

## **Space, Place and Justice: Considering People with Intellectual Disabilities**

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### **Introduction**

The editors of this volume argue that “ideas about justice shape and are shaped by place and space.” This has inspired us to wonder what these foundational concepts say about people with intellectual disabilities<sup>1</sup>, whose issues have been the long-standing focus of our research and who continue to be marginalized in our societies. In this context, we see the idea of place as geographic – the physical places where people with intellectual disabilities are. We think of space as more ephemeral – a mindset or attitude towards these individuals by others. We argue that place and space are inexorably interconnected: people with intellectual disabilities can be found in certain places – and by extension cannot be found in other places – because of the attitudes we have about them and the space we are/not prepared to make for them. In this paper, we use data from two small pilot studies, set against the backdrop of human rights and social justice, to explore this issue.

Notwithstanding the United Nations Convention on the Rights of Persons with Disabilities (CRPD), justice and rights continue to be elusive for people with intellectual disabilities as they face exclusion, abuse and violence (Officer & Shakespeare, 2013). These individuals have experienced an exceptionally long history of discrimination, devaluation and dehumanization (Blatt & Kaplan, 1974; Carlson,

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<sup>1</sup> The American Association on Intellectual and Developmental Disabilities defines “intellectual disability” as “a disability characterized by significant limitations in both intellectual functioning and in adaptive behavior, which covers many everyday social and practical skills. This disability originates before the age of 18.”

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2010; Scheerenberger, 1983; Trent, 1994; Wolfensberger, 2013). This history has resulted in laws, policies and practices throughout the Western world that have robbed people with intellectual disabilities of their very humanity: “These people have been consistently denied personhood; they have been seen as objects of pity, fear, or both; they have been oppressed; and, with the rise of the eugenics movement, they have been seen as a threat to the very quality of the human race” (Parmenter, 2001, p. 268).

Even today, people with intellectual disabilities are “denied the opportunity to live their lives according to their own interests and preferences,” face presumptions of incompetence, and are excluded from full participation in the world (Ward & Stewart, 2008, p. 305). At the beginning of the twenty-first century, Parmenter (2001) argued that positive signs of emancipation have been “quite tenuous within the overall social, cultural, political, and economic milieu” (p. 268).

Yet the concepts of rights and justice are crucial to advancing a good life for all human beings. We argue that a good life includes the recognition that all people are entitled to be seen by others as equal, to be treated with dignity, and to be included in the social fabric of our societies. The purpose of this paper is to explore place, space and justice by revealing how a group of people with intellectual disabilities and a small group of people supporting adults with intellectual disabilities in Manitoba, Canada, talk about their experiences in the context of human rights in focus group settings. We asked people to reflect on and respond to what human rights meant them or to the people they support, and to provide us with examples of when they were or were not able to exercise these rights.

We first provide some context around human rights, social justice and people with intellectual disabilities. We then describe the theories in which we ground our work. After we have set the stage, we provide details of our methodology and methods, before exploring the data and findings. We conclude with our analysis and ways in which to move forward.

## **Human Rights and Social Justice**

The United Nations declares that human rights are “rights inherent to all human beings, whatever our nationality, place of residence, sex, national or ethnic origin, colour, religion, language, or any other status. We are all equally entitled to our human rights without discrimination. These rights are all interrelated, interdependent and indivisible.” Thus documents such as the Universal Declaration of Human Rights provide “an internationally agreed set of principles and standards by which to assess and redress inequality” (Ho, 2011, p. 3).

In 2006, the United Nations created the CRPD, which entered into force in 2008. By 2014, over 150 countries were signatories. Listed below are some of its principles:

- a. Respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of persons;
- b. Non-discrimination;
- c. Full and effective participation and inclusion in society;
- d. Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;
- e. Equality of opportunity;
- f. Accessibility.

Articles of the CRPD are worth noting here include a) recognition of the equality of all persons; b) ensuring accessibility; c) reaffirmation of the right to life; d) recognition of equality before the law; e) the right to liberty and security of the person; f) the right to be free from torture, cruel, inhumane or degrading treatment; g) protection from exploitation, violence and abuse; h) protection of personal integrity; i) the right to live in the community; j) the right to privacy; k)

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elimination of discrimination in areas of marriage, family, parenthood and relationships; l) ensuring an inclusive education system; m) the right to high health standards; n) the right to work on an equal basis with others; o) the right to an adequate standard of living; and p) the right to participate in political, public and cultural life and recreation and leisure.

In Canada, equality rights for people with a “mental or physical disability” have been enshrined in s. 15 of the *Charter of Rights and Freedoms*. Peters (2004) describes the fight by people with disabilities and their allies to be explicitly included in the *Charter*. The original clause stated: “Everyone has the right to equality before the law and to equal protection of the law without discrimination because of race, national or ethnic origin, colour, religion, age or sex” (n.p.). Peters quotes Allan Simpson, prominent disability activist, as saying that the failure “to prohibit discrimination on the grounds of disability in any constitutionally entrenched Charter of Rights and Freedoms which does prohibit discrimination on the grounds of race, national or ethnic origin, colour, religion, sex or age is tantamount to rejecting the fundamental humanity of disabled Canadians...” (n.p.).

Social justice has been defined as “an equitable distribution of fundamental resources and respect for human dignity and diversity, such that no minority group’s life interests and struggles are undermined and that forms of political interaction enable all groups to voice their concerns for change” (Basok, Ilcan & Noonan, 2006, p. 267). Similarly, Ho (2011) argues that “the concept of social justice involves finding the optimum balance between our joint responsibilities as a society and our responsibilities as individuals to contribute to a just society” (p. 2). This notion is particularly relevant to people with intellectual disabilities, who often occupy spaces in the margins of Western societies and do not always find themselves in inclusive places.

## **Justice and People with Intellectual Disabilities**

In light of the CRPD, global literature now includes a body of research on human rights and people with intellectual disabilities in various geographical and social contexts, including health and health advocacy (Brolan et al., 2012; Evans et al., 2012; Feldman et al., 2012; Roberts et al., 2013); sexuality (Abbott, 2013; Foley, 2012; Taylor Gomez, 2012); quality of life (Verdugo, Navas, Taylor Gomez & Schalock, 2012); education (Mckenzie & Macleod, 2012); the use of restraints (Rickard, Chan & Merriman, 2013); support networks (Hillman et al., 2012); ethical requirements for conducting research (Iacono & Carling-Jenkins, 2012); parenting (Llewellyn, 2013); choice (Fyson & Cromby, 2013); and voting (Redley, Maina, Keeling & Pattni, 2012). However, in their editorial for a special issue on human rights and intellectual disabilities, Stainton & Clare (2012) noted the absence of work directly addressing “the impact of human rights on core community living services and structures...” (p. 1012). They also pointed out that, although human rights provides a “fertile framework” for thinking about people with intellectual disabilities, “there is still much to be done both to understand the practical implications of a human rights approach and how it is to be effectively realized” (Stainton & Clare, 2012, p. 1013). It is the effective realization of rights and justice in the frame of place and space to which we turn our attention.

In the following section, we will discuss the framework we use to focus our research questions and ground the data analysis.

### **Conceptual Framework**

Although we could have chosen from multiple theories in the research literature, we decided to use Wolfensberger’s (2013) treatise of social role valorization (SRV) and Nussbaum’s capabilities approach. We chose SRV because of its analysis of devaluation in the specific context of people with intellectual disabilities and we chose Nussbaum’s approach to ground our analysis within the ideas of place and space. Each author provides an explanation of what can

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happen with marginalized groups of people and possible responses to address these concerns.

SRV theory states that people will be better treated and respected if they hold valued social roles. Wolfensberger describes the concept of social devaluation and roles into which devalued people are often cast. He argues that people who are devalued are rejected, separated and excluded from society. They are also often cast into the role(s) of the “other,” sub- or non-human, menace, sinner, object of pity, burden of charity, object of ridicule, eternal child, sick or diseased organism, and/or in the context of death-related images (Wolfensberger, 2013, pp. 32-33). SRV provides us with a means to understand and account for society’s willingness to allow certain people to be marginalized and to live inside those margins.

The second theory is Nussbaum’s capabilities approach (2006), which we use to analyze and discuss the extent to which adults with intellectual disabilities are able to take their place in society. In response to Rawls’ (1972) social contract theory and its failure to consider people with intellectual disabilities because of their perceived inability to think rationally, Nussbaum (2006) introduces the capabilities approach “to provide the philosophical underpinning for an account of core human entitlements that should be respected and implemented by the governments of all nations, as a bare minimum of what respect for human dignity requires” (p. 70). The ten capabilities, which she sees as “as central requirements of a life with dignity,” are a) life; b) bodily health (including adequate shelter); c) bodily integrity (including being able to move freely from place to place and being secure against violence); d) senses, imagination and thought; e) emotions (being able to have relationships and attachments); f) practical reason (“engage in critical reflection about the planning of one’s life”); g) affiliation (engage in social interaction and be treated as “a dignified being whose worth is equal to others”); h) other species (live in relation to the world); i) play; and j) control over one’s environment (political and material) (pp. 76-78).

The two theories are complementary as almost all of Nussbaum's capabilities are explicitly mentioned by Wolfensberger as part of the "good things in life." Having valued social roles can actually help to provide and enhance capabilities for people with intellectual disabilities, feeding into a positive cycle of social inclusion in both place and space.

In the next section several sections, we move to a discussion of the research projects themselves.

### **Methodology**

We used a qualitative research paradigm in these pilot studies, as we situate our epistemological position within social constructionism (Berger & Luckman, 1966; Bogdan & Taylor, 1998). In this type of approach, data are grounded in the perspectives of the participants. Bogdan and Biklen (2003) describe these data collected as "rich in description of people, places and conversations" (p. 2). They talk about research questions as being "formulated to investigate topics in all their complexity" (p. 2). Finally, they suggest that the qualitative researcher "is bent on understanding, in considerable detail, how people ... think and how they came to develop the perspectives they hold" (p. 3). This methodology is well suited to this project as we were interested in gaining a more detailed understanding of how participants defined human rights, how these rights are exercised and any barriers that may stand in the way.

### **Methods**

A total of twenty people participated in this study, in which we conducted three focus groups. Sixteen people were adults with intellectual disabilities (thirteen people participated in one focus group and three in another). The third focus group was comprised of three people who were paid support providers to adults with intellectual disabilities, and one person was the parent of an adult child with an intellectual disability. All participants signed written consent forms. Two versions were available including one in plain and clear language. We went over the forms orally with the group and

answered all questions before anyone committed to participating. Anyone who could not sign made a mark indicating consent. All focus groups were audio recorded and later transcribed verbatim.

We used the process of graphic facilitation as a way to visually represent the ideas presented and as a member-checking tool at the end of each question (Mactavish, Lutfiyya & Mahon, 2000). During this process, a facilitator draws pictures and writes simple words using coloured markers on a large paper poster taped to a wall to keep track of the conversation. This allows participants to follow the conversation and ensure their thoughts and ideas are accurately represented in the data. After each question was discussed, we paused to allow the graphic facilitator to summarize what each person had said and to allow participants to correct and/or add to the graphic poster. At the end of the focus group, the facilitator again summarized the discussion as a whole.

Although we made significant efforts to recruit participants through organizations that support adults with intellectual disabilities, as well as parent organizations, we were disappointed in the low response rate. We suspect that one reason for the lower response for adults with intellectual disabilities may stem from their inability to respond to such opportunities on their own. If they had to rely on others to relay information to them, make arrangements to respond and attend, and find safe and reliable transportation, they may have been prevented from participating. One fortuitous event did assist with recruitment. A workshop on human rights for people with intellectual disabilities was being held as we began our study. This provided us with a pool of people from which to recruit directly. If we were to pursue this work in the future, we would need to identify additional ways to reach participants more directly and to facilitate the ways in which they might contact us.

We can also only speculate on why the study generated so little interest from support providers. One reason may be that paid support providers are busy and are simply uninterested in taking part in work-related studies in their off time. Another possibility may be that their



energies are taken up with the everyday challenges of their jobs and they may not be thinking about support in a human rights context. Unpaid support providers, often parents and family members, are similarly over-extended in trying to support their family member and may not be interested in or have the luxury of attending focus groups. We did have several parents express interest, but scheduling was also a problem. In future research, we might consider using individual interviews to avoid problems of coordinating multiple and busy schedules. Notwithstanding these issues, and based on the data collected here and in past work (Lutfiyya, Updike, Schwartz & Mactavish, 2007), we believe data saturation of the issue under investigation was reached.

After a brief introduction to the project and to each other, three primary questions directed the group conversation:

1. What do human rights mean to you/to the people you support?
2. Can you think of examples where you/the people you support were able to exercise your/their rights?
3. Can you think of examples where you/the people you support were not able to exercise your/their rights?

We went around the table talking about these issues, giving everyone a chance to respond.

### **The Data – People with Intellectual Disabilities**

We were interested in knowing how people with intellectual disabilities understand the concept of human rights. All participants were engaged in the discussion, and each had something to say about the meaning of this phrase. After examining the transcripts from both focus groups, we found many similarities and were able to identify three key themes, all of which relate to place and space: 1) being recognized as a person, 2) making choices/decisions, and 3) feeling safe.

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**Being Recognized as a Person**

It is easy to take certain things for granted in our lives within the context of identifying ourselves as people. However, comments from participants reminded us that these taken-for-granted assumptions are not as straightforward for adults with intellectual disabilities. They were clear about the challenges they face in convincing others they are valued human beings. People were very clear about expressing their humanness and the space that needs to be made for them. “Well we have the rights to go out into the society and not be ostracized or you know just because we’re different doesn’t mean that we’re less of a person” (FG#1/P12). “I think people should look first and ask first. We are humans. We have feelings” (FG#2/P3). They want to be treated with dignity and respect, “as whole” (FG#1/P12), and as an equal. “Human rights are set in place to give a person dignity and freedom of choice and if they are not being heard how else are they going to learn” (FG#2/P3). “The right to speak our minds and stand up for ourselves” (FG#1/P3).

Participants saw themselves as a “person in the world” to be counted. “To have a purpose in life. Otherwise life is going to pass us by and we’re not going to be able to achieve anything that is good and reasonable” (FG#1/P2). One person explained: “And the reason why I am here is because my rights have not been heard and I want to make sure that they get heard because I am 43 years old and people are not respecting me enough” (FG#2/P3).

Several people stressed the importance of having close relationships – such as a fiancé, mother or father. “We have the right to marry someone that cares about you and who is there for you” (FG#1/P?). One individual introduced himself: “I’m presently engaged to be married to my long-time sweetheart ... who I adore immensely” (FG#2/P3).

Place was also mentioned in the context of the importance of having a job and being paid for the work they do. “Hiring a person with a disability is good business and that is the bottom line” (FG#1/P12).

“We have the right to work in Canada” (FG#1/P3). “Well I love my job immensely except I hate the pay. I only make \$50/month. That’s human rights violated and being taken away from me. Because I am worth a lot more than \$50/month” (FG#1/P11). Leisure activities were also considered important. “We have the right to participate in sports even though we have a disability” (FG#1/P9). “Diversity means that there are special programs or there are exceptions so we can be part of the team” (FG#1/P12).

### **Making Decisions/Choices**

Many participants stressed that they did not appreciate being told what to do by others and that they were capable of making decisions for themselves. “Cause at times we are not listened to and we’re put into pretty bad and vulnerable situations” (FG#2/P2). People wanted to live wherever and however they desired. “Human rights means that you have the right to have what you want without being told that you have to have this and that” (FG#1/P9). “To me human rights means we have the right to make our own choices” (FG#1/P6). This included choosing the food they wanted to eat, wearing the clothes they liked and going to bed when they were tired, rather than when someone told them they should. “I think it’s that we can do whatever we want, we should not be told what to do. And I won’t forget this. One time I was told what time to go to bed. And I said you can’t tell me to go to bed, I’m not tired” (FG#1/P5). They wanted the freedom of choice to do what they wanted and go where they wanted.

### **Being Safe**

For the participants, human rights should enable people to be part of the world, but in a safe way. “Human rights means that we are basically on this earth to make right choices and the right to not be bullied or we have the right to make right choices in a very relaxed and positive frame of mind” (FG#1/P2). Another participant said, “We have the right to choose to walk where we want and be safe. And walk freely without being intimidated (FG#1/unidentified participant). “So we have the right as a society to work in a safe

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environment and be respected in that environment too” (FG#1/P2). Another aspect of being recognized as a person is being respected and safe as such. “When I am in the room or doing something like reading or studying and people just go into the room without knocking and I point to the door and say ‘Hey, door-knock.’ And they say, ‘I don’t have to knock.’ And then I say this is my house, knock ... I feel violated” (FG#2/P3).

### **The Data – Support Providers**

Support providers (paid and unpaid) also talked about human rights for people with intellectual disabilities. Although participants seemed to agree that “it should mirror our own with zero limits” (P1), there was much discussion about the ability of people to recognize their own rights. “The people we support don’t actually know what their rights are” (P4). Another said, “I guess the first thing that comes to mind is limited access to justice. Maybe not being able to necessarily see or access the avenues to pursue when their rights are infringed on” (P2). “For me, ‘X’ has the same rights and should be given the same opportunities to make choices as we all do; however, because he’s non-verbal and lacks the ability to communicate, I have the expectation that all those who support him are looking after his human rights” (P3). This participant also observed that “there’s not enough training to the support staff around human rights.”

### **Rights Supported/Rights Denied**

A major focus in response to ways in which rights are and are not exercised centred around decision/choice making. “Those everyday things that we all take for granted, like what am I going to spend my money on or what I’m going to do with my time, that sometimes people in support, like you really have to make sure that you’re conscious of making sure that those rights are respected, right? That it’s not, ‘Well it’s just easier if we do this tonight’; it’s ‘well what does this person I’m supporting want to do’” (P4). Although it was easy to identify opportunities where people ought to be exercising their rights, all participants had experiences where these opportunities

were not always made available to everyone. These included choosing what to eat, what to wear, where and with whom to live and what to do during the day.

Focus group members agreed that exercising the rights of people with intellectual disabilities often depended upon the willingness of others to support it. These others may be family members, paid support providers, service agencies and/or members of the community. “Even sometimes at the managerial level [of service provision agencies] managers tend not to really respect people’s rights. It’s almost as if under the umbrella of they’re being cared for but we still need to run a home without completely balancing people’s rights” (P1).

### **Systemic Barriers**

Unlike the focus groups with people with intellectual disabilities, the people in this focus group spent most of their time discussing ways in which people with intellectual disabilities are stymied in exercising their rights. Much of this conversation centred on systemic barriers that were frustrating to participants. We will discuss these obstacles in the context of two related systems: a) agencies delivering services/supports and b) the larger provincial system within Family Services, the department that funds services and supports for adults with intellectual disabilities.

### Agencies

Many adults with intellectual disabilities in Manitoba live in group homes, meaning that two or more people share a single family dwelling. These homes are often purchased by not-for-profit agencies that staff the homes, with staffing levels based on the needs of the residents. Inevitably, larger agencies have more homes, more staff members and larger numbers of individuals to support. Such agencies also tend to have more bureaucratic processes and procedures to ensure homes run smoothly. All homes must comply with provincial safety standards and licencing requirements.

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One of the issues with this support model is the simple fact that someone must live with the other people assigned to live in that particular home. “They still don’t have easy access to their own housing. Like, if I hated where I was living or didn’t like my roommates I would just start looking for a new apartment whereas our people don’t have that option” (P1 with agreement from P4). Participant 3 said, “If we’re not happy with the home that would be a very difficult process.” The group home dynamic also means that “easier” trumps people’s rights. “I feel like a lot of times their human rights kind of get ignored when it’s sort of easier to do it another way, or it’s easier to feed everyone all together, it’s easier for this, it’s easier. But I’m constantly saying, ‘It’s not about what’s easier, it’s about what’s best for the people we’re supporting,’ but I think sometimes it just sort of gets forgotten because you’re like ‘we just need to get through the day’” (P 4).

The group home dynamic itself means that residents must do things as a group. This includes eating meals together and going on outings together. Participant 1 reported that in a home s/he worked in, the two people living in the home did not get along. One person suffered abuse as a result. “They would eat supper together but the one would always be trying to control the other one and if the other one was trying to do something on [her/his] own then [s/he’d] get hit” (P1). This participant eventually had to voice this concern up the chain of command to get some resolution. Participant 4 added, “If they’re clearly not enjoying a meal together, why should they be forced to?” Other dynamics include eating only from set meal plans and being restricted in what one can or cannot do in leisure time if others in the group want to do something else.

### The Larger System

Two issues arose that generated a lot of discussion among focus group members: a) employment/daytime opportunities and b) support staff realities.

In Manitoba, the government provides several different daytime options for people with intellectual disabilities. These options include day programs, sheltered workshops and supported employment. These options were critiqued by participants, who first asked, “How is it a choice when it’s super limited?” (P1). Programs billed as “work” options are often unrelated to work as we know it. “They’re not work programs. Most of them are day camps and that was one of the big things for me. If ‘X’'s day was filled with a work program that was swimming and bowling and going for a walk and a picnic then what did he do in his off time?” (P3). Another point of contention in the context of human rights was the sheltered workshop. “In these sort of sheltered workplaces, it is insane to me that someone goes to work every day from nine ‘til three or whatever and they make \$56 every second week. Like that’s insane to me. If you’re there working you should be getting minimum wage” (P4). The reality of these options was summed up by Participant 1: “If I don’t like my job, I can go out and get something and it’s very difficult for people with disabilities to find meaningful employment that gives them a sense of self-worth and self-esteem that continues to include them within the community and makes them feel accepted by the community.”

The second issue that can stand in the way of people with intellectual disabilities exercising their human rights is in the context of the interplay between those requiring support and those who provide that support. “Because people with disabilities are not exactly viewed as members of society or even, I use the term sometimes the ‘throw away people.’ Unless the general population sees people with disabilities as valuable members of our society then the level of care isn’t going to be what it needs” (P1). This participant went on to explain, “With Corrections you have to go through a huge exam period, there’s a psychological test and personality test you have to do just to work with people that are criminals. There’s nothing you have to do to get into this field” (P1). The fact that paid support providers in Manitoba who look after our most vulnerable citizens do not have to obtain a certificate or diploma to work in the field speaks

to the low salaries they are paid, particularly those who work in the community. These low salaries often mean high turnover rates and lower quality of support. “Until they’re seen as productive members of our society ... I think that not only are they seen as third-class citizens but the people that are employed to support them are treated less than as well” (P3). Now that we have described the perspectives of the participants, we will provide our analysis.

### **Analysis**

We began these two small companion studies to come to a better understanding of the meaning of human rights and social justice in the context of people with intellectual disabilities. Because the opinions of these individuals are so often ignored, we felt it was important to give voice to them. Not only could our participants articulate what human rights means to them, there is no question that they recognize and dispute their status on the margins. They insist on taking their place in larger society and their right to have some measure of control over their lives.

Many participants discussed systemic barriers, either express or implied, particularly a lack of choice when it comes to who people can live with, where they live, and the limited options they have during the day in terms of “programming.” This discussion speaks to where people with intellectual disabilities live and spend their days. Some people with intellectual disabilities live in totally segregated facilities, such as institutions. Many people live in congregate settings, such as group homes, and spend their days in congregate settings, such as day programs and sheltered workshops. Often they travel to and from these places in segregated buses. Although the institutions, group homes, day programs, sheltered workshops and buses are all found within our communities, they are also separate from them. They are places where people who do not have intellectual disabilities come to work, but not to stay. They are places that many community members do not think about or even know about, unless a group home opens in their neighbourhood. Then this situation can cause no end of aggravation for fellow neighbours, who



worry about the plunging values of their homes and vow, “Not in my backyard.”

Taylor (1988) has written extensively on what he calls the continuum of service options. This continuum is premised on the notion that services will be provided to people with intellectual disabilities on a scale from most restrictive, such as those provided in segregated settings, to least restrictive, such as those provided in the community. He has provided an insightful critique of this model of service provision, arguing that the hallmark of the continuum “sanctions infringement on people’s rights” (Taylor, 1988, p. 47). It is telling that people with intellectual disabilities must start from the premise that they are required to earn a space and place in the community when such space and place is guaranteed for other citizens. From a human rights perspective, recognizing that everyone deserves a space and place is a key starting point. An analysis of this model causes us to ask the question: how can we offer a place in our communities to people with intellectual disabilities if we see them as not entitled to take up space?

Wolfensberger’s (2013) roles, into which marginalized people are cast, can help to provide such an explanation. If we see these people in the role of the other, as non-human or somehow less than human, we are far more likely to look the other way when their rights are infringed or disregarded and they are relegated to the margins. People with intellectual disabilities have been systematically devalued and disrespected in various ways throughout their lives. One of the ways in which this devaluation is expressed is through the service delivery system. Although our society recognizes that we have to provide some sort of support for these individuals, we can “get away with” containing people, rather than enhancing their life opportunities. We can justify this practice using the rhetoric of what people “need” and what is “appropriate.”

In addition to thinking about how roles impact the space and place for people with intellectual disabilities today, it is also worth considering several of Nussbaum’s capabilities: a) bodily integrity (including

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being able to move freely from place to place); b) emotions (being able to have relationships and attachments); and c) affiliation (engage in social interaction and be treated as “a dignified being whose worth is equal to others”). Discussions about human rights in all three focus groups were clear in revealing that the lives of people with intellectual disabilities fall short when measured against even three capabilities. The idea of the ability to move freely is compromised when living accommodations are arranged for people based on placements available, rather than on actual choice. This also holds true for daytime activities, for which choice may be unavailable or, at best, between two or three equally poor alternatives.

Being able to build and maintain personal relationships has always been an area of concern for adults with intellectual disabilities. People often see staff members as friends. However, agency staff members tend to move around frequently due to systemic issues such as low pay and little value to the work. This makes it difficult for these relationships to grow. Because people must live with others chosen for and not by them, there may be also little opportunity to willingly socialize with housemates who may not be socially compatible. Finally, people with disabilities have long been seen as asexual beings. This makes it nearly impossible to have romantic or sexual relationships, as these kinds of relationships are not expected or encouraged. Those participants who were with loving partners were very pleased to proclaim as much and deeply valued their fiancés/fiancées.

There were many examples from all focus groups where people told stories of not being seen as a dignified being. In fact, the idea of being valued, included and accepted for who they are was the hallmark of the focus groups involving people with intellectual disabilities. We heard, over and over again, that participants considered their acceptance and humanness to be of utmost importance to them. When people are excluded from true community participation, when they are assumed to be unable to make decisions for themselves, when they are managed in their daily lives, when they

are precluded from working for real wages, when they are left to waste their days in mindless day programming, when their voices simply do not count, their human rights are being seriously and grievously trampled upon. Adults with intellectual disabilities are clearly capable of engaging in a dialogue about human rights. However, no human rights will be accorded to people or individuals as long as they are without space, and as long as they are seen, consciously or unconsciously, as less than human and unworthy of being included.

What Wolfensberger's and Nussbaum's work forces us to do is to look beyond the rhetoric of what people espouse and instead examine what people with intellectual disabilities are actually getting. We can compare that to what valued citizens receive. When we do this, we can plainly see that there is a discrepancy. People with intellectual disabilities are not able to access many of the spaces and places that other citizens frequent, resulting in further marginalization and a denial of their human rights and social justice principles.

### **Moving Forward**

Human rights and social justice are ideal topics to discuss when considering the extent to which people with intellectual disabilities can claim both space and place in our societies and communities. Since at least the time of the ancient Greeks, these individuals have been seen as lesser beings, lacking the ability to reason and think rationally. Roman laws introduced the concept of guardianship, which continue in various forms today. Thinkers and early physicians from the seventeenth and eighteenth centuries tried to find cures for people with intellectual disabilities, unwilling to see these them as simply another variation of human life. By the nineteenth century, with the emergence of large institutions, people were being excluded on a greater scale, ultimately resulting in their congregation and segregation in human warehouses.

Today, even as the disability movement gains traction and more and more rights are recognized, people with intellectual disabilities still

live their lives as marginalized members. This was confirmed for us by the experiences of people with intellectual disabilities and the people who support them. All participants were very clear that because people with intellectual disabilities are not being heard by others, they have difficulty taking their place in larger society. This is manifested in people refusing to respect their choices and decisions, failing to recognize them as people and causing them to feel unsafe. Support providers also pointed to systemic barriers found in individual agencies and the larger service system. These realities are unlikely to change until we confront and address our beliefs and attitudes about people with intellectual disabilities and the lives they could and should be leading.

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