributions to the development of Ontario policies and the various conditions that facilitated participation and the practice of decision-making more specifically in the context of the participatory exploration of a good life. Given my research goals, qualitative criteria for evaluating research are relevant. The following criteria were developed by Richardson (2000, p.

16) to evaluate what she describes as Creative Analytical Practice Ethnography or CAP ethnography for short. I now discuss my findings in light of her criteria.

Substantive Contribution. Does this piece contribute to our understanding of social life?

The results of this dissertation contributes to our understanding of the priorities of PLWID and the struggles in which they and their supporters have engaged to create conditions for a good life. The results also contribute to our understanding of autonomy, decision-making and participation as relational processes that are radically specific to each individual.

Aesthetic Merit. Does this piece succeed aesthetically? Is the audio/visual piece artistically shaped, satisfying, complex, and not boring?

Although process was prioritized over the end product, I made efforts to present the results of our exploration of a good life in an engaging way. The decision to create short vignettes was motivated by my desire to focus attention on each idea expressed by participants via video vignettes. Furthermore, I added music, text, and paid attention to the order of images and video clips in an effort to make the vignettes engaging for viewers.

Reflexivity. How did the author come to produce this piece? How was the information gathered? Are there ethical issues? How has the author's subjectivity been both a producer and a product of this piece? Is there adequate self-awareness and self-exposure for the audience to make judgments about the point of view?

It was important for me to situate myself as a family member and as someone who continues to be involved in advocacy efforts. Throughout my dissertation, I included excerpts of my journal and described, when needed, prior relationships with participants and supporters. The production of these video vignettes with each participant is the result of multiple iterations of discussing, choosing, viewing, making adjustments. Participants and their supporters had many opportunities to express their opinions about each video vignette. I think that the overall design of the studies including my choice of methodologies, my position as sibling and advocate allow readers and audiences to analyze and judge the results in light of who I am and my point of view.

Impactfulness. Does this affect me emotionally and-or intellectually? Does it generate new questions, move me to write, move me to try new research practices, or move me to action?

My hope is that the results of this study will move other researchers to use participatory visual methods and incorporate various supported decision-making strategies into their research design to learn from PLWID and others who face significant barriers to cognition and communication. It is also my hope that the video vignettes, the Exploring a good life workbook and the visual supports created for the research can inspire researchers and agency staff to explore creative ways to collaborate with PLWID and others who face significant barriers to cognition and communication.

Expresses a Reality. Does this audio/visual work embody a fleshed-out sense of lived experience? Does it seem true—a credible account of a cultural, social, individual, or communal sense of the real?

The six tableaux, particularly the last tableau that included the results of the focus group provide a glimpse into the experience of mothers who have spent considerable time and energy in advising service providers and MCCSS. Their discussion revealed the disappoint they felt as they realized that their contributions had not been incorporated into the transformation of supports and services for their sons and daughters. The video vignettes provide embodied accounts of each participant’s perspective on a good life at a particular time in their lives. The vignettes allow the audience to see facial expressions of concentration, pleasure, and determination. They also allow us to see participants in interacting and communicating with others. Although the video vignettes cannot possibly express everything that is essential to their good lives, participants and supporters had multiple opportunities to select, discuss, question, view and request changes to each video vignette thus providing a credible account of their ideas of the good. The results of Chapter 5 regarding decision-making in the context of participatory research present credible accounts of the various strategies and tools used throughout the exploration of a good life to support participation and decision-making. Images support the narrative accounts of decision-making moments and refer to journal notes as well as to video documentation of all workshops and photo documentation of selective individual data collection sessions.

With respect to my research, it contributes to understandings of social life in that the importance of relationships is conveyed, both for PLWID within their everyday lives, but also within the context of research. My research also revealed possibilities for using participatory audio/visual methods to support articulation and self-representation. In my research, I worked to respond to participants as individuals. There was no one prescribed process for data collection. Rather, I tried to respond to each person’s situation and priorities to include what the participants wanted as opposed to what I thought would make for more visually interesting vignettes.

To conclude this section of the chapter, the CAP principles provide a useful framework for evaluating qualitative research such as this one. I believe my work and my approaches to data collection and analysis are congruent with the CAP principles and that my research may therefore be evaluated favourably. Having summarized my three studies and provided an evaluation of my research, I turn now to an in-depth discussion of the findings.

Discussion of the Results

I now discuss the findings on a good life and its characteristics for researchers, PLWID, families, support workers, service providers, researchers and policymakers. To begin, I present the methodological implications, I then make recommendations at different levels of intervention, I follow with ideas for future research and conclude with some final thoughts.

The first study recounting stories of intellectual disability advocacy in Ontario, reveals the desire of PLWID for autonomy and the right to make one's own decisions. It provides a unique view of the efforts and contributions made by PLWID and their allies to shaping supports and services and the on-going struggles and debates regarding decision-making in Ontario. Although it has long been recognized and agreed upon by various levels of government (e.g., Welch, 1973, Smith, 1981 and Government of Canada, 1998) that people with disabilities are best suited to decide on the kinds of supports and services they need and how they should be delivered, these stories also reveal recurring resistance on behalf of governments to working in partnership with PLWID and family members. Recognition that people with disabilities are best suited to guide the design of supports and services they need has been insufficient. Current structures and practices continue to exclude PLWID from taking part in designing supports and services. Experimentation with structural changes that enable their active and meaningful participation is urgently needed. The results of the second study demonstrate that when creative attempts to accommodate the cognitive and communication styles of PLWID are made, participants convey that a good life is about participation and relationships. The results of the third study suggest that the need for greater recognition and implementation of strategies, tools and approaches that support communication, autonomy, participation and decision-making are needed to enable PLWID to create their own unique life paths. The study also points to the need to discuss and clarify the meaning of terms present in the *Social Inclusion Act, 2008* such as ‘individual choice,’ ‘independence,’ ‘well-being’ and ‘rights’ in light of a radically individual and relational perspective. A liberal conceptualization of independence has not contributed to a good life for those whose support needs are visible and has instead increased vulnerability. The push for independence and independent living is a frightening prospect when independence is understood as doing things alone. Autonomy as something that is practiced in a web of relationships is quite different.

Methodological Implications

Any project or initiative aiming to collaboratively address inequality in partnership with those at a disadvantage, should consider the place of creative approaches such as audio/visual methods, supported decision-making and AAC as used in this study. By embracing a notion of ‘methodological abundance’ (Hannula et al., 2014, p. 22), as I endeavoured to in these studies, researchers remain open to experimentation and to choosing methods that allow the greatest level of individualization and participation of the people involved. Direct and sustained participation by PLWID in research expands our understanding of disability, of a good life and radically inclusive practices. Individualized supports must be accessible to people with disabilities to facilitate autonomy, direct and meaningful participation “where the people who were the object of intervention become the subject of action, experimenting with who they might be and how they might live” (May, 2008, p. 30). Experiences of disability are as varied as there are humans, moments, and places on this earth and without the active participation of this immensely diverse population, a good life will remain an elusive dream for far too many. Theorization must be a collective project based on an a priori assumption that multiple ways of knowing and being in the world are necessary for tackling the challenge of learning to live well together. Not only must everyone be invited to the table but also equitably involved in choosing and setting the table.

In this study, audio/visual methods were used in different modalities. Video was used to record the focus group session and the workshops (an extractive modality) and to involve participants in the research process (a participation modality). Importantly, audio/visual methods were used in modalities of participation “using video to engage participants in a research project in ways that allow them to shape its focus and outcomes” and articulation “using video to help participants voice their opinions and communicate these to others” (Haw & Hadfield, 2011, p. 2). To support participation, the creation of an illustration of the quality of life framework and the potential contents of the eight domains of life represented a novel and accessible way to present a theoretical framework. This approach can be used by researchers to present other theoretical frameworks and abstract content in more accessible. The creation of the *Exploring my good life workbook* also represented a concrete approach to support thinking about a good life with participants. Finally, re-creating a giant tabletop version of the *Good life wheel* and printing screenshots of each video vignette facilitated the discussion about the relationship between vignettes and the QoL domains. The use of a large visual support also facilitated the beginning of the focus group discussion with the mothers. In that first study, I had created a timeline of advocacy events. Using green painter’s tape to create a horizontal line on the wall, I situated each advocacy event along the timeline and represented it by a title, a date and an image. While such visual supports were necessary to facilitate participation in connecting vignettes with QoL domains, they were also helpful when discussing advocacy events of the past with the mothers.

In Chapter 5, I showed that each participant’s unique life situation, communication style, and personality required that I adopt a tailored approach to engaging and supporting participation. Methodological flexibility and willingness to adjust one's approach to the situation is key to creating conditions for meaningful participation in research. The video vignettes show the different communication styles of Maggie, Philippe, Julia, Ilyasse and Rick. The rich multimodal nature of the vignettes provides glimpses into embodied data. Thus, the communicative abilities, talents, voices, movements, smiles and gestures of participants become visible. Audio/visual methods allow research participants to appear as unique individuals. They also facilitate sharing research results in ways that are more accessible and engaging to those directly involved in the study and to those potentially interested in the results.

Recommendations

Based on my research findings and my review of relevant literature I make suggestions to increase opportunities for exercising autonomy, participation and contribution and relationships. I hope that my recommendations will be helpful to researchers, PLWID, family members, support workers and policymakers. As Respecting Rights self-advocates have recently implored it is "Time for Change" (2021). It is time to listen and to experiment with ways of working collaboratively to create conditions that support good lives for PLWID and others who require cognitive and communication assistance.

The results of this research direct attention to the need for methodological innovation, individualized cognitive and communication assistance and systemic change. Having discussed methodological implications of my research, I now discuss ways forward for PLWID individually and systemically. PLWID are lucky if they have family members who have the time and skills required to manage individualized funding since no independent supports are made available to them by the province to assist them with tasks made difficult due to cognitive and communication barriers. As a country, Canada has formally affirmed its commitment to bring its laws up to CRPD standards. Ontario's *Social Inclusion Act, 2008* requires radical changes to reflect the spirit of the Convention, the results of this study and others.

In the table below, I present a spectrum of supporting a good life and propose strategies at different levels of intervention. Minimally, supporting a good life is about preventing harmful social arrangements and ideally, it is about creating conditions for all citizens to thrive. This table summarizes some of the implications and possibilities for support, education, advocacy, and policy that are aligned with my research findings.

Table 1

Spectrum of preventing harm[23] or even better, facilitating a good life

Level of Spectrum	Description of Level	Inspiration
Level 1 Provide individualized supports for decision-making, self-advocacy, and meaningful participation.	PLWID and their families have access to independent facilitators or assistants on a long-term basis to practice decision-making and to facilitate relationships and participation.	CRPD Article 19, access to personal assistance, Article 12, access to the support they need to make their own decisions.
Level 2 Raising Awareness	Provincial and municipal governments collaborate with PLWID to choose best strategies design and deliver awareness campaigns regarding cognitive and communication diversity. *Individualized supports are made available to PLWID to facilitate meaningful contribution in discussions.	CRPD Article 8: awareness raising

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[23] The idea of a spectrum was modeled on Cohen's Spectrum of prevention (Cohen & Swift, 1999).

Level 3 Educating Service Providers	Local service providers in partnership with PLWID and families develop staff training programs based on province-wide standards. The Ontario Ministry of Training, Colleges and Universities works collaboratively with PLWID and trusted allies as primary stakeholders to develop and amend the Developmental Services Worker Program Standard and Personal Support Worker delivered by community colleges across Ontario. *Individualized supports are made available to PLWID to facilitate meaningful contribution in discussions.	CRPD Article 3: General principles
Level 4 Supporting Coalitions and Networks of self-advocacy and family advocacy	PLWID and families have sufficient funding and support to gather, to learn from one another and to generate ideas that enable a good life. Advocacy groups exist in all 9 regions. Wider networks connect these groups. *Individualized supports are made available to PLWID to facilitate meaningful contribution in discussions.	Article 29: participation in political life ((ii) Forming and joining organizations of persons with disabilities to represent persons with disabilities at international, national, regional and local levels.)
Level 5 Provincial policy development and law reform	PLWID and family members actively and meaningfully take part in policy and law reform to ensure that they reflect the priorities PLWID and their families, including those with the greatest need for assistance. *Individualized supports are made available to PLWID to facilitate meaningful contribution in discussions.	CRPD Preamble (o) Considering that persons with disabilities should have the opportunity to be actively involved in decision-making processes about policies and programmes, including those directly concerning them.

Regardless of the level of intervention, access to individualized assistance by PLWID is inescapable. Without access to tailored supports, only those with the least support needs or access to the most informal supports (e.g., family members and friends) can and do take part. In other words, without adequate individualized assistance, those with the least informal support and the greatest support needs never take a seat at the table, much less take part in choosing or designing it. Considering the importance of direct human assistance that was necessary to support participation in the research process, it is exceedingly difficult to imagine how this research could have taken place during the pandemic restrictions.

Spectrum Level 1: Provide Individualized Supports for Decision-Making, Self-Advocacy, and Meaningful Participation

Based on the results of this research, my recommendation is that the province allocate sufficient funding for individualized supports for PLWID and others with similar needs thus complying with Canada's commitment to bring its laws up to CRPD standards. More specifically, I recommend, as mentioned in Chapter 3, that PLWID receive assistance from a professional such as an independent facilitator, whose role is to work with PLWID and their informal supports (e.g., family members and friends) on a long-term basis akin to a long-term educational assistant proposed by Malhotra and Rowe (2014). A long-term relationship allows for the development of trust, a deep knowledge of the person, their life story, their unique communication style, and cognitive abilities. This formal individualized and on-going support may assist with advocacy and tasks such as managing an individualized funding budget, contribute to enlarging informal circle of supports, provide support with decision-making, aid in researching, planning, and facilitating the implementation of the person's ideas of the good. Independent facilitators may experiment with visual methods, they co-create video vignettes and narrative descriptions such as were produced in the context of this research to document the views and life story of the individual being supported. In this study, we saw how Philippe was supported by his mother to communicate. Access to individualized support to train additional people in supported typing would reduce sole reliance on a parent. To take part in this study, participants received support with accessing information regarding the study, on-going assistance with communication and scheduling, transportation, and data collection. An independent facilitator could take on some of the tasks currently expected of parents, siblings, group home or day program staff. Until those types of supports are available to all PLWID, researchers must offer assistance in these areas and depend on family members when no personal assistance is available.

In this study and in my own experience as a sibling and advocate, family members too often take on this facilitative role and those without family support are at a great disadvantage. Furthermore, families have widely varying abilities and availability to provide such assistance and their needs as caregivers may conflict with the wishes of their family member with a disability. When PLWID have no informal supports, service providers are left to fill the void. They may manage the person's individualized funding, support the PLWID with making decisions, connect the person with support workers, provide housing and daily support in one of their group homes. Even with the best intentions, this leaves many PLWID in situations of extreme vulnerability where a change in service providers represents the loss of one's home and entire support structure.

Spectrum Level 2: Raising Awareness

Based on the results of this research, I recommend that provincial and municipal levels of government work collaboratively with self-advocacy and family groups to conduct or fund awareness campaigns. Article 8 of the CRPD requires the promotion of "positive perceptions and greater social awareness towards persons with disabilities" (United Nations, CRPD, 2006). This includes greater awareness regarding cognitive and communication disabilities and communicative access. In other words, tools, and strategies used as part of AAC, SDM and SCA.™ Thus, the general population has a better understanding of cognitive and communication disabilities and increased awareness of various skills and approaches to become a better communicator. Awareness campaigns may also contribute to reducing fear of interacting with people who communicate using AAC. The Holland Bloorview Kids Rehabilitation Hospital's *Dear Everybody*[24] campaign and *ReStorying Autism*[25] are great examples of raising awareness about ableism.

Further community-based and participatory studies should be conducted to document and make visible the "contributions of persons with disabilities to the well-being and diversity of communities, to the workplace, to advances in human, social and economic development." (CRPD, 2006). Although it is essential to remember and share stories about the contributions of famous people with disabilities,[26] it is equally important to make visible positive changes realized on a smaller scale.

Spectrum Level 3: Democratizing Program Development and Service Provision

Based on the results of this research, I recommend that the Ontario Ministry of Training, Colleges and Universities work collaboratively with PLWID and trusted allies to develop and amend the Developmental Services Worker Program Standard[1] as well as university-level health, rehabilitation and social work programs thus implementing section (o) of the Preamble of the CRPD "persons with disabilities should have the opportunity to be actively involved in decision-making processes about policies and programmes, including those directly concerning them"

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[24] https://deareverybody.hollandbloorview.ca/

[25] https://www.restoryingautism.com/

[26] See Tom Shakespeare's blog showcasing the contributions of disabled people in all spheres of life: http://disabledlives.blogspot.com/

(United Nations, CRPD, 2006). Locally, independent committees of PLWID and allies work collaboratively with colleges and universities to ensure that programs reflect provincial standards and the ever-changing sociocultural context. Courses introduce students to critical disability history, the CRPD, the social model of disability and relational understandings of autonomy, capacity and reasoning.

I also recommend that service providers democratize their decision-making processes including budget decisions.[27] To achieve this, service providers collaborate with PLWID to design a structure that fosters direct and meaningful participation. The provision of supports and services is founded on principles inspired by the CRPD, results of studies such as this one and agreed upon by PLWID and their trusted allies. There is on-going dialogue about the meaning and manner of fostering autonomy, participation, contribution, relationships, and other topics identified as important. I recommend that service providers center relationships and opportunities for contributing to one's community and society.

Service providers may investigate alternative governance structures. For example, multi stakeholder cooperatives serve as a source of inspiration for providing services and supports. Multistakeholder cooperatives are on the rise as they bring together different classes of members such as employees, service users and community members. Single stakeholder cooperatives exist in the disability landscape. Examples are consumer or service user coops such as L'Avenir in

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[27] Participatory budgeting provides opportunities for citizens (or service-users) to vote on items in a budget thus exercising real power. For an example from Ontario, see Pinnington, E., Lerner, J. and Schugurensky, D. (2009). Participatory budgeting in north america: the case of Guelph, Canada, *Journal of Public Budgeting, Accounting & Financial Management*, Vol. 21 No. 3, pp. 454-483. https://doi.org/10.1108/JPBAFM-21-03-2009-B005

Manitoba,[28] the Support Services Group Coop in Nova-Scotia,[29] the Wise Owl McClure Co-operative Centre[30] or the Developmental Services Worker Coop[31] in Ottawa, Ontario. Cooperative structures do not guarantee that PLWID effectively guide service provision. Therefore, I recommend that service providers follow the example of organisations such Independent Living Resources Centres require that “More than 51% of people directly involved in the organization’s management and decision-making are people with disabilities” (Ottawa Independent Living Resource Centre) to ensure that service users, including those facing significant barriers to communication and cognition remain in control.

Spectrum Level 4: Coalitions and Networks of Self-Advocacy and Family Advocacy

Based on the results of this research, I also recommend that sufficient public funding and support is available to PLWID and families to gather in-person, to share ideas and practice peer-to-peer support, to discuss local and provincial priorities thus implementing section b(ii) of Article 29 - Participation in political and public life (United Nations, CRPD, 2006). These coalitions and networks adopt democratic structures wherein PLWID retain majority control. Advocacy groups and networks ensure meaningful involvement of PLWID, including those who face barriers to cognition and communication. Self-advocacy groups exist at the local and regional levels. Province-wide networks connect such regional groups. I recommend that PLWID receive information about these groups through their high school and receive the necessary supports to take part in these groups.

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[28] https://lavenircoop.ca
[29] https://ssgns.ca/about-ssg
[30] https://ysowlmaclure.org
[31] https://dswcoop.ca

Spectrum Level 5: Provincial Policy Development and Law Reform

Finally, I recommend that MCCSS co-operate with PLWID and families to co-design an accessible structure and process that supports meaningful participation in the development of provincial policies. To ensure meaningful participation, policies are translated into plain language and available in a variety of accessible formats such as those used in this research. On-going accessible dialogue among PLWID, families and policy-makers is the new norm. The previous Provincial Partnership Table and the Regional Peer Advocacy Committees suggested by Joffe (2010) may serve as inspiration for the structure.

Muldoon (2016) suggests that Arendt’s Council System challenges us to think how to spark the imagination and abilities of citizens to work from the realities of our current structures towards more democratic practices. Arendt’s Council System is founded on the presumption that anyone can be a political actor. Muldoon (2016) does not suggest recreating Arendt’s Council System in our present-day context but he believes, and so do I, that through experimentation, we can create more direct forms of democracy that include all citizens. It would be essential to choose methods of selecting council members that ensure participation by PLWID and citizens from all walks of life. Ontario’s Ministry of Education has an Advisory Council On Special Education in which different classes of membership are identified, including people with developmental disabilities (Public Appointments Secretariat, 2022). However, membership to the board of directors of the Ministry of Health and Long-Term Care’s soon to be established Health and Supportive Care Providers Oversight Authority does not include people with disabilities, it is comprised primarily of executives from both public and private sectors (Public Appointments Secretariat, 2022b).

The CRPD committee is another source of inspiration for designing democratic structures and processes to ensure the involvement of persons with disabilities in shaping policies, services and supports. The Committee offers clear guidelines for communication for all committee activities, these include allowing the participation of personal assistants to facilitate access to information and method of communication of choice, provide information in accessible formats and ensure physical access for meeting (rule 7. Accessibility). The Committee identifies the modes of communication it uses for its activities and allows for recognition of new modes that may develop in the future (rule 24. Methods of communication). In terms of content or general policy direction that reflects the importance of relationships, Nedelsky and Malleson's *A care Manifesto: (Part) Time Work For All* (Nedelsky, 2018) is an interesting proposition that should be explored by disability activists and researchers. She proposes that all adults should work part-time and do unpaid care work part-time allowing everyone to experience first-hand providing care and support to address the "care/policy divide." Nedelsky (2018) asserts that as long as one group of people does the policy-making and a different group provides care, it is very hard to imagine policy-making coming to be seen as equal to care in value. In other words, the care/policy divide itself sustains the denigration of care. When those in powerful positions of high-level decision making (whether in corporations or government) know very little about care, they will continue to believe it is of low value and enact policy making accordingly (Nedelsky, 2018, p. 2).

Suggestions for Future Research

I suggest further research into the rich history of advocacy by PLWID and their allies and into organizations and service providers led by PLWID to learn more about creative approaches for facilitating direct participation and decision-making. I also suggest further empirical research to explore the role of arts-based methods in facilitating participation of PLWID and others requiring cognitive and communicative assistance. Finally, I suggest that researchers continue to explore the role of relationships in the lives of PLWID and others facing barriers to cognition and communication and the role of policy in facilitating and shaping relationships.

Last thoughts

The findings of this research reveal that PLWID value participation and relationships and the opportunity to practice autonomy. My research points to the importance of creating the conditions that ensure that all citizens take part in the process of defining the good for themselves and for society. This includes opportunities to contribute to research. Ableist ideas about competence, reasoning and how one can legitimately make decisions have created unnecessary exclusions and have contributed to the denial of rights to those perceived as incapable of reasoning and decision-making the correct way. My research also shows how visual methods combined with assistance for thinking and communicating can be used to assist PLWID who face significant barriers to share their perspective of a good life. The results of this study, I hope, have contributed to the positive project of demonstrating how PLWID and others with cognitive and communicative impairments may indeed formulate and articulate their own ideas of a good life.

Autonomy is recognized as a fundamental good by researchers, law, disability advocates and rehabilitation professionals. The narratives and video vignettes presented as part of this research reveal that relationships permeate the practice of autonomy and opportunities for participation. The practice of autonomy is both dependent upon relationships (e.g., interpersonal, institutional) and creates opportunities for the development of new connections. Similarly, participation is intricately entangled with relationships. When relationships are supportive of autonomy, they can facilitate opportunities for participation and opportunities for contribution. Relationships appear in narratives and video vignettes as a meaningful aspect of participation.

The Convention affirms that "(m) Recognizing the valued existing and potential contributions made by persons with disabilities to the overall well-being and diversity of their communities," (United Nations, CRPD, 2006, Preamble, (m)) and supporting the full participation of people with disabilities and the respect of their rights will produce "significant advances in the human, social and economic development of society and the eradication of poverty" (United Nations, CRPD, 2006, Preamble, (m)). The organization of society without genuine consideration and direct participation of PLWID and other devalued groups, creates a social deficit thus limiting our collective capacity to build a world that is good for all. Democratic processes must be implemented in all social institutions, including educational institutions, to end decision-making by those already privileged by the reproduction of current social arrangements.

When supported to meaningfully participate in research and in decision-making processes, the presence of PLWID who use AAC trigger future action and unexpected outcomes. This setting things in motion, according to Arendt (1998), is the reason we are born. Action happens in concert with others, it "is never possible in isolation; to be isolated is to be deprived of the capacity to act" (Arendt, 1998, p. 189). The CRPD, the short-lived, *Advocacy Act, 1992*, Justin's release from the Rideau Regional Centre, Ilyasse and Gaël playing sports, Julia and her gymnastics teammates, Maggie and her roommates, Philippe baking a pie with his mother, Rick riding his new bike, even the production of the video vignettes all serve as examples of the power of acting in concert with others.

Our current form of democracy according to Muldoon (2016) rests on the delegation of decision-making to a class of guardian elites. However, real democracy is founded on “a faith in the political capacities of ordinary citizens” (p. 203). I have argued in favor of conceptualizing autonomy and decision-making as relational processes. I have also argued for the recognition and respect of autonomy and decision-making of all citizens, including those who require extensive cognitive and communication assistance. Guardianship as a framework and as a practice must be discarded in favour of frameworks and practices that facilitate participation and autonomy. Earlier in this chapter, I summarized my findings regarding the role and skills required to provide individual cognitive and communication supports. The purpose of implementing these supports serves to engage PLWID in the design, implementation, and evaluation of services and supports. In summary, there is a need to uproot and examine deep seated beliefs regarding the delegation of decision-making to a specialized few to make decisions for PLWID at an individual level and for citizens when it comes to the arrangement of social processes and structures. To truly uphold autonomy and self-determination as valuable both at an individual and societal level, requires profound structural changes in the ‘social scaffolding’ (Mackenzie, 2014) to enable identify the guarantees necessary for participation on an equal basis with any other citizen, including in research.

Following Schostak (2019), I believe that democracy should be situated and practiced in everyday interactions, whether with family members, support staff, agency management, teachers, or policymakers, to interact as equals and to demand that all be present. “Choosing to implement, in all forms of organization, a discourse of equality based on radical inclusion is just that: a choice” (Schostak, 2019, p. 1110). Schostak then asks if it is realistic. It is impossible to know if this is feasible until attempts are made to normalize the practice of listening to those who are usually ignored and search for solutions collectively. Health and social work professionals, policymakers must take a radical approach by asking ‘What is most important to you?’ ‘How are you affected by the way services are currently organized?’ and ‘What do you propose?’ A society that claims to be committed to inclusion, equality and justice must not only proclaim to respect different ideas about the good, but it must also, as Silvers and Francis (2009) propose, recognize, and enable different ways of thinking through and articulating one’s ideas of the good.

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Appendix A

Recruitment Poster for Study 1

Study participants wanted!

What? Join a focus group discussion about intellectual disability advocacy in Ontario. Share your knowledge and perspective.

Why? This study will help us **learn about past actions of self-advocates and advocates** who have worked to improve the lives of people who have been labelled with an intellectual or developmental disability.

Who should participate? Advocates, self-advocates, and others with an interest in intellectual/developmental disability advocacy in Ontario.

What will we do? We will meet in a group of 6-8 people for about 1.5 hours to talk about the events and stories that I have found in old newspaper articles, books, academic journals, newsletters, reports, and websites.

Our group discussion will **inform the final study** on the history of intellectual disability advocacy in Ontario.

Interested?

Contact Josée Boulanger, PhD candidate, School of Rehabilitation Sciences, University of Ottawa

email@uottawa.ca or by telephone: **000-123-4567**

Appendix B

Recruitment Videos for Studies 2 & 3

English version

This study will help us learn about a good life from your perspective and the necessary strategies to ensure meaningful participation in research.

https://youtu.be/H2jULdnEVC4

French version

Dans une série de 4 ateliers ainsi que pendant votre temps libre, vous recevrez du soutien pour utiliser la vidéo, la photo et l'art pour exprimer ce qui est important selon vous pour une bonne vie.

https://youtu.be/UZ5uETu916A

Appendix C

Recruitment Posters for Studies 2 & 3

English version

A good life: What is important **to you**?

What? Research participants needed for 4 hands-on workshops. Using **video, pictures** & **art** to explore what is important for a good life.

For whom? Adults who have been labelled with an **intellectual or developmental disability** *and* who face **barriers to communication.**

Supporters welcome! (Family members, staff, or friends)

Why? To learn about your perspectives on a good life and to make visible the strategies necessary to support meaningful participation in research.

Sounds interesting? Contact me at:

email@uottawa.ca
Cell: **000-123-4567**

uOttawa

French version

Une bonne vie : qu'est-ce qui est important selon toi ?

Quoi? Des participants recherchés pour 4 ateliers sur l'exploration d'une bonne vie avec la vidéo, des photos et l'art.

Pour qui ? Les adultes étiquetés d'une déficience intellectuelle ou handicap du développement et qui font face à des obstacles à la communication.

Accompagnateurs bienvenus ! (Membres de famille, personnel de soutien et amis)

Pourquoi ? Pour connaître votre perspective d'une bonne vie et pour rendre visibles les stratégies nécessaires qui favorisent votre participation à la recherche.

Ça vous intéresse? Contactez-moi:

courriel@uottawa.ca
Cellulaire: **000-123-4567**

uOttawa

Appendix D

Easy Read Consent Form and Data Release Form for Study 1

uOttawa

Université d'Ottawa

Faculté des sciences
de la santé

École des sciences de la
réadaptation

University of Ottawa

Faculty of Health
Sciences

School of Rehabilitation
Sciences

☎ 613-562-5436
📠 613-562-5428

451 Smyth
Ottawa ON K1H 8M5 Canada

www.uOttawa.ca

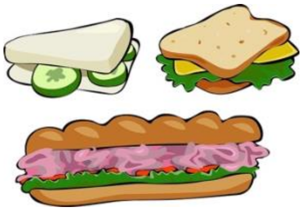
Project title: Ways of knowing, ways of being: exploring a good life through participatory audio/visual ethnography with people labelled with an intellectual disability	
Study 1: Exploring the history of intellectual disability advocacy in Ontario	
No? Yes?	Part I: Research Participant Information and **Consent Form for Study 1.**
	My name is Josée Boulanger. I am a PhD candidate at the University of Ottawa. Email: email@uottawa.ca Cell: 000-123-4567
	My supervisor is: Roanne Thomas, PhD Faculty of Health Sciences University of Ottawa (613) 562-5800 ext. 8645, Email: Roanne.Thomas@uottawa.ca

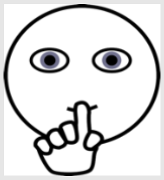
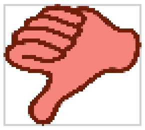
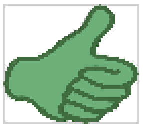
	I am conducting a study entitled: *Ways of being, ways of knowing: Exploring a good life through participatory visual ethnography with people labelled with an intellectual disability.*
	This study is the first study of three that I must complete as part of my PhD dissertation.
	The purpose of this study is to document and think about the history of intellectual disability advocacy (the work done to create positive change for people labelled with an intellectual disability) in Ontario.
	It is important to learn from the past to think about possibilities for the present and the future.
?	**Study procedures: What will we do?**

	We will meet in a small group of 6-8 people for about 1.5 hours.
	Together, we will talk about advocacy actions that have made an individual or collective impact.
	We will make decisions about which stories are most important. We will talk about their meaning and who should know about these stories.
	Our focus group discussion will be video recorded.
	The video recording will help me to remember what we talked about.

	I will use what we have said during the focus group discussion to write the final research report.
 ?	**Are there any risks or benefits?**
	It is possible that you might feel frustrated or even sad when talking about things that have not gone well for people labelled with an intellectual disability in the past or that things have not changed enough.
	If you feel that you need to talk to someone like a counsellor, I will give a list of free local resources at the beginning of the workshops.
	You decide what you want to talk about or share with the group or with me, the researcher. You do not have to talk about or share anything if you do not want to.

	As a benefit: You may learn new things about the history of intellectual disability advocacy (the work done to create positive change for people labelled with an intellectual disability) in Ontario and meet other people with similar interests.
?	**How will I be compensated?**
	You will receive $20.00 for your participation in this study.
	I can give you OC Transpo bus fare to get to the workshop.
	I can help you to book para transpo to travel to the workshop location.

	A light lunch and refreshments will be provided.
 Patrick Smith said...	If you decide to disclose your identity, your name may appear alongside your contributions and in my research reports.
 **?**	**What if I change my mind?**
 **I'm done!**	You can end your participation in the study at any time and for any reason. It is up to you and there is no penalty for choosing to stop participating.
	If you choose to stop participating in the research, any video or other data you have contributed will be destroyed beyond recovery at your request.

 ?	**Confidentiality:** During our group discussion, we may share stories or opinions that we don't want everyone to know about. We will make a promise to each other to not share those stories and opinions with others.
Mr. John Doe 	You may choose to remain **anonymous** and have your identity protected. To remain anonymous, you will be assigned a pseudonym and any information that may identify you such as the image or sound of the video recording will not be used nor will anything you have said that could identify you.
   **No?** **Yes?**	Please let me know if you prefer not to appear in the **video recording**. You may choose to sit outside the frame of the video camera so that you are not seen at all. You could choose to keep your back to the camera or ask that your identity be protected by blurring your facial features.

	Despite all the efforts to keep information confidential, and given the nature of group work, I cannot guarantee absolute confidentiality.
?	**Where will the information be kept and stored?**
 Laurel L. Russwurm CC BY 2.0 	All the information, including text and video files will be stored on an external hard drive and a back up external and be stored in a locked cabinet when not in use at my home office in Vars. These files will be accessed through a password protected computer at my home office in Vars. After five years, if the data is chosen to be destroyed, it will be destroyed beyond recovery.
?	**Where will the results of the study be shared?**

 Patrick Smith said... If you decide to disclose your identity, your name will appear alongside your contributions. **What if I change my mind?** **I'm done!** You can end your participation in the study at any time and for any reason. It is up to you and there is no penalty for choosing to stop participating. If you choose to stop participating in the research, any video or other data you have contributed will be destroyed beyond recovery at your request.	The results of the study will be presented in easy read documents to make them accessible to self-advocates and any other person who could benefit from a more accessible format such as this consent form.
	The results of the study will be presented at academic conferences.
	The results of the study will also be shared in online academic journals. They may be also posted on websites.
?	**Recognizing & respecting your contribution**
	I will make sure that you have a say in how your contributions, including any images or video, are presented.

	I will also make sure that you receive copies of the easy read version and online articles and invitations to public presentations of the research results.
	If you have any questions about the study, you may contact the researcher: Josée Boulanger PhD Candidate Faculty of Health Sciences University of Ottawa 451 Smyth Rd., Ottawa, ON K1H 8M5 Cel: (000) 123-4567 Email: email@uottawa.ca
	Or, you may contact her supervisor: Roanne Thomas, PhD Faculty of Health Sciences University of Ottawa 451 Smyth Rd., Ottawa, ON K1H 8M5 (613) 562-5800 ext. 8645, Email: Roanne.Thomas@uottawa.ca

If you have any questions regarding the ethical conduct of this study, you may contact a Protocol Officer for Ethics in Research, University of Ottawa, Tabaret Hall, 550 Cumberland Street, Room 154, Ottawa, ON K1N 6N5

Tel.: (613) 562-5387

Email: ethics@uottawa.ca

Acceptance: I, __________________________________, agree to participate in the above research study conducted by *Josée Boulanger* of University of Ottawa's School of Rehabilitation Sciences*, which research is under the supervision of* Roanne Thomas*.*

There are <u>two</u> copies of the consent form, one of which is mine to keep.

Participant's signature:____

Date: ________________________________

sig	Parent or legal guardian's signature (if under 18 yrs or under guardianship): _________________________________ Date: __________________________
sig	Researcher's signature:_____________________ Date:________________________
🗣	Verbal Consent Obtained: ____________________ (Date)

Project Title: Ways of being, ways of knowing: Exploring a good life through participatory visual ethnography with people with disabilities.

Study 1: Exploring the history of intellectual disability advocacy in Ontario

Part II: Data release form

This data release form allows you to choose whether your name will OR will not appear in any reports, conference presentations, publications, videos and/or websites about this study.

Some participants may prefer to be credited for the contributions they have made to this project.

Some participants may prefer to remain anonymous. By remaining anonymous, any opinions and stories shared during the focus group session will not be identified as your own. You may choose to use a pseudonym to protect your identity.

You can choose to be anonymous, to have only your name used, or to have both your name and your image and sound revealed in the video and/or video stills (capture screens taken of the video footage).

I have been offered the opportunity to reveal my identity or de-identify myself in the study: Exploring the history of intellectual disability advocacy in Ontario.

I will have the opportunity to revisit my choices once the study findings are ready for publication.

I have chosen to ____reveal my identity in the video in the data to be used in this study. The data may be:

- Video documentation of the focus group session
- Video stills (image) taken from the video
- Quotes from the focus group session

Ex.: A short video is shared during a presentation to discuss the focus group. The audience sees you and hears you sharing your opinions about the study topic. Your name appears on the screen.

I have chosen to _____only reveal my identity in the following data to be used in the study:

1. Video documentation the focus group session. Ex. An audioclip of your contribution is included in a presentation about the study.

2. video stills (image). Ex.: A picture of you is included in an article published about the focus group session along with your name.

3. quotes from the focus group session. Ex.: "Sharon, a long time advocate for disability rights, expressed surprise at learning about this particular policy: "I had never heard of this. This is relevant to our efforts..."

I have chosen to ______ remain anonymous using a pseudonym. I do not wish to be identifiable.

I HAVE RECEIVED A COPY OF THIS FORM FOR MY RECORDS.

_____________________________(Participant's Name) _______________ (Date)

_____________________________(Signature of Participant)

_____________________________(Parent or legal guardian's Name)_______ (Date)

_____________________________(Signature of Participant)

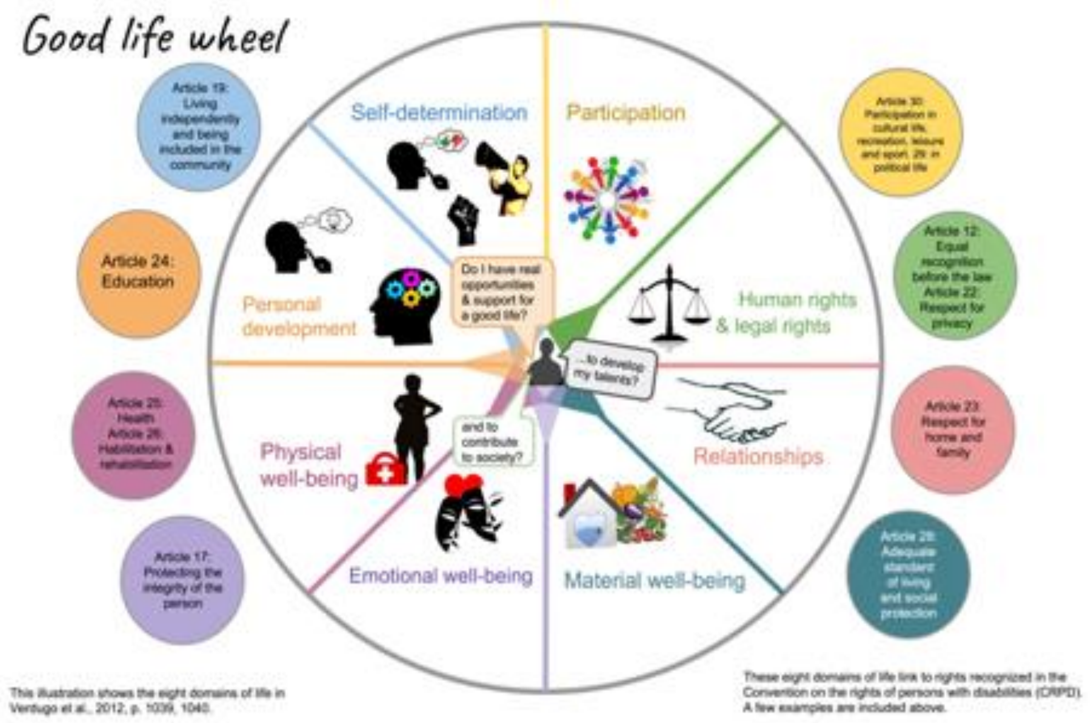
_____________________________(Researcher' Name) ______________ (Date)

_____________________________(Signature of Researcher)

Verbal Consent Obtained: _____________________________ (Date)

Appendix E

The Good Life Wheel

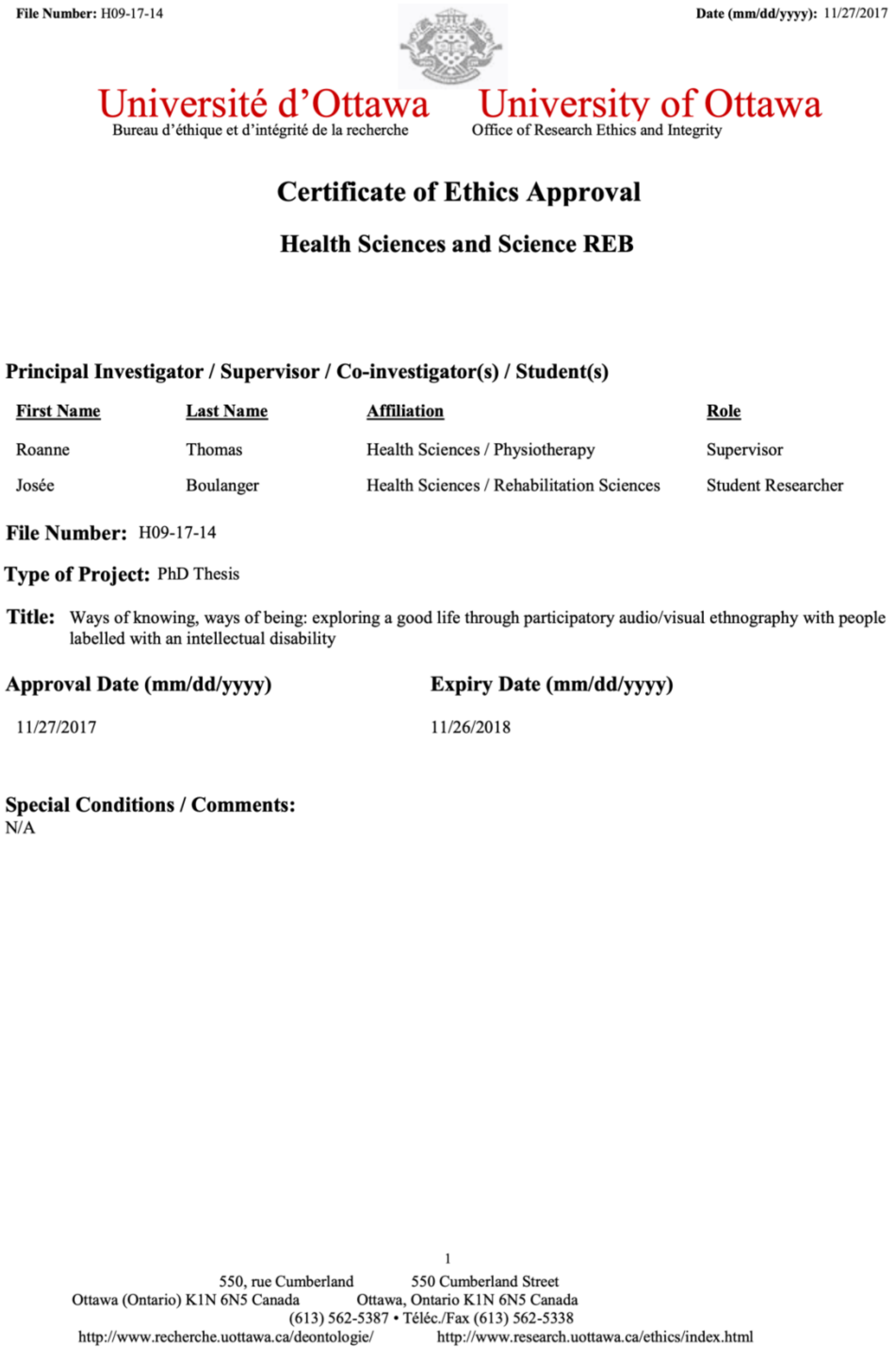


This illustration shows the eight domains of life in Verdugo et al., 2012, p. 1039, 1040.

These eight domains of life link to rights recognized in the Convention on the rights of persons with disabilities (CRPD). A few examples are included above.

Appendix F

Ethics Approval



File Number: H09-17-14

Date (mm/dd/yyyy): 11/27/2017

Université d'Ottawa
Bureau d'éthique et d'intégrité de la recherche

University of Ottawa
Office of Research Ethics and Integrity

Certificate of Ethics Approval

Health Sciences and Science REB

Principal Investigator / Supervisor / Co-investigator(s) / Student(s)

First Name	Last Name	Affiliation	Role
Roanne	Thomas	Health Sciences / Physiotherapy	Supervisor
Josée	Boulanger	Health Sciences / Rehabilitation Sciences	Student Researcher

File Number: H09-17-14

Type of Project: PhD Thesis

Title: Ways of knowing, ways of being: exploring a good life through participatory audio/visual ethnography with people labelled with an intellectual disability

Approval Date (mm/dd/yyyy)	Expiry Date (mm/dd/yyyy)
11/27/2017	11/26/2018

Special Conditions / Comments:
N/A

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550 Cumberland Street
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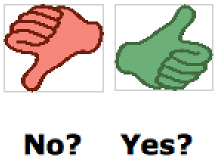
http://www.recherche.uottawa.ca/deontologie/
http://www.research.uottawa.ca/ethics/index.html

Appendix G

Easy Read Consent Form and Data Release Form for Studies 2 & 3

<table>
<tr><td>uOttawa</td><td colspan="2">Project title: Ways of being, ways of knowing: Exploring a good life through participatory audio/visual ethnography with people labelled with an intellectual disability.</td></tr>
<tr><td></td><td colspan="2">Study 2: Exploring necessary conditions for a good life: audio/visual stories by people labelled with an intellectual disability who face barriers to communication
Study 3: Exploring conditions for meaningful participation in research of people labelled with an intellectual disability who face barriers to communication</td></tr>
<tr><td></td><td> </td><td>Part I: Research Participant Information and Consent Form for Study 2 & 3</td></tr>
<tr><td></td><td></td><td>My name is Josée Boulanger. I am a PhD candidate at the University of Ottawa.
Cell: (000)123-4567
Email:email@uottawa.ca</td></tr>
</table>

Université d'Ottawa
Faculté des sciences
de la santé

École des sciences de la
réadaptation

University of Ottawa
Faculty of Health
Sciences

School of Rehabilitation
Sciences

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451 Smyth
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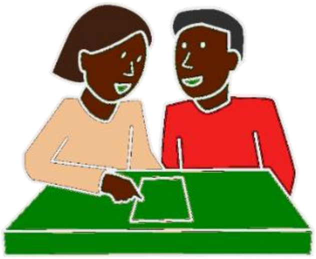
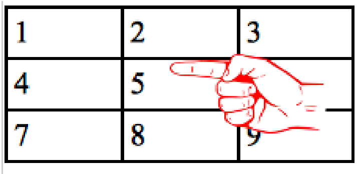
My supervisor is:
Roanne Thomas, PhD
Faculty of Health Sciences
University of Ottawa

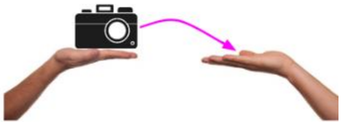
(613) 562-5800 ext. 8645,
Email:
Roanne.Thomas@uottawa.ca

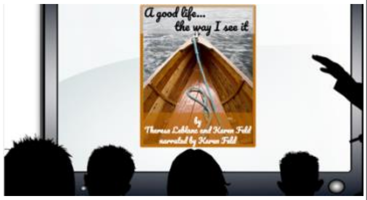
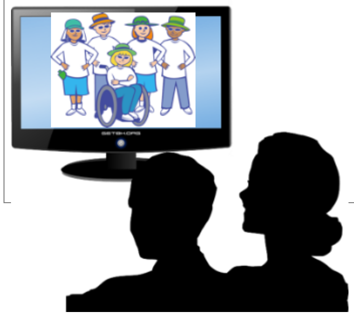
I am conducting a study entitled: Ways of being, ways of knowing: Exploring a good life through participatory visual ethnography with people labelled with an intellectual disability.

These are the 2nd and 3rd studies of 3 that I must complete as part of my PhD dissertation.

	The purpose of these 2 studies is to: 1) explore necessary conditions for a good life from the perspective of PLWID using audio/visual methods; 2) to explore, document and analyze necessary conditions for PLWID to engage in the knowledge production process as co-researchers
Good life?	A good life can be about things, people, activities and places that are important and even necessary for you to live well. We will think about this together.
Study 2 Study 3	Studies 2 & 3 will happen at the same time and same place.
	• It is important to know what you think is necessary for a good life. • It also important to learn more about how to help you share your ideas and opinions in ways that you enjoy and are meaningful.

?	**Study procedures: What will we do for study 2 & 3?**
	A small group of 4-5 people who are labelled with an intellectual disability will participate in a series of 4 workshops + one optional final meeting.
	You can invite someone you trust to support you during the workshops. This could be one of your parents, a friend or a support worker.
	During the workshops, we will also talk about what you think is important to have a good life.
	We will use storyboards to help organize your video, pictures and drawings into a story.

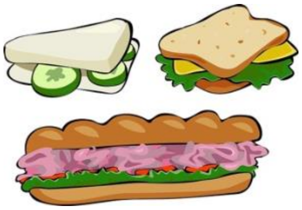
	Once you have some ideas, I will ask you to take pictures and videos of the things, places, people, activities and situations that are part of your good life or that you would like to have part of your life to make a good life possible.
	You may also use meaningful objects, old photos or artwork to express your ideas.
	If you want help with taking pictures or video, I can help you. I have made many videos.
	You may borrow a camera from the researcher to take pictures or video. You will not be held responsible if the camera is damaged during the project.

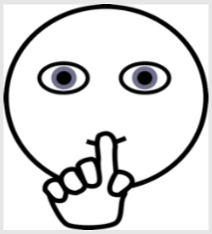
	You may use words to tell parts of your story. You may also ask someone else to say a few words in your story.
	Together, we will decide who we want to share the stories with. We will organize a screening to celebrate the end of the workshops and the stories.
?	**Study procedures: What will we do for study 3?**
	A video camera will record all 4 workshops and the last meeting if you decide to attend.
	The video recording will help us to remember what happened during the workshops.
	If we all agree, we will watch some of the video recordings together.

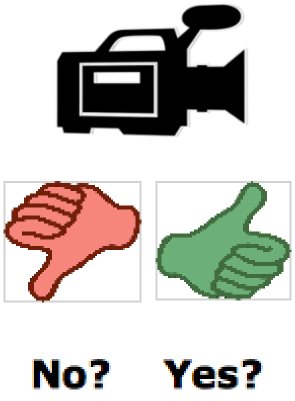
	As we watch the video, will think about what went well during the workshop and what didn't go so well.
Who Did What? 	At the end of each workshop, we will use the 'Who Did What?' Checklist to help us think about the types of supports and strategies that were used for communication and participation.
	After each workshop and meeting, I will type some notes about what I think about we did during the workshop.
	I will use the video recordings, the results of the 'Who Did What?' checklist and my observations to help me write my research report.

⚠ ?	**Are there any risks or benefits?**
	It is possible that you might feel sad or frustrated when talking about things that are not going so well in your life.
	If you feel that you need to talk to someone like a counsellor, I will give you a list of free services that may help you.
	You can choose what you want to talk about or share with the group or me, the researcher. You do not have to talk about or share anything with the group or me, the researcher, if you do not want to.

	As a benefit, you will have the opportunity to think about a good life, to use video and images to share your perspective and to keep a copy of your video or photo story.
?	**How will I be compensated?**
	You will receive $10.00 at the beginning of each workshop for a total of $40.00 for your participation in this study.
	I can give you OC Transpo bus fare to get to the workshop.
	I can help you to book para transpo to travel to the workshop location.

	A light lunch and refreshments will be provided.
My story 	Your video or photo story is yours to keep. You may share it with friends, family and current or potential support staff.
 Patrick Smith said...	If you decide to disclose your identity, your name may appear alongside your contributions and in my research reports.
?	**What if I change my mind?**
 **I'm done!**	You can end your participation in the study at any time and for any reason. It is up to you and there is no penalty for choosing to stop participating.

	If you choose to stop participating in the research, any video or other data you have contributed will be destroyed beyond recovery at your request.
 ?	**Confidentiality:** We will share stories and opinions that we don't want everyone to know about. We will make a promise to each other to keep those stories and opinions among the group and <u>not</u> share them with others unless you decide to do so.
 Mr. John Doe	You may choose to remain **anonymous** and have your identity protected. To remain anonymous, you will be assigned a pseudonym and any information that may identify you such as the image or sound of the video recording will not be used nor will anything you have said that could identify you.

	Please let me know if you prefer not to appear in the **video recording during the workshop**. You may choose to sit outside the frame of the video camera so that you are not seen at all. You could choose to keep your back to the camera or ask that your identity be protected by blurring your facial features.
	Despite all the efforts to keep information confidential, and given the nature of group work, I cannot guarantee absolute confidentiality.
?	**Where will the information be kept and stored?**
 Laurel L. Russwurm CC BY 2.0	All the information, including text and video files will be stored on encrypted external hard drives. These will be stored in a locked cabinet when not in use at my home office in Vars.

	These files will be accessed via a password protected computer at my home office in Vars. After five years, if the data is chosen to be destroyed, it will be destroyed beyond recovery.
?	**Where will the results of the study be shared?**
	The results of studies 2 & 3 will be presented at academic conferences.
	The results of studies 2 & 3 will also be shared in online academic journals.
	If you consent, your video or photo story and or image may appear in part or entirely in an online journal.

	If you have any questions about the study, you may contact the researcher: Josée Boulanger PhD Candidate Faculty of Health Sciences University of Ottawa 451 Smyth Rd., Ottawa, ON K1H 8M5 Cel: (000) 123-4567 Email: email@uottawa.ca
	Or, you may contact her supervisor: Roanne Thomas, PhD Faculty of Health Sciences University of Ottawa 451 Smyth Rd., Ottawa, ON K1H 8M5 (613) 562-5800 ext. 8645, Email: Roanne.Thomas@uottawa.ca
	If you have any questions regarding the ethical conduct of this study, you may contact a Protocol Officer for Ethics in Research, University of Ottawa, Tabaret Hall, 550 Cumberland

✉	Street, Room 154, Ottawa, ON K1N 6N5 Tel.: (613) 562-5387 Email: ethics@uottawa.ca
✓	**Acceptance:** I, ______________________________, agree to participate in the above research study conducted by *Josée Boulanger* of University of Ottawa's School of Rehabilitation Sciences, *which research is under the supervision of* Roanne Thomas.
	There are <u>two</u> copies of the consent form, one of which yours to keep.
sig	Participant's signature:_________________________________ Date: ______________________________

sig	Parent or legal guardian's signature: __________________________________ Date: ____________________________
sig	Researcher's signature:______________________ Date:__________________________
🗣	Verbal Consent Obtained: _________________________________(Date)

Part II: Data release form

This data release form allows you to choose whether your name and image will OR will not appear in any reports, conference presentations, publications, videos and/or websites about this study.

I will have the opportunity to revisit my choices once the study findings are ready for publication.

I choose to ____reveal my identity in the data to be used in this study. The data may be:

- Video documentation
- Images (video stills or photographs)
- Quote

I choose to ____only reveal my identity in the following data to be used in the study:

1. **_____Video documentation.** Ex. : Your video or photo story about a good life is published in an online academic journal.

1. ______**Video stills (image) or photograph.** Ex.: A picture of you is included in an article published about a good life from the perspective of people labelled with an intellectual disability.

- **______Quotes from your video story.** Ex.: “I would like to live with my best friend” or “Jake is supported to volunteer with elderly people.”

I choose to ______ remain anonymous using a pseudonym. I do not wish to be identifiable.

I HAVE RECEIVED A COPY OF THIS FORM FOR MY RECORDS.

Participant’s Name:______________________________
_______________ (Date)

Participant's signature:_____________________________

Parent or legal guardian’s
name:____(Date)

Parent or legal guardian's
signature:_______________________________________

Researcher’ Name: ______________________________
______________ (Date)

Researcher's signature:_____________________________

Verbal consent obtained: ________________________ (Date)

Appendix H

Conventional Consent and Data Release Form for Supporters in Studies 2 & 3

Université d'Ottawa
Faculté des sciences de la santé
École des sciences de la réadaptation
University of Ottawa
Faculty of Health Sciences
School of Rehabilitation Sciences

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📠 613-562-5428
451 Smyth
Ottawa ON K1H 8M5 Canada
www.uOttawa.ca

Project Title: Ways of being, ways of knowing: Exploring a good life through participatory visual ethnography with people with disabilities.

Study 2: Exploring necessary conditions for a good life: audio/visual stories by people labelled with an intellectual disability

Study 3: Exploring conditions for meaningful participation of people labelled with an intellectual disability as co-researchers

Part I: Research Information and Consent Form for Supporters

You are being asked to participate in a research study conducted by Josée Boulanger from the University of Ottawa. She is doing this research as part of her PhD at the University of Ottawa. She is working under the direction of Dr. Roanne Thomas of the University of Ottawa's School of Rehabilition Sciences.

This consent form is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your role will be. Please take the time to read this carefully and to make sure you understand what it means. If you would like more information, feel free to ask. You will have your own copy of this consent form to keep with you.

Purpose of these two studies:

The purpose of study 2 is to is to explore necessary conditions for a good life from the perspective of people labelled with an intellectual disability (PLWID) who face barriers to communication using audio/visual methods. The purpose of study 3 is to explore, document and analyze necessary conditions for PLWID to engage in the knowledge production process as co-researchers. These two studies are the second and third of three studies be completed by the researcher. It will contribute to the researcher's completion of her PhD dissertation.

Research Procedures

This study consists of a series of 4 workshops that will take place at theSpace Ottawa at 391 McArthur Avenue at dates and times deemed convenient for study participants.

To collect data for study 2, participants will be supported to express their perspective of the necessary conditions for a good life using video, pictures and other arts such as drawing. During the workshops, a good life will be explored using a variety of visual supports and ideas stemming from a combination of frameworks such as qualify of life framework, disability human rights and capabilities approach which looks at opportunities that people have to be or do what they reason to value.

As as a supporter, you may contribute by facilitating communication and helping with taking pictures and video or identifying existing pictures and video that may help to explore and express a good life from the perspective of the participant you are supporting.

You may attend the workshops alongside the key participant or support them in other contexts (for eg.: at home, leisure, work or day program).

To collect data for study 3, the researcher will video record each workshop and one individual audio/visual data collection session by a participant. These video recordings of the workshop will help the researcher, the participants and supporters to think about what works well and what does not work well when using audio/visual methods to explore a good life with people who face significant barriers to communication. We will evaluate each workshop and our work as we go along.

Time required

The total time required for Studies 2 & 3 is expected to take approximately 18 hours. Each workshop is expected to last 3 hours for a total of 12 workshop hours. It is expected that participants will spend 1 to 2 hours per data collection session for a total of 6 hours.

Risks: Are there any potential risks or benefits?

If you experience strong emotions in relation to this research project, I will provide you with contact information for services available in the Ottawa region. You have the right to choose what you would like to share and you prefer to keep private.

You have the right to choose what you would like to share and you prefer to keep private. If you experience strong emotions in relation to this research project, I will provide you with contact information for services available in the Ottawa region.

Direct benefits to you from participating in this study: As a benefit, you will have the opportunity to think about a good life alongside the person you are supporting and to think about the necessary conditions for meaningful participation of people who face considerable barriers to communication.

Payment for participation

You will receive $10.00 at the beginning of each workshop for a total of $40.00. You may also request bus fare to travel to and from the workshop location. A light lunch and refreshments will be provided.

Right to withdraw or to end your participation in the study

You may decide to end your participation at any time during the study without penalty of any sort. You do not need to talk about or answer any questions that make you feel uncomfortable or that you simply do not want to talk about.

Voluntary participation:

1. Your participation in this study is voluntary.
2. You can decide to stop at any time, even part-way through a workshop for whatever reason.
3. If you decide to stop participating, there will be no consequences to you.
4. If you decide to stop we will ask you how you would like us to handle the data collected up to that point.
5. This could include destroying it or using the data collected up to that point.

Confidentiality: Your personal information will be kept confidential unless you choose for it to be associated with your contributions to the study. Confidentiality: We may share stories or opinions that you do not want to share outside the workshops. As a group, we will make a promise to each other to keep those stories and opinions among ourselves and not share them with others unless you decide to so.

As a participant, you will be part of the decision making process about which stories and information about you must remain confidential and which ones can be shared in my report. If you feel that certain information you have shared is too sensitive, personal or private to be shared in my research report, you may tell me and I will leave it out. You may also choose to use a pseudonym, a name that is not yours.

Personal information such as phone numbers, addresses, and organizational affiliations will be kept confidential and any other information that may identify third parties associated with participants will be deleted or altered (i.e. names of support workers, service providers, doctors, social workers, family members, etc.).

> **1. Anonymity and pseudonyms:** You may choose to remain anonymous and have your identity protected. To remain anonymous, you will be assigned a pseudonym and any information that may identify you such as the image or sound of the video recording will not be used nor will anything you have said that could identify you.
>
> **2. Video recording:** A video recording will be taken of the workshops. It is likely that you be identifiable in this video recording. Please let me know if you prefer not to appear in the video recording. You may choose to sit outside the frame of the video camera so that you are not seen at all. You could choose to keep your back to the camera or ask that your identity be protected by blurring your facial features. We will review images and footage together that may appear in research reports.
>
> **3. Limits to confidentiality in group work:** Despite all the efforts to keep information confidential, and given the nature of group work, I cannot guarantee absolute confidentiality.

Storage of data: All information collected for this study, including video footage, photographs, researcher field notes, contact information will only be available to me, the only researcher working on this study. This data will be stored on encrypted external hard drives in a locked cabinet and all records, including video files, will be kept on a password protected computer at my home office in Vars, Ontario. After five years, if the data is chosen to be destroyed, it will be destroyed beyond recovery.

Dissemination of findings: The findings of this research study will appear in participants' video or photostory, conference presentations and/or online academic journal articles, as well as other appropriate online platforms.

Respecting your contribution: The researcher is committed to ensuring that you are given an opportunity to have a say in how your contributions, including any images or video, are presented. She is also committed to ensuring that you will receive the benefits and products of your participation (e.g., copies of online articles and video or printed images, invitations to public presentations of the research findings).

Questions about the study:

If you have any questions concerning the study, please feel free to ask at any point; please do not hesitate to contact the researcher with any questions about the research or findings. You can contact:

Researcher:
Josée Boulanger
PhD Candidate
Faculty of Health Sciences
University of Ottawa
451 Smyth Rd.,
Ottawa, ON K1H 8M5
Cel: (000) 123-4567
Email: email@uottawa.ca

Supervisor:
Roanne Thomas, PhD
Faculty of Health Sciences
University of Ottawa
451 Smyth Rd.,
Ottawa, ON K1H 8M5
(613) 562-5800 ext. 8645,
Email: Roanne.Thomas@uottawa.ca

Questions about your rights as a research participant

Protocol Officers for Ethics in Research
University of Ottawa Research Ethics Board
550 Cumberland St., Room 154
Ottawa ON
(613)-562-5387
email: ethics@uottawa.ca

Giving of Consent

I have read this consent form and I understand what is being requested of me as a participant in this study. I freely consent to participate. I have been given satisfactory answers to my questions. The investigator provided me with a copy of this form.

I give consent to be video recorded during the workshops. ________(initial)

I, ____, agree to participate in the above described research studies conducted by Josée Boulanger, University of Ottawa.

There are two copies of the consent form, one of which is mine to keep

___________________________(Participant’s Name) _________(Date)

___________________________(Signature of Participant)

___________________________(Name of parent or legal guardian if under 18 yrs of age or guardianship)______(Date)

___________________________(Signature of parent or legal guardian if under 18 yrs of age or guardianship)

___________________________(Researcher’ Name) ____________ (Date)

___________________________(Signature of Researcher)

Verbal Consent Obtained: ___________________________ (Date)

Data release form for Study 2 & 3

Project Title: Ways of being, ways of knowing: Exploring a good life through participatory visual ethnography with people with disabilities.

Study 2: Exploring necessary conditions for a good life: audio/visual stories by people labelled with an intellectual disability

Study 3: Exploring conditions for meaningful participation of people labelled with an intellectual disability as co-researchers

Part II: Data release form

This data release form allows you to choose whether your name will OR will not appear in any reports, conference presentations, publications, videos and/or websites about this study.

Some participants may prefer to be credited for the contributions they have made to this project.

Some participants may prefer to remain anonymous. By remaining anonymous, any opinions and stories shared during the focus group session will not be identified as your own. You may choose to use a pseudonym to protect your identity.

You can choose to be anonymous, to have only your name used, or to have both your name and your image and sound revealed in the video and/or video stills.

I have been offered the opportunity to reveal my identity or de-identify myself in the study 2: Exploring necessary conditions for a good life: audio/visual stories by people labelled with an intellectual disability and Study 3: Exploring conditions for meaningful participation of people labelled with an intellectual disability as co-researchers.

I will have the opportunity to revisit my choices once the study findings are ready for publication.

I have chosen to ____reveal my identity in the data to be used in this study. The data may be:

- Video documentation
- Video still (snapshots of video footage) or photograph
- Quote

I have chosen to ____only reveal my identity in the following data to be used in the study:

1. Video documentation. Ex. : Your video or photo story about a good life is published in an online academic journal.

2. Video stills (image) or photograph. Ex.: A picture of you is included in an article published about a good life from the perspective of people labelled with an intellectual disability.

3. Quotes from your video story. Ex.: "I would like to live with my best friend" or "Jake is supported to volunteer with elderly people."

I have chosen to _____ remain anonymous using a pseudonym. I do not wish to be identifiable.

I HAVE RECEIVED A COPY OF THIS FORM FOR MY RECORDS.

___________________________(Participant's name) _____________ (Date)

___________________________(Signature of participant)

___________________________(Parent or legal guardian's name)______ (Date)

___________________________(Signature of parent or legal guardian)

___________________________(Researcher' name) _____________ (Date)

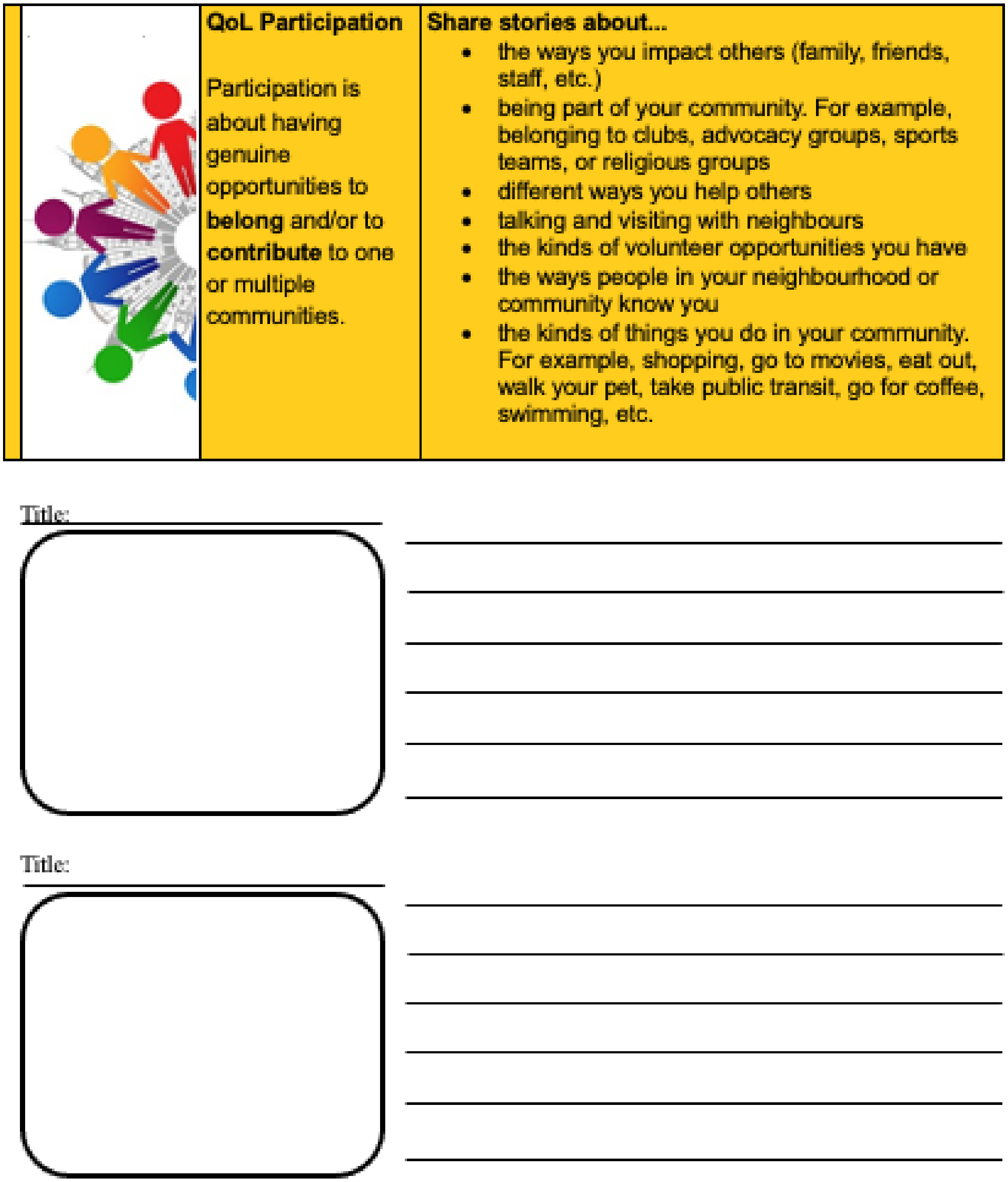
___________________________(Signature of researcher)

Verbal consent obtained: ___________________________ (Date)

Appendix I

Exploring My Good Life Workbook

Below is an example of one of the pages of the workbook. Each quality of life domain is presented in a similar manner. The space on the left side of the page allows for sketching or gluing images. The lines to right allow for taking notes.



QoL Participation

Participation is about having genuine opportunities to **belong** and/or to **contribute** to one or multiple communities.

Share stories about...

- the ways you impact others (family, friends, staff, etc.)
- being part of your community. For example, belonging to clubs, advocacy groups, sports teams, or religious groups
- different ways you help others
- talking and visiting with neighbours
- the kinds of volunteer opportunities you have
- the ways people in your neighbourhood or community know you
- the kinds of things you do in your community. For example, shopping, go to movies, eat out, walk your pet, take public transit, go for coffee, swimming, etc.

Title:

Title:

Appendix J

Third Party Release Form

Project title: Ways of being, ways of knowing: Exploring a good life through participatory visual ethnography with people labelled with an intellectual disability.

Study 2: Exploring necessary conditions for a good life: audio/visual stories by people labelled with an intellectual disability

Study 3: Exploring conditions for meaningful participation of people labelled with an intellectual disability in research

👎 👍

No? Yes?

Third Party Release Form

My name is Josée Boulanger. I am a PhD candidate at the University of Ottawa.
Cell: (000)123-4567
Email: email@uottawa.ca

uOttawa

Université d'Ottawa
Faculté des sciences
de la santé

École des sciences de la
réadaptation

University of Ottawa
Faculty of Health
Sciences

School of Rehabilitation
Sciences

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My supervisor is:

Roanne Thomas, PhD
Faculty of Health Sciences

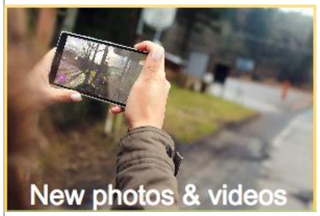
University of Ottawa
(613) 562-5800 ext. 8645,
Email:Roanne.Thomas@uottawa.ca

I am conducting a study entitled: Ways of being, ways of knowing: Exploring a good life through participatory visual ethnography with people labelled with an intellectual disability (PLWID) and who face barriers to communication.

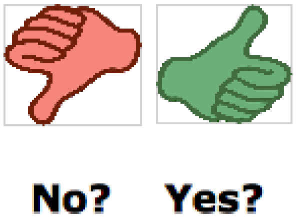
The purpose of these 2 studies is to:

1) explore necessary conditions for a good life from the perspective of PLWID using audio/visual methods;

2) to explore, document and analyze necessary conditions for PLWID to engage in the knowledge production process as co-researchers



Participants are taking pictures and recording video clips to express what is important to them for a good life.

	This form asks your permission to use a picture or a video clip in which you appear as part of this study.
	The results of studies 2 & 3 will be presented at academic conferences. Many people could see the images.
	The results of studies 2 & 3 will also be shared in online (Internet) academic journals. Anybody could see the images.
	If you consent, the photograph or video clip in which you appear may be published in part or entirely in an online (Internet) journal. Anybody could see the images.

If you have any questions about the study, you may contact the researcher:

Josée Boulanger
PhD Candidate
Faculty of Health Sciences
University of Ottawa
451 Smyth Rd.,
Ottawa, ON K1H 8M5
Cel: (000) 123-4567
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Or, you may contact her supervisor:

Roanne Thomas, PhD
Faculty of Health Sciences
University of Ottawa
451 Smyth Rd.,
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(613) 562-5800 ext. 8645,
Email: Roanne.Thomas@uottawa.ca

If you have any questions regarding the ethical conduct of this study, you may contact a Protocol Officer for Ethics in Research, University of Ottawa, Tabaret Hall, 550 Cumberland Street, Room 154, Ottawa, ON K1N 6N5

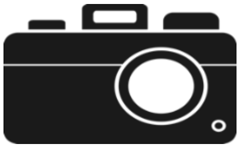
Tel.: (613) 562-5387

Email: ethics@uottawa.ca

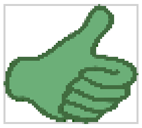
I,

____,have looked at the photographs and/or watched the video clip(s) taken by the participant for this study.

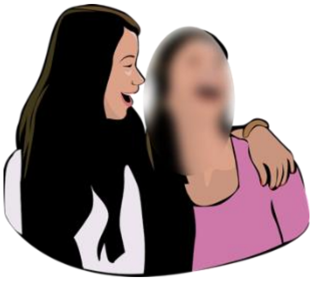
I understand the above.



____________I agree to be identified in the **photographs of myself** to be used in the study and in the publications and presentations.



____________I agree to be identified in the **video clips of myself** to be used in the study and in the publications and presentations.

 👎	_________I **do not want to be identified** in the photographs and video clips for the study and the publications and presentations.
sig	Name of person in photo or video: ___________________________________ Signature:__________________________ Date: __________________________
sig	Participant's signature:___________________________ Date: __________________________
🗣	Verbal Consent Obtained: __________________________________ ________________________________(date)