

CANADIAN JOURNAL OF

Disability Studies

Published by the Canadian Disability Studies Association · Association Canadienne des Études sur l'Incapacité

Canadian Journal of Disability Studies

Published by the Canadian Disability Studies Association

Association Canadienne des Études sur l'Incapacité

Hosted by The University of Waterloo

www.cjds.uwaterloo.ca

cjdseditor@uwaterloo.ca

Factors Contributing to the Construction of Personhood of Individuals with Intellectual and Developmental Disabilities in Kinshasa, Democratic Republic of the Congo

Heather Aldersey, Ph.D.
Research Associate, Mental Health and Society Research Group
Douglas Mental Health University Institute
haldersey@gmail.com

Ann Turnbull, Ph.D and Rud Turnbull, Ph.D
Co-Directors, Beach Center on Disability and Distinguished Professors in Special Education at
the University of Kansas

Abstract

For support for people with intellectual and developmental disabilities (IDD) to be relevant and effective, support providers and policy makers should consider the social and cultural construction of IDD when creating, providing, and funding support. In this article, we adopt the O’Conner et al. (2007) conceptual framework for understanding personhood (i.e., subjective experience, the interactional environment, and the socio-cultural context) to discuss key factors related to the construction of personhood of people with IDD in Kinshasa and the impact that this construction may have on creation of and/or access to support. We conclude by suggesting various future support interventions that may facilitate the achievement of full personhood for individuals with IDD in Kinshasa and arguably in similar contexts.

Keywords

Personhood, Intellectual and Developmental Disability, Kinshasa, Democratic Republic of the Congo, Africa

**Factors Contributing to the Construction of Personhood of Individuals with Intellectual
and Developmental Disabilities in Kinshasa, Democratic Republic of the Congo**

Heather Aldersey, Ph.D.
Research Associate, Mental Health and Society Research Group
Douglas Mental Health University Institute

haldersey@gmail.com

Ann Turnbull, Ph.D and Rud Turnbull, Ph.D
Co-Directors, Beach Center on Disability and Distinguished Professors in Special Education at
the University of Kansas

In this article, we draw upon the findings from a seven-month study that we conducted in Kinshasa, Democratic Republic of the Congo (DRC), to discuss factors that contribute to the construction of personhood (i.e., the social standing or status) of individuals with IDD in Kinshasa. Specifically, we address the research question: What factors contribute to the construction of personhood of individuals with IDD in Kinshasa and how might these factors affect current and future support for people with IDD?

We will provide a brief overview of the site of study and the constructs of IDD and personhood. We will then utilize the O'Conner et al. (2007) framework for understanding personhood to discuss key factors related to people with IDD in Kinshasa. We highlight the impact that personhood may have on the creation of or access to support and we conclude with suggestions for future support interventions that may facilitate the achievement of full personhood for individuals with IDD in Kinshasa and in other similar contexts.

Kinshasa, DRC

The Democratic Republic of the Congo is a large Central African nation with a complicated political history, including two successive wars between 1996 and 2003. Unrest continues within

and among national and international actors along its eastern borders today. In part because of its political struggles, the DRC government has been unable to shoulder the full responsibility for the provision of social services (such as education, healthcare, or public transportation) that are often government-operated or supported in other nations (de Coster, 2012; Titeca & de Herdt, 2011). Instead, Congolese residents, local and international non-governmental organizations (NGOs), religious institutions, and community-based solidarity networks often fill the gap in the provision of social services (CIDA, 2012; Titeca & De Herdt, 2011; Trefon, 2011).

Congolese employ a range of viewpoints on the explanation and treatment of disability, with causal descriptions including biomedical, cosmological, and environmental aspects of impairment (Aldersey, Turnbull, & Turnbull, In press; Devlieger, 1995). A study of illness (and disability) perceptions in Central Africa identified natural; physical and environmental; social; broken taboos; heredity; witchcraft, sorcery, and poisoning; and punishment from ancestors to be the primary causal understandings of illness (Sabuni, 2007). All seven categories fall under the classification of either "natural" or "metaphysical" (Sabuni, 2007). Causal understanding of disability can have an important impact on local understanding of personhood. As such, we discuss causality of disability in Kinshasa at length elsewhere (Aldersey et al., In Press) as well as below.

Kinshasa, the capital city of the DRC, is one of the largest cities in sub-Saharan Africa. It has a population that exceeds nine million, and amounts to over 12% of the population of the entire country (De Herdt & Marivoet, 2011). Many Kinshasa residents live on less than \$50 per month, which is barely enough to cover food expenses (Trefon, 2004). In spite of persistent and debilitating poverty present in Kinshasa, the city nevertheless offers disability-related infrastructure, such as special education services and disability rehabilitation centers, for those

who are able to afford it. Such services are rare or nonexistent in many Congolese locales outside of the capital city. Kinshasa is also home to a multitude of vocal disability-rights organizations which are working tirelessly to expand support and increase government involvement to improve the quality of life of persons with disabilities nationwide (Aldersey, 2013).

IDD and Personhood

We defined IDD as intellectual function and adaptive behavior (everyday social and practical skills) that differs significantly from what is normative in a person's society; and this difference originates before the age of 18 (AAIDD, 2011). Personhood, widely used in the discipline of anthropology and others, refers to society's understandings and laws regarding how an individual is represented and treated by others (Gotto, 2009; Jackson & Karp, 1987; Janzen, 2002). Kitwood (1997) defines personhood as "the standing or status that is bestowed upon one human being, by others, in the context of relationship and social being" (p. 8). Devisch (1993) describes how the Yaka ethnic group in the DRC sees the body as being like cloth on a loom, continuously woven throughout life, yet bearing a biographical tapestry. It is through working on a loom that Yaka people come to understand life as being like weaving, through crafting social relationships and creating cosmological understanding. Janzen (2002) has also used weaving as a metaphor and argued that it is useful to understand personhood by thinking of it as a woven social fabric that includes ideologies, economies, histories, and ecologies. This fabric is dynamic; it is constantly woven in shifting patterns, adjusting values, and goals inherited from the past to the problems and realities of the present (Jackson & Karp, 1987). Thus, as society changes over the years, so does the conceptualization of and criteria for obtaining personhood within that society.

In a review of the literature addressing the personhood of people living with dementia, O’Conner et al. (2007) developed a framework for understanding personhood. The framework is comprised of three key dimensions: subjective experience (e.g., awareness of self, personal life experience, elaboration of strengths and needs), the interactional environment (e.g., interactions with others, relationships, communication, and use of physical space), and the socio-cultural context (e.g., values, norms, beliefs, and assumptions; socio-economics; organizational culture). It is important to note that this framework was developed in a Western disability context, and thus, we acknowledge critics who may caution against applying a Western analytical model upon non-Western cases and settings. We argue that in the absence of the ideal - an existing model for personhood and IDD created by Congolese authors – the O’Conner et al. framework provides an important initial framework for analysis, and indeed one which incorporates the socio-cultural context as an integral component. Moreover, we found the O’Conner et al. framework to be particularly helpful for our purposes because it is created not only for understanding personhood but also for supporting personhood and because it examines the life of people whose intellectual functioning may be compromised.

Methods

We utilized a qualitative approach that consisted of participant observation and semi-structured interviews. The primary author engaged in data collection in the field and analysis and write-up. The second and third authors engaged in data analysis and write-up. Participant observation occurred in homes, on the streets, in schools and vocational centers specialized for people with intellectual disabilities, and during association meetings and outings. The primary author conducted semi-structured interviews with 19 adults with IDD, 24 family members of a

person with IDD, and 60 community members: 24 without experience with people with IDD (e.g. vendors, pastors) and 36 with experience with people with IDD (e.g. psychologists, teachers).

Sampling

Sampling of participants for all aspects of the study was theoretical: We chose in a strategic way the next people to interview to obtain data for comparison to those with whom the primary author have already talked (Agar, 2008). Table 1 outlines further sampling variation considerations.

Table 1
Participant Sampling Grid

Demographic	People with IDD	Family Members	Community Members
Gender	Male Female	Male Female	Male Female
Neighborhood	City Center (e.g., Gombe) City Outskirts (e.g., Kimbanseke)	City Center City Outskirts	City Center City Outskirts
Experience with IDD	N/A	N/A	Disability Service Provider Friend(s) or member has extended family member with IDD No experience with IDD
Family Structure	Nuclear (mother/father) Single parent Grandparent-headed Extended family- headed	Nuclear (mother/father) Single parent Grandparent-headed Extended family- headed	N/A

We sampled participants from a range of sources, including a self-help association (*L'Association Nationale des Parents des Enfants Vivant avec Handicap Mentale en RDC*) and through contacts of our research assistant, Delphine Assumani, and the Association of Centers for People with Disabilities in Central Africa (ACHAC). Ms. Assumani is the secretary of ACHAC, a longtime advocate for disability rights, and a person with a disability herself. She facilitated the initial contact with the majority of the study participants and enabled the first author's entry as participant observer in the specialized schools and centers. Her long service and visibility in the above associations and institutions enabled us to gain the trust and interest of various potential study participants, many of whom we arranged to interview at later dates.

Data Collection

Initially, the first author engaged solely in participant observation in eight homes of families that had members with IDD and the wider community surrounding them. Although she spent an entire week with each of the eight families, she continued interacting with and observing these families after the initial week when she saw their children in the schools, participated in association meetings, and paid social visits. She joined participants to do daily chores, visit their workplace, go to the market, and on various association-related activities and trips. She also observed in eight different schools that provide special education services to children with IDD. In all of these experiences, she observed exchanges relating to personhood and disability status, such as perceived ability or inability to participate in mainstream social activities. She wrote field notes every evening or as soon as possible after an experience and the second and third author read field notes and other research memos and provided initial analysis and feedback throughout the data collection process.

For semi-structured interviews, we used a separate protocol of questions adapted slightly for each category of person. We used interviews to build upon themes already identified through participant observation and to explore issues related to personhood. We audio recorded and transcribed all interviews. Table 2 outlines the interview questions.

Table 2
Semi-Structured Interview Questions

Adults	Family	Community Members
<ul style="list-style-type: none"> • Would you please introduce yourself? • Describe a typical day in your life for me? • What do you like to do most? • Do you regard yourself as having a disability? <ul style="list-style-type: none"> ○ Why or why not? • Who told you that you have a disability? <ul style="list-style-type: none"> ○ When? ○ Why did they say you have a disability? ○ What difference in your life has it made that people think you have a disability? • Who are the people who are most helpful to you? • Who are the people who are least helpful to you? • Where do you go for help when you need it? • What kinds of things in 	<ul style="list-style-type: none"> • Please tell me about your family. <ul style="list-style-type: none"> ○ Who are the members of your family? ○ How did they become members – by marriage, by birth? • What do you do on a day-to-day basis? What do you do on a typical day? • Tell me about (name). <ul style="list-style-type: none"> ○ What do you like most about (name)? ○ What are some of your biggest challenges (name) presents to your family? ○ How does your family respond to those challenges? ○ What are the most positive aspects of life with (name)? ○ What does (name) do best? • Do you believe (name) has an intellectual disability? <ul style="list-style-type: none"> ○ Why or why not? ○ Who has told you (name) has IDD? 	<ul style="list-style-type: none"> • How would you define a person with IDD? (If you were to see a person on the street, what would make you think they had IDD?) • Have you ever had any experiences with such a person? Could you tell me about them? • To what extent have those experiences shaped how you see people with IDD? • Do you believe they are treated differently in their communities? How? • Whose responsibility is it to provide support for people with IDD? • Can you provide examples of a community valuing or not valuing a person with a disability or having/avoiding responsibility to support the person and the person’s family? • If you found out that one of your children had IDD,

<p>your daily life do you often need help doing?</p> <ul style="list-style-type: none">• What kind of help is most useful to you (discuss emotional, physical, financial, informational support)?• Would you describe for me a time when you felt life was going really good?• Would you describe for me a time when you felt life was going really bad?• What is the importance of education in your life?• What is the importance of religious organizations in your life?• What is the importance of self-help groups in your life?• What are your dreams for the future?• Is there anything else that you think is important for me to know but that I have not yet asked?	<ul style="list-style-type: none">• What difference does it make, in terms of your quality of life, that you or other people regard (name) to have IDD?• What changes have happened in your family life as a result of (name) being a member of your family? What really hasn't changed at all?• How have your neighbors and extended family responded to (name)?• Where do you go for help when you need it?• What kinds of things in your daily life do you often need help doing?• What kind of help is most useful to you (discuss emotional, physical, financial, informational support)?• When have you, (name), and your family been happiest? Please give me an example of a particularly happy time for your family.• When have you, (name), and your family been most challenged as a result of (name's) disability? Please give me an example of a particularly challenging time for your family.	<p>what first thoughts would run through your head?</p> <ul style="list-style-type: none">• What is your understanding about what goes on in various settings of support [society, family, government]?<ul style="list-style-type: none">○ Do you think such settings are useful?○ Why or why not?• Would you ever hire a person with IDD to work for you? Why or why not?• Would you accept if one of your relatives wanted to marry a person with IDD? Why or why not?• Do you have any other thoughts about people with IDD that I have not yet asked you but you would like to share?
---	---	---

- What are your dreams for the future?
 - Is there anything that I have not yet asked but you think is important?
-

Data Analysis

We conducted data analysis concurrently and recursively within and across observations and interviews, using a constant comparative method (Charmaz, 2006; Patton, 2002) to identify emerging themes. As we wrote up field notes and transcribed interviews, we engaged in preliminary analysis and noted observations we wanted to make in the future and new questions that we needed to ask. Transcription of interviews began while the first author was in the field and enabled us to note key themes that were coming up and expand upon these themes in future interviews. We imported all field notes, memos, and interview transcripts into qualitative analysis software (NVivo, 2010) to identify and organize analytical categories.

At the end of data collection, we presented a summary of the research and highlighted emerging themes to approximately 60 participants (which represents a 59% attendance rate). At this member-check we encouraged attendees to agree with, disagree with, or provide additional information about what we presented. We also provided paper surveys with open-ended questions for any written reactions to the presentation. The general response to emerging themes was positive, and there were no major disagreements with data presented, although a number of participants requested that the researchers ensure they present more of the negative aspects of the lives of people with IDD in Kinshasa, in addition to the positives.

Ethical Considerations

This study was approved by the University of Kansas Institutional Review Board before researchers entered the field. Before commencing participant observation or interviews, we explained the study to potential participants, and they signed an informed consent form written in French and Lingala. We offered them the option to either keep their identity confidential or waive confidentiality. We applied pseudonyms to the data of those who chose to remain confidential (approximately 10%).

Findings

In the section that follows, we outline findings in the key personhood domains of subjective experience, the interactional environment, and the socio-cultural context (see Figure 1).

Construction of Personhood

Connects to:

Subjective Experience	Interactional Environment	Socio-Cultural Context
-Awareness of self	-Language	-Self-Sufficiency
-Elaboration of strengths and needs	-Neglect	-Low expectations
	-Mockery	-Investment
	-Taking Advantage	-Contribution
	-Marriage and children	

Figure 1.

Subjective Experience

This aspect of understanding personhood includes awareness of self and elaboration of strengths and needs (O'Conner et al., 2007).

Awareness of self. Awareness of self is how a person sees herself in relation to the world around her. This awareness was particularly apparent when discussing issues related to disability and how participants with IDD thought they "fit" with the rest of the community. Participants with IDD oftentimes did not consider themselves to have IDD. They argued that they were just the same as everyone else and wanted to be treated that way. It is interesting that when those participants who refused to accept that they had IDD were asked if others mocked them or told them that they were unintelligent, nearly all could recount experiences where members of the community told them that they had IDD or used the more derogatory term *kizengi* (idiot) toward them. No adults ever identified with the identity of *kizengi*. When we asked one adult with IDD what she thought about the word, she said "It hurts my heart. [Interviewer: Why?] Because people say I'm *kizengi*, but I am not *kizengi*. Would God create a *kizengi*?" (Angele, adult with IDD). Participants who did accept that they had IDD often engaged in narratives of sickness to explain this difference.

Me, the sickness started since my childhood, since I was 4 months old. So when I was born, I was born normally, but when I arrived at the house, I became sick, I just cried and cried and cried. ... They took me to the hospital, and the doctor told my parents that I had meningitis. (Chantal, adult with IDD)

Elaboration of strengths and needs. When asked to elaborate on their strengths and needs, most participant responses were centered on the idea of contribution. For example, many participants with IDD cited cleanliness and diligence as their strongest traits, particularly as it relates to doing housework and contributing to the household. When we asked adults with IDD what they thought their best qualities were, they often maintained how well they clean the house, wash the dishes, cook, etc. Being able to contribute to household affairs was a source of pride for many respondents.

Similarly, when asked to elaborate on needs, most adults with IDD discussed needs that, if met, would enable them to contribute more, both to their homes and to wider society. For many adults with IDD, their dreams for the future were associated with lucrative work. Generally, when people with IDD expressed a desire to have money, they desired money not only to meet their own needs but also to be able to contribute to the family and the community. For example, a number of people with IDD expressed a desire to be able to earn money so that they could contribute in their churches. They saw others coming forward with financial contributions to help the church or to help parishioners (e.g., the church comes together to buy someone in the congregation a wedding gift) and wanted to do the same.

Interactional Environment

According to O'Conner et al. (2007), the interactional environment of people with IDD involves interactions with others, relationships, and communication. For this study, this includes language, neglect, mockery, taking advantage, and marriage and children.

Language. The language used to describe people with IDD is largely negative. It also often has aspects that hint at metaphysical causation, again affiliated with the negative. When speaking in French, family members or members of the community would sometimes refer to a person with IDD as someone who is *gâché*, meaning wasted, ruined, or squandered. For example, when we asked a community member what he would think if he had a child with IDD, he responded that he would be very upset: "Because that child would be *gâché*, there is no hope. For every parent that would make him upset." (Celestin, no experience with IDD) People with IDD were often referred to as *fou*, meaning crazy. A person with IDD is often pejoratively referred to in

Lingala as *kizengi*, idiot, or *zoba*, stupid. In simple, everyday life, Kinshasa call those who do not have IDD *kizengi* as a way to insult them.

When one sees a person with IDD, they take them in Kinshasa terms, *kizengi*, that signifies imbecile, someone who cannot be considered, someone who has no value. And even us, when we walk with our children, we are ridiculed! 'Look... is that a teacher?' Our teacher friends here in Congo, they call us the teachers of imbeciles! (Esperant, support provider)

Neglect. In addition to negative language, we heard stories of neglect of people with IDD. Families and community members told of children with IDD who were deprived of food, water, and medical care by their families in the hopes that the children would die quickly. Other instances of neglect were less severe, but nonetheless distressing, such as paying for all children to go to school or have new clothes except for the child with IDD. As one special educator laments,

Really, they are not treated well. You will see, [the person with IDD] will have brothers and sisters who study. But for him, parents don't pay the school fees, sometimes when school has already come back in session, the social worker has to go to the family homes to encourage the family to simply send their child to school! You will see that they come to school all dirty. Sometimes, in my class the little Miranda [name changed] sometimes she smells like pee. You smell her skirt, and she has peed in her clothes. She returns to school the next morning, and she still smells of pee. They don't clean her. It's sad. (Anne Mereille, support provider)

Mockery. A number of special education teachers have witnessed their students being mocked on the streets. This is in line with observations made during participant observation with families that have members with IDD. Yet, although participants gave the impression that most people with IDD were treated poorly, oftentimes with firsthand accounts of witnessing teasing and neglect, this difference in treatment of people with IDD was certainly not all that the observations showed us. Much of the time, the adults and children with IDD with whom the first author interacted were clean, healthy, and well-loved in the family and community.

Taking advantage. Another aspect of the interactional environment described by participants was when individuals would take advantage of people with IDD because of their difference in intellectual capacity. For example, as one man with IDD told us, with the help of his sister filling in the blanks, that he works in a flour mill, transporting flour to the market for businesswomen. Instead of paying him the going rate of 1000 francs for a large bucket, they will often try to pay him 200 francs, thinking that he will not know the difference because of his disability. A community member explained to me that people with IDD are often strong and diligent, and because of this, others will exploit them for their labor:

[The general population] consider him [a person with IDD] as an animal. ... For example, to dig a hole. One would prefer a crazy who knows well how to dig a hole, and he will ask for nothing. Ha! And plus he will do it quickly. In the time it takes someone who is normal to dig a hole, he could finish [digging] two or three! ... So some will treat them like they are sick; some will treat them like a crazy, *moto mpamba*, useless person; and some will consider them like a good manual laborer, a good machine to exploit. (Robert, no experience with IDD)

We also heard numerous second-hand stories of sexual abuse of people with IDD from a number of community respondents. A woman with IDD recounted to us an experience with a pastor who took her away from her home under the guise of "healing" her, but then took her to a nightclub and then to a hotel room and had sex with her. But, when looking at issues related to sex, marriage, and childbirth for people with IDD who often do not have the capacity for consent to sexual relationships, often the line between abuse and valorization is complicated, as explained by one special educator:

There was a young woman with IDD, I am not sure if you met her, she had three children with a man. The man was never put in prison; rather the woman had testified that the child was his, they called him [to the court] and he said "Yes, OK, this is my wife". They didn't make a problem... And plus, since the man had accepted to take care of the children, that stopped there for the family. Perhaps, I don't know how they saw things, but maybe this man valorized their sister by giving her a child, two children, three children, but that's a bit

difficult. But, in principle, that is a person who should be in prison to make an example for others. (Oscar, support provider)

Marriage and children. Marriage and having children are important aspects of the interactional environment that contribute to full personhood in Kinshasa society. Adults with IDD often expressed a desire to be married; however, others had no interest in marriage. Many family members of people with IDD also expressed a desire for their member to be married; however others admitted that because of their members' IDD, they have lost hope that their family member will ever marry one day.

Community members were often divided about whether people with IDD should marry, either with other people with IDD or with people who do not have disabilities. Many people, when asked if people with IDD could marry, responded in the exact same way: "Of course! They are people!" (Ralph, support provider). If community members did not agree with the idea that people with IDD should marry, the reasoning that they gave was usually related to children. For example, some feared that a couple with IDD would produce children who had IDD. Others feared that a couple would not be able to take care of the children. Interestingly, a number of families expressed a desire for their female member to get married, particularly because she would then have children who could take care of her. We encountered four women with IDD who were not married but who had children. In general, their children were a positive and socially valorizing force, giving the mother meaning and social standing in her family and in society. For example one mother of a woman with IDD told me: "This is the best thing that has come from her, since I only gave birth to girls, she gave me four beautiful grandsons!" (Douceur, mother of adult with IDD)

Socio-Cultural Context

The socio-cultural context of personhood for people with IDD consists of various social values, norms, beliefs, and assumptions. O’Conner et al. (2007) highlight socio-cultural contexts of ideas related to race and ethnicity, social location, organizational/institutional culture, and societal discourses (e.g., shared understanding of autonomy, independence, and usefulness). In this section we highlight the most salient values, norms, and beliefs that emerged in this study’s findings: self-sufficiency, low expectations, investment, and contribution.

Self-sufficiency. People with IDD were considered in a more positive light when they experienced high levels of independence or self-sufficiency. Indeed, most special education teachers cited student self-sufficiency as an overall goal of their work. Members of the community without experience with IDD also argued that a way for people with IDD to become integrated and “useful” in society is to become self-sufficient and, conversely, when people with IDD were significantly dependent on others, they were seen as a burden on society and less worthy of full personhood.

For most of the families we interviewed, self-sufficiency, particularly self-sufficiency through education and ultimately paying work, was their major dream for their member with IDD. Assuring their child’s self-sufficiency is an important way for parents to reassure themselves that their son or daughter with IDD will have a desirable life even upon the death of the parents. One family of a young woman with IDD also cited self-sufficiency acquired through work as a way for her to be less likely to be taken advantage of by men.

Low expectations. Societal expectations for people with IDD are low. Parents often communicated a sense of low expectations for their child with IDD as it relates to their ability to learn, work, or interact positively with others:

I told myself, we are going to put her in school, ok, but who will be with her there? For me, at least if she had intelligence, I could accept, but an intellectual disability and a physical

disability, both at the same time, even her sisters and brothers told me, "It is not worth it, we will always worry, who will be with her to take her to the toilet, all that" That is why we didn't allow her to study. (Sarah, mother of adult with IDD and visual impairment)

Members of the community also often had pre-existing ideas and low expectations about the capacity of people with IDD. In the lucrative work place, participants often denied that people with IDD would be capable of doing a task or feared that the individual would hurt himself on the job, not acknowledging that people with IDD can have a very wide range of capacities and abilities.

Investment. In Kinshasa society, children are generally seen as an investment for their progenitors. In absence of a true system of social security and retirement, children are expected to meet their aging parents' needs. Because common understanding is that people with IDD are often both a physical and financial burden and generally incapable of studying or obtaining and holding a job, they are seen as a poor investment for families.

[Neighbors told me] "You must leave him, throw him somewhere, wake up in the morning at 4 am and get rid of him." ... So, I don't like to be around such people. I have stopped being around them because they tell me, "What good comes of him? Is this child going to become someone?" When you have a child, this child must take care of you when you are old. They must bring more sons into the family. So, they tell me that Jeremy is useless. He's a throw-away child. I said, "No, I can't just get rid of someone like that- we're attached to him!" (Salome, mother of child with IDD)

Special school administrators told of parents who would invest hundreds of dollars in the education of their children without disabilities but refuse to spend anything on the education of their children with disabilities: An educated child without a disability will provide returns to the family when that child goes on to find a job and care for aging parents; whereas a child with IDD will never provide a return on an educational investment. Some families even recounted experiences where medical professionals viewed spending time or money on healthcare for the member with IDD as a poor investment of the family money.

Although ideas of investment usually affected people with IDD in the negative sense, a number of families proudly shared how investment in their member with IDD had truly paid off in helping him or her become a full member of society.

We knew that he had an intellectual disability, but he didn't show it very much because my father made sure that he was well taken care of. Father sent him to good schools ... [and after his training] he was a person who was integrated. He created his own carpentry workshop at Masina. He worked, and he brought the fruits of his labor home to the family. He helped sustain the family also! My own brother! ... It's a great success for the family. Because we invested in him and he gave back the essential. (Gabriel, brother of an adult with IDD)

Contribution. Related to ideas of investment, a full person in Kinshasa is one who contributes to society in various ways. Respondents highlighted contribution in three major categories: lucrative work, house work, and social life.

The first aspect of contribution in Kinshasa society is through lucrative or remunerable work. This sort of work is services exchanged for money and can be anything from shining shoes informally on a street corner to running a large business or working in a non-profit. If one is able to do work and make money, this provides one with higher social standing or status. Work helps a person with IDD achieve self-sufficiency, a key social value discussed above.

Even if an individual with IDD does not engage in lucrative work, many are still able to contribute to society through chores and other house work. Thus, a person with IDD who is particularly apt at house work may be highly socially valorized both by the family and by the wider community. This is particularly the case for women with IDD, because in Kinshasa it is accepted practice for women to choose to engage solely in house work and to not work outside of the home; however, men with IDD were still highly valued when they contributed to household work as well. When we asked families what they thought the greatest qualities were

for their member with IDD, most often families would sing praises about how well the individual helps around the house and how useful he or she is to the household.

Finally, even if people with IDD are unable to contribute to society through lucrative work or house work, they were still able to achieve higher status in society if they could contribute to others through social contact.

I go and see my family members. Even if they don't come to see me, I go see them anyway. I go to my aunt's, my maternal uncle's. They even call me the head of the family because I always go and visit everyone. One of my aunts was sick. She could only get out of bed with difficulty. I would go and help her from time to time when she wanted to get up. (Mbiya, adult with IDD)

People who provided support to people with IDD said that they often did it because they liked their personalities and the atmosphere that they create. They noted that oftentimes they are funny, highly spiritual, and have a lot of love and consideration for others.

In sum, even if people with IDD are considered "different" and treated negatively because of this perceived difference in Kinshasa, this is not the case for every individual; indeed many individuals are highly loved and valued in their families and communities. A number of ways to increase social value and to combat a sense of difference is through self-sufficiency, investment, marriage and children, and contribution in the forms of lucrative work, house work, and social contact.

Discussion

In this section, we summarize the findings from this study. We complement these findings with a brief discussion of causality as it relates to the personhood of people with IDD. Finally, we outline potential limitations and discuss some of the major implications for future research, policy, and practice.

Summary of Findings

The findings of this study were organized in line with O'Connor et al.'s (2007) framework for understanding personhood in the three domains of subjective experience, interactional environment, and socio-cultural context. The data from this study fit well within the O'Connor et al. framework, and thus we argue that this framework, originally created to examine the personhood of people with dementia, can also apply to people with IDD.

The data from this study illustrated the subjective experience of 19 adults with IDD in Kinshasa, particularly the ways in which they see themselves, either as not having IDD or as having IDD but understanding a medical causation behind the disability. Subjective experience was also captured in the ways adults with IDD elaborated on their strengths and needs and particularly demonstrated how people with IDD value themselves as it relates to contribution in lucrative work and around the household. The theme of contribution also arose, along with the interactional environment theme of marriage and children and the socio-cultural themes of self-sufficiency and investment, as important ways for people with IDD to claim value in society and methods through which they may become closer to achieving full personhood. Finally, these findings have demonstrated that although there may be a number of potential ways for people with IDD to improve their social standing in society, in general, people with IDD in Kinshasa are not yet accorded full personhood. This lowered status was demonstrated not only in the interactional environment, through the themes of language, neglect, mockery, and taking advantage but also in the socio-cultural context themes of self-sufficiency (if the IDD is such that it renders a person not self-sufficient), low-expectations, and investment. Ultimately the ability of a person with IDD in Kinshasa to achieve full personhood seems to lie in their ability to engage in social relationships and contribute to society. Even the theme of self-sufficiency, at

first glance an individualistic aspect of personhood, becomes social because this self-sufficiency is valued as a way to move the family and community forward, as opposed to being a "burden" on others. This finding aligns with Whyte and Whyte (1998) who, in the context of personhood in Uganda, argue that individual achievement is valued largely because those who are successful will be able to help their relatives.

Personhood is not static for people with IDD in Kinshasa. People with IDD are often excluded, neglected, and lack full personhood in society. Depending, however, on one's individual capabilities (particularly one's ability to be self-sufficient, contribute, marry and have children), a person with IDD can also enjoy full personhood or very nearly full personhood. This complicated construction of personhood as changing for each individual aligns with the scholarship of Whyte (1998) who studied the personhood of people with IDD in Uganda and argues that "managing as a social person involves a variety of skills that individuals display to a greater or lesser extent. ... These abilities overlap and facilitate one another" (p. 155). As our results often showed, personhood of people with IDD in Kinshasa often had a social character to it; people achieved full personhood through the performance of relational tasks (e.g., marrying and having children, contributing, providing a return on an investment). This type of personhood is what Whyte (1998) calls "sociocentric personhood;" in this characterization of personhood "all of the capacities for interaction are embodied in individuals; but in practice competence is always a function of the social situation" (p. 172).

Personhood and Causality

The findings from this study are connected to a complementary study (Aldersey et al., In Press) of the impact of causality on the personhood of people with IDD in Kinshasa. In this study

we demonstrate that personhood is affected by conceptions of how IDD has come to exist in an individual. Generally, people understand IDD to arise due to biomedical or metaphysical causes, or a combination of both. Our use of the term "metaphysical" mirrors language employed by Congolese researcher Sabuni (2007) in his study of understandings of disability and illness in the Congo. There is extensive literature on ideas of difference and misfortune on the continent of Africa (e.g., Corin, 1998; Devlieger, 1995; Livingston, 2005; White, 2004). These authors note that often, sources outside the tangible world, such as God, ancestors, spirits or sorcerers, are just as important as more tangible factors, such as nature and biomedicine, to the onset, maintenance or remediation of difference or (mis)fortune. For example, Whyte (1998) notes that mental disability in eastern Uganda is often dealt with in an explanatory idiom that posits spirit and human causes for misfortune, where spirit refers to the ancestors and the use of sorcery.

Depending on the attributed cause of IDD, people may be stigmatized or pitied to varying degrees. Causality may have a number of impacts on the additional factors impacting the construction of personhood identified in this study. For example, when there is a metaphysical causation attributed to personhood, people with IDD may be subject to greater degrees of mockery or neglect. Causality may impact ideas of investment (e.g., a family would not want to invest in a child that is a sorcerer; a father may invest MORE in a child with IDD if he thinks he is the cause of a child's IDD due to his use of fetish) and the opportunities ultimately provided to an individual with IDD (e.g., an employer does not hire a person with IDD because he fears the individual is a sorcerer and wants to avoid potential negative repercussions that may arise from having him in the workplace). Although space does not permit a greater discussion of the implications of causality for the personhood of a person with IDD, it is important to note that

ideas of causality may play a strong influencing factor upon a number of the themes identified in this article.

Limitations

One limitation of this study is that although we heard many second-hand stories of family neglect, we were personally unable to observe such neglect or interview people who had actually abandoned their family member with IDD. That was so, even though we crafted sampling efforts in an attempt to represent a diverse range of participants and specifically (but unsuccessfully) tried to find families who neglect their members with IDD. There is likely a continuum of treatment of people with IDD in Kinshasa, and we may have been welcomed only into the circle of people who were proud of their member and who were unashamed of the way they treated him or her. This is a potential limitation in the population represented in this sample. However, it is possible that discourse around abandonment and abuse of people with IDD in Kinshasa is exaggerated, or that abuse is an exception to the norm. This phenomenon of the "myth" of neglect was outlined by Ingstad (1995) in her study of people with disabilities in Botswana wherein she claimed that popular imagination saw exceptional cases of abuse as the norm.

Additionally, although we sought diversity in sampling, this study population only scratches the surface in representing the enormous diversity among inhabitants of Kinshasa. This limitation is particularly evident when examined in light of the theory of relocalization, whereby De Boeck and Plissart (2005) argue that Kinshasa has become composed of separate neighborhoods that resemble a set of villages, distinct and cut off from one another. Accordingly, generalizing these findings to the wider population of Kinshasa is inappropriate.

Finally, as we acknowledge earlier, we structured our analysis from an analytical framework developed in a non-Congolese context. There are limitations inherent in applying theoretical or analytical models in contexts different from where they were developed. Although the framework that we employed incorporated sociocultural considerations as integral to the analysis, a Congolese-developed framework of IDD and personhood may have provided a more nuanced structure for which to guide analysis for a context where personhood may be broader and more relational or where other cultural models exist that are different in character from those developed in the Western academic and clinical world.

Implications

In this section we highlight the potential implications that this study may have, particularly as it relates to research, policy, and practice.

Research. Because this study was primarily limited to a number of key sites (e.g., homes, schools, meetings), future studies should seek to expand upon this study of personhood of people with IDD in Kinshasa by engaging in new sites of study (e.g., workplaces, churches) to identify complementary or additional aspects that may contribute to the construction of personhood of people with IDD in Kinshasa. Moreover, researchers may gain greater understanding of personhood of people with IDD by expanding this study to include all disability groups in Kinshasa (e.g., physical disabilities, sensory disabilities) and then analyzing the similarities and differences with other disability groups.

Policy. There are a number of public policy implications that emerge from this study. First, there is a necessity to protect people with IDD from infringement of their human rights because of their lowered status in society. The DRC does not yet have a national disability policy;

however, disability advocates are pushing for one, and the government demonstrates a willingness to enact such a policy in the future (Aldersey, 2013). This situation renders policy implications even more timely and relevant, given that a national policy is still in the creation phase. Public policy must protect people with IDD from neglect and abuse (including mockery and being taken advantage of) and consist of enforceable punishment (e.g., fines, jail time) for those who infringe upon the inherent human rights of people with IDD. Moreover, public policy should include concrete budget measures to help provide the individual and family support outlined above.

Practice. Because this study aligned with that of Whyte (1998) who argued that "social incompetence of mentally disabled persons lies in their inability to extend and strengthen their families through social activities and relationships" (p.173), it follows that future support (resources and strategies that aim to enhance individuals' functioning and well-being) for people with IDD should be targeted not only for the individual but also for their families, friends, and neighbors.

Future support interventions may seek to improve the social standing of people with IDD by discouraging the use of negative language and mockery, encouraging families to take care of their child with IDD just as they take care of their children without disabilities and decreasing occasions where people with IDD are taken advantage of. Much of these interventions involve combatting stigma. Anti-stigma interventions may occur through television public education campaigns, for these campaigns were identified by a number of respondents to be a useful, relevant, and necessary future intervention.

Instances of neglect will also likely decrease when families are given appropriate support to meet the needs of their member with IDD. This support may be provided by the government, by

international and national NGOs, or by other extended family members or private individuals.

Support can include such things as respite care for the primary caregiver, family financial allotments to meet basic needs, assistance in enrolling the individual in school or finding the individual employment, information about how to talk about IDD with the rest of the community, or peer support from parents who have older children with IDD and who can share their successes and provide information to new parents.

Support to increase the positive theme of marriage and children in the interactional environment domain may come through increased financial, logistical, and social assistance to enable people with IDD to find partners, marry, and have children. Public education campaigns that show the wider population that people with IDD can and do marry and have children successfully may also help to change attitudes related to people with IDD's ability to marry and have children in Kinshasa. Support can also be related to the social-cultural context domain. For example, earning money provides the opportunity to contribute financially to one's society, an important aspect of personhood status in Kinshasa. Future support should involve the creation of lucrative work and housework opportunities, as well as job training and workplace support so that people with IDD may have the opportunity to contribute to their family and wider society. Moreover, the more opportunities that are provided for people with IDD to establish themselves as full persons through contribution, the more likely that negative ideas of investment and low expectations will decrease.

Because the DRC government does not always take a strong role in the provision of support, such as that outlined above, these recommendations may be most relevant to associations (inclusive of national and international NGOs), as these are often the key providers of support in a Kinshasa context.

Conclusion

People with IDD in Kinshasa experience varying levels of personhood, depending on their subjective experience as well as their abilities to interact with society in the interactional environment and the socio-cultural context. Ideas of causation may also have an impact on factors that contribute to personhood construction. The numerous recommendations for research, policy, and practice outlined here may contribute to increasing the levels of personhood enjoyed by people with IDD in society. Just as various forms of support can impact the personhood of people with IDD, ideas of personhood can also impact the availability of and access to support. When a person with IDD is considered in society to be less than a full person, family, government, and support providers may not deem it necessary to provide education, training, or employment opportunities to that individual. In a vicious and cyclical fashion, the opportunities that may have enabled an individual with IDD to become employed, marry, or otherwise contribute to society are unavailable and result in diminished personhood. It is necessary to break this cycle through the creation of opportunities that may serve to enhance the personhood of people with IDD in Kinshasa.

Acknowledgments

The authors would like to gratefully acknowledge the important contributions of Delphine Assumani throughout the data collection process of this study. We would also like to express appreciation to ACHAC, ANAPEHMCO, Villages Bondeko, Koli, CEIEHMA, Bon Depart, Kikesa, and all of the other organizations that graciously welcomed us as participant observers and for participant recruitment. Finally, we would like to acknowledge Glenn Adams, Shana Haines, John Janzen, Ed Meyen, Garth Myers, Jean Ann Summers, and two anonymous reviewers for their comments and insight on previous drafts.

References

- AAIDD. (2010). *Intellectual Disability: Definition, classification, and systems of supports. The 11th Edition of the AAIDD Definition Manual*. (11th ed.). Washington DC: American Association on Intellectual and Developmental Disabilities.
- AAIDD. (2011). Definition of Intellectual Disability. Retrieved September 9, 2011, from http://www.aaid.org/content_100.cfm?navID=21
- Agar, M. H. (2008). *The professional stranger* (2nd ed.). Bingley: Emerald Group Publishing Ltd.
- Aldersey, H.M. (2013). Disability advocacy in Kinshasa. *Disability & Society*, 28(6), 784-797.
- Aldersey, H.M, Turnbull, H.R., Turnbull, A.P. (In Press) Intellectual and Developmental Disabilities in Kinshasa, Democratic Republic of the Congo: Causality and Implications for Resilience and Support. *Intellectual and Developmental Disabilities*.
- Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis*. Thousand Oaks: Sage.
- CIDA. (2012). Democratic Republic of the Congo. Retrieved April 30, 2012, from <http://www.acdi-cida.gc.ca/drc>
- Corin, E. (1998) Refiguring the person: the dynamics of affects and symbols in an African spirit possession cult. IN : M. Lamberk et A. Strathern(Eds), *Bodies and Persons. Comparative Perspectives from Africa and Melanesia*. Cambridge(UK), Cambridge Univeristy Press: 80-102.

- Creswell, J. (2002). *Educational research: Planning, conducting, and evaluating quantitative and qualitative research*. Upper Saddle River: Merrill Prentice Hall.
- Creswell, J. (2005). *Qualitative inquiry and research design: Choosing among five traditions*. Thousand Oaks: Sage.
- De Coster, J. (2012, September 4). Pulled towards the Border: Creating a Disability Identity at the Interstices of Society. *Disability Studies Quarterly*. Retrieved from <http://dsq-sds.org/article/view/3196/3067>
- De Herdt, T., & Marivoet, W. (2011). Capabilities in place: Locating poverty and affluence in Kinshasa (Democratic Republic of the Congo). *Journal of Human Development and Capabilities*, 12(2), 235–256.
- Devisch, R. (1993). *Weaving the threads of life: The Khita gyn-eco-logical healing cult among the Yaka*. Chicago: University of Chicago Press.
- Devlieger, P. (1995). Why disabled? The cultural understanding of physical disability in an African society. In Benedicte Ingstad & S. Reynolds Whyte (Eds.), *Disability and Culture* (pp. 94–106). Berkeley: University of California Press.
- Gotto, G.S., (2009). Persons and nonpersons: Intellectual disability, personhood, and social capital among the Mixe of Southern Mexico. In Marshall, C.A., Kendall, E., Banks, M.E., & Gover, R.M.S. (Eds.), *Disabilities: Insights from Across Fields and Around the World, Volume 1, 2, and 3* (pp. 193-209). Westport: Praeger.
- Jackson, M., & Karp, I. (1987). *Personhood and Agency: The Experience of Self and Other in African Cultures*. Uppsala: Uppsala Studies in Cultural Anthropology 14.
- Janzen, J. M. (2002). *The Social Fabric of Health: An introduction to medical anthropology*. New York: McGraw-Hill.

- Kitwood, T. (1997). *Dementia Reconsidered: The person comes first*. Buckingham: Open University Press.
- Luckasson, R. (1992). *Mental Retardation, Definition, Classification, and Systems of Supports*. (9th ed.). Washington: American Association on Mental Retardation.
- NVivo. (2010). Qualitative data analysis software. QSR International Pty Ltd.
- O’Conner, D., Phinney, A., Smith, A., Small, J., Purves, B., Perry, J., Drance, E., et al. (2007). Personhood in dementia care: Developing a research agenda for broadening the vision. *Dementia*, 6(1), 121–142.
- Patton, M. Q. (2002). *Qualitative Research and Evaluation Methods*. London: Sage.
- Sabuni, L. P. (2007). Dilemma with the local perception of causes of illnesses in Central Africa: Muted concept but prevalent in everyday life. *Qualitative Health Research*, 17, 1280–1291.
- Titeca, K., & De Herdt, T. (2011). Real governance beyond the “failed state”: Negotiating education in the Democratic Republic of the Congo. *African Affairs*, 110(439), 213–231.
doi:10.1093/afraf/adr005
- Trefon, T. (2004). *Reinventing Order in the Congo: How people respond to state failure in Kinshasa*. London: Zed Books.
- Trefon, T. (2011). *Congo Masquerade: The political culture of aid inefficiency and reform failure*. London: Zed Books.
- Whyte, S.R., & Whyte, M. A. (1998). The values of development: Conceiving growth and progress in Bunyole. In H. B. Hansen & M. Twaddle (Eds.), *Developing Uganda*. London: James Currey.

Whyte, S. R. (1998). Slow cookers and madmen: Competence of heart and head in rural Uganda.

In R. Jenkins (Ed.), *Questions of Competence: Culture, classification and intellectual disability* (pp. 153–175). Cambridge: Cambridge University Press.