

INTELLECTUAL AND DEVELOPMENTAL DISABILITIES IN KINSHASA, DRC:
PERSONHOOD AND SUPPORT

By
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Abstract

This dissertation consists of four individual, but related chapters. Chapter 1 provides an introduction to the key constructs of this dissertation: intellectual and developmental disabilities (IDD), personhood, and support. It provides information about the context of the study, which was conducted in Kinshasa, Democratic Republic of the Congo. Finally, it provides a general overview of the other chapters in this dissertation. Chapter 2 is a study of local understandings of causality as it relates to the personhood of people with IDD in Kinshasa. It finds that understandings of causality are generally either biomedical or metaphysical, or a combination of the two. Chapter 3 is a study of the factors that contribute to the construction of personhood of individuals with IDD in Kinshasa. These factors are organized under the O'Connor et al. (2007) framework of subjective experience, the interactive environment, and the socio-cultural context. Chapter 4 is a study of support for families that have members with IDD in Kinshasa. It identifies available and needed family support and highlights a parent self-help association, ANAPEHMCO, as an example of a strong and innovative support provider.

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Dedication

This dissertation is dedicated to Delphine Assumani Wenda, a steadfast advocate devoted to improving the lives of people with disabilities in the DRC. This is yours as much as mine.

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CHAPTER 1: Overview: Investigation, Purpose, and Scope of Research

The study of disability across cultures recently has emerged as a key area of interest in the social sciences. Disability classification, identification, and discrimination can all have an impact on the personhood of a person with a disability. Scholars of disability have analyzed disability identity (Putnam, 2005; Shakespeare, 1996; Watson, 2002), how society identifies and classifies people with disabilities (Mbogoni, 2009; O'Brien, 2007; Simeonsson, 2006), and how people with disabilities are subjected to discrimination (Hahn, 1988; Silvers, Wasserman, & Mahowald, 1998). Much of their scholarship has focused on populations in countries where there is an established governmental system both to diagnose disabilities and also to bestow rights and entitlements to support (Meekosha, 2011). Studies of the experiences and approaches of persons with disabilities in contexts wherein the state is absent are, however, comparatively rare. Yet they can provide different insight into the identification, discrimination, and societal inclusion of people with disabilities. This dissertation utilizes qualitative methods to examine the construction of personhood of people with intellectual and developmental disabilities (IDD) in Kinshasa, Democratic Republic of the Congo (DRC), access of support for people with IDD and their families in Kinshasa, and the interaction between personhood and support.

The assumptions underlying my research were that (a) the personhood of people with IDD is strongly influenced by family, various forms of support, and wider society; (b) in the absence of a strong state mechanism to provide support, people with IDD and their families create innovative ways to gain access to support; and (c) this innovative support-seeking behavior has a reciprocal relationship with the construction of personhood. In the sections that follow I will (a) outline the literature pertinent to IDD, (b) outline the literature pertinent to personhood, (c) outline the literature pertinent to support, (d) describe Kinshasa, DRC as the context of this

study, specifically as it relates to geographical location, social structures, and culture, and (e) outline my research questions and the structure of this dissertation.

Disability and Intellectual and Developmental Disability

Many regard disability as a culturally created phenomenon (WHO, 2011). Under this point of view, a person's identification as having a disability depends less on the nature or degree of a person's inherent impairment and more on societal standards for normative bodies, minds, behaviors, and roles (Estroff, 1993; Ingstad & White, 1995). The social-construction perspective applies to all types and extents of disabilities, including IDD.

For the purposes of this research, I base my understanding of IDD on an adaptation of the standard definition of a person with IDD, as developed by the American Association on Intellectual and Developmental Disabilities (AAIDD, 2011): a person may be classified as having IDD if his or her intellectual function and adaptive behavior (i.e., everyday social and practical skills) differ significantly from what is normative in his or her society; and this difference originated before the age of 18. The amendment to the AAIDD definition was the addition of "from what is normative in his or her society." Amending this definition enables one to use a social constructivist approach and by incorporating "normative" within my definition, I recognize that IDD is constructed based upon norms in one's society for when the person's intellectual function and adaptive behavior are atypically low. In this study, there were a few instances where intellect could not be assessed; therefore, some study participants may have only had developmental disabilities and normal intellectual function but due to their difficulty communicating, families and the community would classify them as having abnormal intelligence and behavior. Because of the context and the fact that I did not want to get trapped in a narrow definition of ID, I included those individuals with DD who, because of the context and

the viewpoints of those around them, may functionally have ID. Therefore, although this study's focus was on individuals with ID (as outlined in the chart below) it may have also included individuals with DD. As a result, I have chosen to call this dissertation a study of people with both intellectual and developmental disabilities (IDD).

In defining intellectual disabilities in the DRC, I followed AAIDD's (2010) system of definition of ID, with minor adjustments for a Kinshasa context, specifically as it relates to measurement, as IQ testing is not as widespread of a practice as in the United States. Table 1 highlights my adaptation of AAIDD's definition of ID for the purposes of this study. Although beyond the scope of this study, future studies may probe whether there is a more appropriate and effective country-wide definition and identification system; however, for the purposes of this study, the AAIDD adaptation served as a starting point in identifying the target population.

Table 1

Adaptation of AAIDD Definition of Intellectual Disability

Criteria	AAIDD	Kinshasa Adaptation
Intellectual functioning	“An IQ score that is approximately two standard deviations below the mean, considering the standard error of measurement for the specific assessment instruments used and the instruments' strengths and limitations” (AAIDD, 2010, p. 27).	Intellectual functioning that is significantly below what is normative in society, as reported by school records, medical records, and other relevant records and information as well as through interviews with a person or persons who know the individual well and who can be relied on to report whether the person is regarded as having ID
Adaptive behavior	“Performance on a standardized measure of adaptive behavior that is normed on the general population including people with and without ID that is approximately two standard	Significant difficulties in conceptual skills (language, reading and writing, money, time, number concepts), social skills (interpersonal skills, social responsibility, self-esteem,

	<p>deviations below the mean of either (a) one of the following three types of adaptive behavior: conceptual, social, and practical or (b) an overall score on a standardized measure of conceptual, social, and practical skills” (AAIDD, 2010, p. 27)</p>	<p>gullibility, naiveté, following rules/obeys laws, avoiding being victimized, social problem solving), and practical skills (personal care, occupational skills, use of money, safety, health care, transportation, schedules/routines, telephone use) as deemed normative in society and as measured by direct observation, school records, employment records, and other relevant records and information as well as interviews with a person or persons who know the individual well.</p>
Age of onset	Prior to age 18	Prior to age 18

It was beyond the scope of this study and my training to administer intelligence and adaptive behavior evaluations. Thus, when this information was not readily available (most of the time), I relied on self-reporting, professional opinions and school/medical records, interviews, and observation to determine if an individual did indeed fit my adapted criteria of having IDD. I recognize that this is a problematic method that will be open to critique for the subjectivity of IDD determination. My method of identifying IDD is pragmatic, as is required in a country that does not have the same resources, personnel, and infrastructure as many North American and European countries. Indeed, as Njenga (2009) notes, the diagnosis of IDD in many African countries is complicated by many factors, such as the very small number of trained psychiatrists and psychologists as a whole on the continent.

For the purposes of this study, I defined a family member to be any person who is affiliated with the person with IDD by consanguinity, affinity, or co-residence. Family is important in the lives of people with IDD because the perceptions of disability, as well as the roles assigned to a

person with IDD, are greatly informed by the family structure and the person's place within the family (Rao, 2006). Family also often plays a strong support-type role throughout the life course of a person with IDD (Turnbull, Turnbull, Erwin, Soodak, & Shogren, 2010). Moreover, in many sub-Saharan African societies, the extended family has for years been a source of social security and support during times of need and crisis, such as when family members are unemployed, disabled, sick, bereaved, or aged (Mokomane, 2012).

Personhood

Personhood 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). Further, Conklin and Morgan (1996) argue, "generally, anthropologists agree that 'personhood' is a social status granted in varying degrees to those who meet (or perform) socially sanctioned criteria for membership. All societies make determinations about who can belong and be accorded social value" (p. 662). Many scholars have used the concept of personhood to understand disability across cultures (Ingstad & White, 1995; Mehrotra & Vaidya, 2008; Shuttleworth, 2004). They regard personhood as more than a biological or legal concept. Rather, it has a "value-added" quality that Mauss (1960) calls a "moral fact" (p. 350): Personhood cannot be dissolved by technical or legal considerations; it is shaped by societal values, morals, and understandings that, in turn, determine how an individual is (or is not) accepted as a person within the society. Personhood is not an intrinsic property of the individual; rather, it is conferred by others on a person. "Personhood is bestowed by society, and earned by achieving and maintaining expected social roles and ideals" (Luborsky, 1994, p. 240). Having introduced the concept of personhood, in the

section that follows I will discuss (a) embodiment, context, and rites of passage, (b) African perspectives on personhood, and (c) a framework for discussions of personhood.

Embodiment, Context, and Rites of Passage

Personhood is not a fixed status and can change over time. Another key way in which scholars have come to understand personhood is through changes in the body and questions of embodiment and interactions between flesh and society. “Contrasts within and between different views of personhood can be ‘read’ through social theories of the body. The beginning of life – the time when new flesh must be interpreted, shaped, and transformed into socially meaningful forms – is especially revealing of how competing views of personhood are worked through the body” (Conklin & Morgan, 1996, p. 663). Each biological body is produced through a set of cultural practices appropriate to various social contexts, and individual bodies are produced and monitored through cultural practices such as tattooing, feasting and fasting, beautification, and daily patterns of work (Fowler, 2004).

Fowler (2004) further complicates ideas of personhood when he explains that all features of an individual’s identity are contextual:

The kind of person one may be in a certain context is quite different from the kind of person one might be in another. This is the case whether or not a fixed individual aspect of the person is accentuated. However, these contexts are themselves events in which different social interests are mediated. Personhood is only fully intelligible in relation to gender, caste, descent and ethnic identity: in fact any features of identity that influence social interaction” (p. 24).

Personhood is forever changing and can be constantly in flux, as Fowler (2004) notes, defining personhood as

The condition or state of being a person, as it is understood in any specific context. Persons are constituted, de-constituted, maintained and altered in social practices through life and after death. This process can be described as the ongoing attainment of personhood.

Personhood is frequently understood as a condition that involves constant change, and key transformations to the person occur throughout life and death. People may pass from one state or stage of personhood to another. Personhood is attained and maintained through relationships not only with other human beings but with things, places, animals and the spiritual features of the cosmos. Some of these may also emerge as persons through this engagement. People's own social interpretations of personhood and of the social practices through which personhood is realized shape their interactions in a reflexive way, but personhood remains a mutually constituted condition (p. 4).

Rites of passage, or actions or understandings marking major life transitions, such as marriage or funeral practices, often accompany life transitions and also have the potential to affect personhood.

Rites of passage, particularly initiation rites, are communal affairs that synchronize the experience of many members of an age group, for example, co-ordinating social identity. Other rites of passage like marriages and mortuary rites bring together a community and transform relations within it. Personhood is monitored and regulated through these events as much as through everyday practice, and ... identity is a community affair in which public performances play a vital part. Death and the treatment of the dead should be placed in this context, though this does not mean they can be reduced to simply symbolic acts or self-replicating social technologies (Fowler, 2004, p. 45).

African Perspectives on Personhood

Within the socio-cultural context, a key component of Kinois' (what people from Kinshasa are called) personhood may be tied up in what Temple (2012) calls the "metaphysical consciousness:"

The very basic unit of existence in Africa, the smallest unit of African metaphysical consciousness, is not the individual, but the clan. Unlike in the west where Cartesian metaphysics placed all human ideals in the cogito or the thinking self, the clan defines the highest ideal of personhood. In Cartesian metaphysics, it is on the basis of the thinking subject that God is revealed and the external world exists. In Africa, the human person is not merely a thinking thing but a communal being and a being of faith. This definition of personhood puts the ordinary African in a position where his identity is determined by the clan, the religion, or the cult (p. 60).

Snyder's (2002) study of personhood in northern Tanzania helps to reveal some of the qualities of personhood. Snyder explains that, among the Iraqw communities in northern Tanzania, personhood is a lifelong process developed through elements over which Iraqw have very little control. These elements include kinship and descent, as well as marriage or other actions of exchange (e.g., assistance in farming, giving of food, loaning of goats). Furthermore, Snyder (2002) reveals that Iraqw personhood is formed both through relations and individual agency: "Identity is the public face of personhood, involving more strategic actions through which individuals emphasize different qualities, whether it is ethnicity, gender, modernity, or tradition" (p. 157).

Devisch (1993) describes how the Yaka ethnic group in the DRC sees the body as being like cloth on a loom, actively woven throughout life, yet bearing a biographical tapestry. This metaphor describes both the body as the locus of social relations and the kind of process through

which the body is generated: The experience of being in social relations is like the work of weaving at the loom. 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), a scholar of healing and ritual in DRC, 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).

The relational aspect of personhood evident in the above cited literature was also prevalent in the findings of personhood in this study. Ideas of relational personhood can be seen as a great benefit to Kinosis, who create and utilize relationships as a means of physical survival in Kinshasa (Trefon, 2004).

Framework for Discussions of Personhood

This study's understanding of personhood, as described above and in contrast to those that posit understanding of personhood on intellectual capacity or ability to reason, is applicable to persons with severely compromised cognitive function (O'Conner et al., 2007). 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 that 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). Given its relevancy for understanding the personhood of people with varying levels of intellectual functioning, I use this

framework as a conceptual framework for organizing a discussion of factors contributing to the construction of personhood of Kinois with IDD in Chapter 3 of this dissertation.

Support

Having discussed the literature related to personhood, I will now outline the literature related to the second key construct studied in this dissertation: family support. The idea of support for families who have members with IDD has been informed by perspectives on support for individuals with IDD. Just as I used AAIDD's definition of IDD as a basis for this study, I also incorporate its definition as a starting point for my understanding of support. Recently, AAIDD has expanded upon its understanding of individual support and individual quality of life to also incorporate ideas of family support and family quality of life. I define support as: resources and strategies that aim to enhance individual functioning and promote the development, education, interests, and well-being of a person (Luckasson, 1992, p. 151).

Support is a crucial aspect in the lives of people with IDD and their families. Indeed, the degree and type of support often determines whether a person may be classified as having IDD at all (AAIDD, 2010). When there is a mismatch between the person's individual capacity and environmental demands, the result is a need for support (AAIDD, 2010). Put another way, support is "the bridge between '*what is*' (i.e., a state of incongruence due to a mismatch between personal competency and environmental demands) and '*what can be*' (i.e., a life with meaningful activities and positive personal outcomes)" (Thompson et al., 2009, p. 136). AAIDD (2010) recommends systems of supports to improve the personal outcomes of a person with IDD. Outcomes of support "may include more independence, better personal relationships, enhanced opportunities to contribute to society, increased participation in school and/or community settings and activities, and a greater sense of personal well-being/life satisfaction" (AAIDD,

2010, p. 112). Table 2 provides examples of the various types of systems of supports that may be available to persons with IDD. Supports can be provided to enhance physical, mental, behavioral, emotional, social, environmental, and spiritual wellbeing.

Table 2

Systems of Supports from AAIDD (2010)

System of Supports	Examples
Organizational systems	Laws, funding systems, regulations affecting the supports organization
Incentives	Compensation and income, feedback on performance, recognition, encouragement
Cognitive supports	Documentation of service functions, knowledge relative to the assessment of ID
Tools	Technical aids, information and communication technology, transportation
Physical environment	Quality of home, work, and leisure settings, accessibility of services and settings, safe and secure environments
Skills/knowledge	Competencies and skills, training, teaching, study activities
Inherent ability	Health, physical vitality, matching tasks to an individual's relative strengths and interests, maximizing intrinsic motivation

Although not as widely discussed as supports for individuals with disabilities, there has also been a recognition of the necessity for families of individuals with IDD to receive support at a

family level (Kyzar, Turnbull, & Summers, 2012). Evolving across a series of national meetings of family leaders (H. R. Turnbull et al., 2007), family support is:

A set of strategies directed to the family unit but that ultimately benefit the individual with ID/DD. Family Support strategies are intended to assist family members, who have a key role in the provision of support and guidance to their family member with ID/DD. These strategies are designed, implemented, and funded in a flexible manner that addresses the emotional, physical, and material well-being of the entire family (Hecht, Reynolds, Agosta, McGinley, & Moseley, 2011, p. 12).

High quality, effective family support is critical in meeting the needs of families who have members with disabilities (Dunst & Trivette, 2009; Singer, Biegel, & Ethridge, 2009) and is an important factor in achieving positive family outcomes for families who have children with disabilities (Kyzar et al., 2012). Support is typically provided by a wide range of individuals and institutions, including family, friends, professionals, neighbors, other parents, co-workers, social groups/clubs, church members/ministers, services, and schools (Kyzar et al., 2012).

Family support may pertain to reducing stress and improving positive feelings (emotional); improving knowledge on how to address family needs (informational); assisting with practical tasks such as transportation to medical appointments, childcare, and access to community resources (logistical); or obtaining economic resources to cover family needs (financial) (Kyzar et al., 2012). Examples of emotional support may be someone to talk with or family acceptance of disability. An example of informational support may be having further information about the etiology and typical treatment of the child's specific disability. Examples of logistical support may be assistance changing diapers or bathing the individual with the disability. Examples of

financial support may be finding resources to meet basic needs, visit the doctor, or pay for transportation to appointments.

Just as support to the individual with IDD is provided with the eventual goal of improving positive outcomes, family support is also provided with improved outcomes as the overall goal. Based on factor analysis, family outcome domains may be related to Family Interaction (e.g., spend time together, talk openly with each other, solve problems together), Parenting (e.g., help children, teach children, take care of individual needs), Emotional Well-being (e.g., have friends who provide support, have time to pursue individual interests, have available outside help to take care of special needs, feel safe), Physical/Material Well-being (e.g., get needed medical care, opportunities for recreation and leisure, have available transportation, have a way to take care of expenses, family income), or Disability-related Supports (e.g., support at school/workplace, support to make progress at home, support to make friends, have good relationship with support provider) (Hoffman, Marquis, Poston, Summers, & Turnbull, 2006).

Context

Having introduced the two key constructs of study in this dissertation, personhood and support, I will now introduce the context of the study, including a brief introduction to the Democratic Republic of the Congo in general and a more in-depth discussion of its capital city of Kinshasa.

Democratic Republic of the Congo

The DRC is the second largest French-speaking country in the world (Trefon, 2004). It has a complicated history of conflict, including two successive and complex wars between 1996 and 2003. The complexity of these wars stems from the legacies of colonial and autocratic rule, wars in neighboring countries, and the fact that up to nine states (in addition to a number of rebel

groups) were militarily involved in the DRC (Prunier, 2009). The most recent conflict lasted until 2003. Termed Africa's World War, the DRC was at the center of a five year conflict that pitted government forces, supported by Angola, Namibia, and Zimbabwe, against rebels backed by Uganda and Rwanda (Prunier, 2009). This war was in part fueled by the DRC's vast mineral wealth, with all sides competing for access to the rich natural resources (which have been rumored to fuel continued fighting) (Trefon, 2011a). The war has claimed an estimated five million lives, either as a direct result of fighting or because of disease and malnutrition (Bavier, 2008). DRC President Joseph Kabila signed a peace accord in 2003, yet unrest continues, especially in the eastern portion of the country, where the population is threatened by sexual and physical violence, displacement, and looting by various militia and the army (BBC, 2012).

The DRC is characterized by an absence of a national government, especially in terms of provision of social services that are typically government-operated or supported, such as education, sewage, road transport, and electricity (de Coster, 2012; Titeca & de Herdt, 2011). Instead, the DRC is recognized as a setting whose residents invent new social and economic survival strategies, largely under the "shadow" of government, in which the state has retreated from the public domain and has a concomitant inability to provide basic public services (Ferguson, 2006; Titeca & de Herdt, 2011; Trefon, 2004). In the government's stead, grassroots organizations, local and international non-governmental organizations (NGOs), and community-based solidarity networks form the basis for an emerging civil society. Non-state actors such as NGOs and religious structures negotiate control of the national educational system (Titeca & De Herdt, 2011) and the government has limited capacity to ensure the security of the citizens and provide them with health, water, and sanitation services (CIDA, 2012).

The general absence of the state is a salient point for Congolese, as Trefon (2011) has observed: “(O)rdinary Congolese often repeat expressions like ‘the state is dying but not yet dead’ or ‘the state is ever present but completely useless’” (p. 1). The state absence has an impact on people with disabilities inasmuch as such support typically provided to people with disabilities by their governments (e.g., health care, education, caregiving remittances) is not provided in the DRC. Indeed, unsolicited lamentations of “the state does nothing for us” were frequent from a diverse range of Congolese with disabilities whom I interviewed in 2011, who argued that they suffered because their government was not fulfilling its citizen-perceived responsibilities to them as a vulnerable population (Aldersey, in press).

Since the DRC gained independence from Belgium in 1960, its national government has been nearly silent about the rights of its citizens with disabilities. This silence can contribute to continued marginalization of people with disabilities in society, both in terms of positive and negative rights: People with disabilities have no explicit remedies (such as due process mechanisms) for discrimination. Additionally, the government is condemned by local disability advocates as making little to no effort to facilitate their integration in the community as full and active Congolese citizens (Aldersey, in press).

In recent years, however, there have been two small constitutional acknowledgments of the existence of people with disabilities in national policy. The first was in Article 52 of the Transitional Government’s Constitution, adopted in 2003. This article acknowledged the specific rights of “the elderly, the sick, and people with disabilities to protection and support in line with their physical, intellectual, or moral needs” (Synergie, 2010).¹

¹ “La personne du troisième âge, la personne avec handicap et la personne invalide ont droit à des mesures spécifiques de protection en rapport avec leurs besoins physiques, intellectuels et moraux” (Synergie 2010, p. 2)

Buoyed by the language set out in the transitional constitution, advocacy groups (including advocacy groups for persons with IDD) banded together and, on February 25, 2005, delivered a petition to the transitional government institutions to urge the government to take the rights of persons with disabilities as an urgent matter to be written into policy (Lusambila & Kinkela, 2010). Accordingly, Article 49 of the 2006 constitution continued the transitional constitution's assertion of the specific rights of people with disabilities to protection and to support for their physical, intellectual, or moral needs. Additionally, it stipulated that the state has an obligation to ensure people with disabilities have a presence in national, provincial, and local institutions, and that a national law will be created to further secure and operationalize the rights promised in the article² (Synergie, 2010).

The 2006 constitution now governs the organization and exercise of power in the DRC and guarantees the rights and fundamental freedoms of its citizens. Although only Article 49 explicitly addresses the rights of people with disabilities, over 60 of the constitution's 229 articles are devoted to human rights, including civil and political rights, economic, social and cultural rights, collective rights, and the rights of specific groups (United Nations, 2009). Within the government, the provision of care for persons with disabilities is now under the jurisdiction of the Ministry of Social Affairs and Humanitarian Action. The office within the ministry that coordinates rehabilitation services oversees the National Vocational Training Centre for Persons with Disabilities, the National Service for Rehabilitation and Retraining, and the National Institute for the Blind (United Nations, 2009).

Kinshasa

² “La personne du troisième âge et la personne avec handicap ont droit à des mesures spécifiques de protection en rapport avec leurs besoins physiques, intellectuels et moraux. L'Etat a le devoir de promouvoir la présence de la personne avec handicap au sein des institutions nationales, provinciales et locales. Une loi organique fixe les modalités d'application de ce droit” (Synergie 2010:2).

Having introduced the DRC and the relevant national policy concerning persons with disabilities, I will now turn to a discussion of the Kinshasa-specific context. Kinshasa is one of the largest cities in sub-Saharan Africa. Although it was populated by barely 500,000 people at the time of independence, Kinshasa's population now exceeds eight million, amounting to over 12% of the population of the entire country (De Herdt & Marivoet, 2011). The majority of Kinshasa residents live on less than \$50 per month, which is barely enough to cover food expenses (Trefon, 2004). Indeed, in many other ways, Kinshasa is a city that many see as a city of sacrifice. For example,

[Kinois] do without fuelwood, they do without primary health services and they do without safe drinking water. They also do without political participation, security, leisure, or the ability to organize their time as they would like. Parents are not only forced to decide which children will be able to go to school in a given year, they also have to decide who shall eat one day and who shall eat the next (Trefon, 2004, p. 4).

Kinshasa residents constantly and pragmatically order and reorder their lives as active participants in their own social agenda. Indeed, residents "create, define, and transform new sites of transportation, new configurations of interlaced spatialities, new public spaces of work and relaxation, new itineraries and clusters of relations, new social interactions, new regimes of knowledge and power" (DeBoeck, 2011, p. 271). Kinshasa has been described as a city that, in the context of an absent state, has residents who have

developed remarkably creative people-based 'solutions' to address the challenges of daily survival. ... The Kinois have entered into a new phase of post-colonialism by combining global approaches to local problems while blending traditional belief systems and behaviors with their own unique forms of 'modernity' (Trefon, 2002, p. 481).

The resourcefulness of the general population in Kinshasa may provide insight into the specific resourcefulness of people with IDD and their families in the absence of state support. In previous research in Kinshasa, I observed that, although state support is lacking for people with IDD and their families, a wide range of support exists and fills the void that, elsewhere, is occupied by state action (Aldersey, N.D.). The observation of creative and widespread support in the absence of public infrastructure in Kinshasa aligns with the assumption underlying my research that, in the absence of legally or professionally imposed classification models and models of care/rehabilitation, creative understandings of disability and responses to disability emerge and may have an impact on personhood.

It is particularly important to examine human relationships embedded within aspects of personhood and support in this study, as Kinshasa is a city in which nearly every singular life is woven into a multiplicity of relationships.

Many of these relationships are defined by family and kinship ties, but many others have to do with the specific ways in which one inserts oneself – has to insert oneself – in multiple, complex, often overlapping, networks that include friends, neighbors, colleagues, acquaintances, members of one’s church congregation, professional relations, and so on. ... This capacity ‘to belong,’ to socially posit oneself within as many different collectivities as possible, and thereby to obliterate anonymity – in itself an almost unthinkable concept – is crucial to survive and to exist beyond the raw reality of mere survival and bare life (DeBoeck, 2011, p. 273).

People with disabilities in Kinshasa. Estimates of prevalence of disability in the DRC would help paint a more vivid picture of the importance and urgency of policies and programs for people with disabilities. Although desirable, it is difficult to provide an exact figure of

disability prevalence in Kinshasa, first and foremost because “measures of disability vary according to the purpose and application of the data, the conception of disability, the aspects of disability examined – impairments, activity limitations, participation restrictions, related health conditions, environmental factors – the definitions, question design, reporting sources, data collection methods, and expectations of functioning” (WHO, 2011, p. 21). Second, and more specific to the DRC, neither the government, nor academics, nor NGOs have collected such data on disabilities in the country. Although exact measures of disability prevalence in the DRC do not exist, the World Report on Disability reports global prevalence rates of disability to be between 10 and 15% of the population (WHO, 2011). Given recent estimates that place the population of Kinshasa at 8.4 million (CIA, 2012), DRC’s capital city is likely home to between 840,000 and 1.3 million persons with disabilities.

Research Questions and Dissertation Structure

Having outlined the two major constructs of study, personhood and support as well as the literature related to the context of study, I devote the remainder of this chapter to outlining the structure of my dissertation and discussing how each chapter addresses my three main research questions, namely, (a) How do people with IDD, their families, and other individuals or entities in Kinshasa create meaning about IDD and how does this meaning contribute to the construction of personhood of the individual with IDD?; (b) What support do people with IDD and their families need and/or utilize to navigate daily life in Kinshasa and how do they access such support in the absence of a strong state?; and (c) How does the construction of personhood influence families to search for and secure access to support; and, conversely how does support influence the construction of personhood?

The remainder of this dissertation consists of three chapters, with each chapter describing particular findings of this study and providing implications for future policy and practice. Chapter 2, a study of the creation of meaning of IDD, particularly as it relates to Kinshasa's understanding of causality, directly responds to research question (a). It also addresses how this creation of meaning may have particular implications for personhood and creation of and access to family support (questions a and c). Chapter 3 utilizes 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 (question a) and discusses the impact that these factors may have on support creation or access (question c). This chapter also suggests various support interventions which may facilitate the achievement of full personhood for individuals with IDD in Kinshasa in the future (question c). Finally, Chapter 4 outlines support availability for and needs of families who have members with IDD in Kinshasa (question b). This chapter also highlights a particularly strong and innovative source of support that has emerged in the absence of the state: self-help associations (question b). It discusses the ways in which self-help associations may impact the construction of personhood of people with IDD (question c), and it concludes by offering suggestions about how future policy makers and practitioners may build upon identified support strengths in future policy and practice.

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CHAPTER 2: The Creation of Meaning about Intellectual and Developmental Disabilities in Kinshasa: Understandings of Causality

ABSTRACT

Identifying the cultural understandings about disability is an important step in ensuring that policy and interventions are relevant and effective. In this chapter I draw upon results from a seven-month qualitative study to discuss the creation of meaning about intellectual and developmental disability (IDD) in Kinshasa, Democratic Republic of the Congo. Findings are particularly related to Kinosis' (what people from Kinshasa call themselves) understanding of causality. I then apply this understanding to discuss particular implications for the personhood of people with IDD and for the creation of and access to support for families who have members with IDD in Kinshasa and in similar contexts worldwide.

CHAPTER 2: The Creation of Meaning about Intellectual and Developmental Disabilities in Kinshasa: Understandings of Causality

In this chapter, I discuss findings related to the creation of meaning of intellectual and developmental disabilities (IDD) in Kinshasa. These findings are part of a larger qualitative study that explored the personhood of individuals with IDD and their families' access to support in Kinshasa, Democratic Republic of the Congo. Specifically, in this chapter I will address the research question: How do people with IDD, their families, and other individuals or entities in Kinshasa create meaning about IDD? It is important to explore the social and cultural understandings of disability in a given context in order to ensure that support for individuals with disabilities and their families are culturally relevant and useful in improving quality of life.

For the purposes of this research, I defined IDD as a person whose intellectual function and adaptive behavior (i.e., everyday social and practical skills) differ significantly from what is normative in his or her society; and this difference originated before the age of 18 (AAIDD, 2011). Although I targeted individuals with intellectual disability specifically, some families had members with developmental disabilities who were unable to communicate their intellectual capacity. The family members classified the individual as having ID, but I was not always certain of this fact. Thus, the majority of individuals had ID but some may have only had DD. I have therefore chosen to use the term IDD to describe my study population. Given that ideas of disability vary across cultures (Ingstad & White, 1995) and that it was beyond the scope of this study and expertise to administer such instruments as IQ tests and tests of adaptive behavior, Table 3 demonstrates the ways in which I determined levels of intellectual functioning and adaptive behavior of individuals in Kinshasa. My method is pragmatic, as is required in a country that does not have the same resources, personnel, and infrastructure as many North

American and European countries in which sophisticated psychometrics are widely used. Indeed, as Njenga (2009) notes, the diagnosis of intellectual disability in many African countries is complicated by a number of factors, such as the limited amount of trained psychiatrists and psychologists as a whole on the continent.

Table 3

Adaptation of AAIDD Definition of Intellectual Disability

Criterion	AAIDD	Kinshasa Adaptation
Intellectual functioning	“An IQ score that is approximately two standard deviations below the mean, considering the standard error of measurement for the specific assessment instruments used and the instruments’ strengths and limitations” (AAIDD, 2010, p. 27).	Intellectual functioning that is significantly below what is normative in Kinshasa, as reported by school records, medical records, and other relevant records and information, as well as interviews with a person or persons who know the individual well.
Adaptive behavior	“Performance on a standardized measure of adaptive behavior that is normed on the general population including people with and without ID that is approximately two standard deviations below the mean of either (a) one of the following three types of adaptive behavior: conceptual, social, and practical or (b) an overall score on a standardized measure of conceptual, social, and practical skills” (AAIDD, 2010, p. 27)	Significant (below the norm) difficulties in conceptual skills (language, reading and writing, money, time, number concepts), social skills (interpersonal skills, social responsibility, self-esteem, gullibility, naiveté, follows rules/obeys laws, avoids being victimized, social problem solving), and practical skills (personal care, occupational skills, use of money, safety, health care, transportation, schedules/routines, telephone use) as measured by direct observation, school records, employment records, and other relevant records and information, as well as interviews with a person or persons who know the individual well.
Age of onset	Prior to age 18	Prior to age 18

The Construction of Meaning about Disability

This study follows a long line of scholarship about the explanation and treatment of misfortune in Africa. The research “has shown the distinctive cosmologies, rituals, and social relationships of African societies” (Whyte, 1995, p. 234). Indeed, as Devlieger (2010) argues, “local African concepts of disability reflect the boundaries of a worldview that includes ideas of life and death, this world and the supernatural, social relations, causal attributions, and a categorization of the extraordinary body” (p. 77). In their seminal volume addressing culture and disability, Ingstad and Whyte (1995) note that the concern with the cause of impairment is predominant in all of their contributions from non-Western contexts:

Personalistic causal agents in the form of spirits or human beings reflect the relational nature of personhood in these settings. Individuals are so fundamentally involved with other beings that their bodies and minds are readily affected by agents outside themselves. Just as causes are relational, so are the life expectations against which people with disabilities are measured (p. 37).

Many studies have demonstrated that various populations in Africa attribute the cause of various forms of disability to sorcery and the use of fetish. For example, in his study of the perception of causes of illness in Central Africa, Sabuni (2007) identifies natural; physical and environmental; social; breaking of taboos; heredity; witchcraft, sorcery, and poisoning; and punishment from ancestors to be the primary causal understandings of illness. Sabuni then classifies these seven categories as either natural or metaphysical. Livingston (2005) examined the various intertwining social and political factors related to understanding illness and impairment in Botswana, including how incidents of “misfortune” (including disability and illness) are “easily understood as the outcome of natural processes or as part of the mysterious

logic of *Modimo* [sorcery]” (p. 86). Whyte (1998) has found that mental disorders in eastern Uganda are 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. In his explanation of understandings of physical disability among the Songye of the DRC, Devlieger (1995) argues that “an explanation of the cause of a disability can never be limited to the biomedical level. The explanation is part of a broader inclusive view. Although a biomedical explanation may be accepted, that does not mean it is sufficient” (p. 103).

The phenomenon of sorcery and fetish identified by researchers studying disability in African contexts may be unfamiliar to Western readership and thus necessitates further elaboration. In a Kinshasa-specific context,

Sorcellerie (sorcery) is a mostly nocturnal activity that cannot necessarily be controlled. It is the bulimia of evil and a way of life. *Fétichisme*, by contrast, is action that is premeditated, voluntary and usually limited in space and time. ... Both terms are part of a larger cluster of words having to do with the occult. Like the term ‘witchcraft’ in English, the word *fétiche* is used with a wide range of meanings in Kinshasa (White, 2004, p. 175).

Fétiche is part of many Kinois’ moral universe: If it is performed properly (e.g., the sacrifice of something of close personal value such as a friend or family member), it can lead to success in politics, love, money, and music (White, 2004).

This chapter builds upon Devlieger’s discussion of the construction of physical disability and ideas of incompetence (Devlieger, 1995, 1998, 1999, 2010) and posits that rehabilitation (one aspect of support) must be provided to the family, rather than to the individual because of the relational nature of disability (Devlieger, 1995). This chapter’s findings demonstrate that many of Devlieger’s assertions about the Songye construction of meaning related to disability also

apply to individuals with IDD in Kinshasa. This chapter aims to build upon the body of literature on understandings of causality of disability in Africa by linking such understandings to ideas of family coping. It then expands upon Devlieger's (1995) call for increased focus on support to the whole family (as opposed to interventions aimed just at the individual with IDD) by suggesting specific support, policy, and research that may work to improve family quality of life in Kinshasa.

Methods

This study utilized a qualitative approach, consisting of participant observation and semi-structured interviews as the primary means of data collection. Participant observation took place in homes, on the streets, in schools and vocational centers specialized for people with IDD, and during association parent meetings and outings with the children. I conducted interviews with 19 adults with IDD, 24 family members of a person with IDD, and 59 community members: 24 without experience with people with IDD (e.g., vendors, taxi drivers, pastors) and 35 with experience with people with IDD (e.g., psychologists, nurses, teachers).

Sampling

Sampling of participants for all aspects of the study was theoretical in the sense that I chose in a strategic way the next people to interview to obtain data for comparison with the individuals and groups with whom I had already talked (Agar, 2008). Additionally, as my research progressed, I selected community participants strategically to test or elaborate on emerging themes. For example, when a significant number of family and community members mentioned that the Pentecostal or locally-grown revivalist churches were at the base of much of the sorcery accusations towards individuals with IDD, I deliberately sought out pastors from such churches in a variety of neighborhoods to participate in my study. I strategically considered gender,

neighborhood of residence (typically an indicator of socio-economic status), type and amount of experience with IDD, and family structure. Table 4 provides further information about participant sampling.

Table 4

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

Adults with IDD, a key population that participated in this study, had various capacities for telling me about their lives. Some were quite competent to respond to the questions and probes; others were not as competent but still had some ability to respond, while still others were not sufficiently competent or lacked communication capacity to give useful answers. To the maximum extent practicable in light of the varying capacities of the adults with IDD, I solicited responses from them. When they were partially able to respond, I solicited their responses and then also sought clarification or corroboration from surrogates in their families. When the

individual was significantly unable to respond, I relied on surrogates. Generally surrogates were the primary caregivers for the person with IDD: A mother, a father, a grandparent, or a sibling.

I sampled participants from a range of varied sources. First, with the help of leaders from a parent self-help association, ANAPEHMCO (*L'Association Nationale des Parents des Enfants Vivant avec Handicap Mentale en RDC*), and through contacts of my research assistant, Delphine Assumani, I identified the eight families who welcomed me in their homes for participant observation. Ms. Assumani also facilitated my entry as participant observer in the specialized schools and centers (Bon Depart, CEIEHMA, Villages Bondeko, Kikesa, and Koli). Delphine Assumani is the secretary for the Association of Centers for People with Disabilities in Central Africa (ACHAC) and a person with a disability herself. Given her credentials as a person with a disability and a longtime disability rights activist, Delphine's endorsement of the research project enabled me to gain access and trust much more rapidly than I would have on my own. Additionally, my time and visibility in the above associations and institutions enabled me to gain the trust and interest of various potential adult, family, and community interview respondents, many of whom I arranged to interview at later dates (e.g., parents of children at the schools, former students from the schools, teachers, and physical therapists). Once I began spending time with the parent association members, these members often introduced me to other families in the community who also had children with disabilities but who were not affiliated with the association. I also spoke about my study on a Catholic radio station (Radio Elikya) on three different occasions in the early, middle, and final stages of my time in Kinshasa. In each of these instances, I provided my contact information to individuals interested in being interviewed for my study. Each occasion yielded interested study participants, particularly for the family category.

Data Collection

I collected data through participant observation and semi-structured interviews. For the first two months of study, I engaged solely in participant observation in family homes and the wider community surrounding these eight family homes. Through participant observation in homes, I examined the similarities and differences among people with IDD and the families and communities around them, and I took note of their interactions with other community members with and without disabilities, including family members, friends, and neighbors. Although I spent an entire week (from sun up to sun down) with each of the eight families (for a total of 8 weeks), I continued my interaction with and observation of these families after the initial week when I saw their children in the schools, participated in association meetings, and paid short social visits to the family home. I accompanied participants to do daily chores, visit their workplace, go to the market, and participate in various association-related activities and trips. I also observed in eight different schools providing special education services to children with IDD.

I wrote up field notes every evening or as soon as possible after the experience that I documented. My field notes included descriptions of people, places, interactions, and events in as much detail as possible; important researcher reflections or rich points; preliminary analysis (as relevant); and identification of areas for further exploration (Agar, 2008). To facilitate my memory during the field note write-up process, I carried a small notebook with me and noted key terms and important quotations while I was in the process of participant observation. The use of a field notebook to note key terms or “memory joggers” helped to ensure that I remembered the key points to be documented by the time I got to my computer to write my notes.

Semi-structured interviews with the families with whom I was participating in daily life were most successful at the end of my intensive week spent with them because by this time, the family was used to having me around and had a number of research-relevant issues fresh on their minds from recent informal conversations with me. Thus, family interviews commenced as soon as I concluded my first week of participant observation. Similarly, while conducting participant observation in schools, I often found it advantageous at this time to have interviews with various personnel; thus the interviews with community members with experience with disability commenced opportunistically while I was engaged in participant observation in the schools. I conducted the majority of the interviews with families who were not a part of my participant observation homes, community members without experience with disability, and with adults with IDD four months after my entry into the field.

Semi-structured interviews used a separate protocol of questions adapted slightly for each category of person. Table 5 contains the interview questions. I used semi-structured interviews to build upon themes I had already identified in participant observation and to explore issues related to personhood. In these interviews I gathered detailed information about multiple dimensions of the participants' lives, including their day-to-day activities, stigma, disability in general, IDD specifically, sources of strength, and hopes for the future. I used an audio recorder, and I conducted approximately three-quarters of the interviews in French and one-quarter of the interviews in French and Lingala, with the Lingala translation assistance of my research assistant.

Table 5

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 your daily life do you often need help doing? • What kind of help is most useful to you (discuss emotional, physical, financial, informational) 	<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? • What difference does it make, in terms of your quality of life, that you or other people regard (name) to have 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, what first thoughts would run through your head? • What is your understanding about what goes on in various settings of support [society, family,

<p>support)?</p> <ul style="list-style-type: none"> • 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 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? • What are your dreams for the future? • Is there anything that I have not yet asked but you think is important? 	<p>government]?</p> <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?
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Data Analysis

I conducted data analysis concurrently and recursively within and across observations and interviews, using the constant comparative method of data analysis (Charmaz, 2006; Patton, 2002) to identify themes as they emerged. Specifically, each step of the data analysis process directed my next steps (Maxwell, 2009). For example, as I wrote up my field notes and transcribed interviews, I engaged in preliminary analysis and noted observations I wanted to make in the future and new questions that I needed to ask. I organized and analyzed my data using the management techniques recommended by Creswell (2002), including three phases: (a) preparing and organizing the data; (b) describing and developing themes; and (c) interpreting the data and reporting findings. Although I conducted these phases in a linear way, I circled back to phases to further check to ensure accuracy and trustworthiness.

Every night or as soon as possible after the event, I typed my field notes into computer files. With the help of my research assistant and a Congolese transcription assistant, I transcribed all of the semi-structured interviews in full. The transcription of interviews was an important aspect in preparing and organizing the data. Each transcript went through three iterations; I personally conducted two of the three iterations. I began the transcription process while I was in the field, thus enabling me to note key themes that were coming up in the interviews and expanding upon these themes in future interviews. I imported all field notes, memos, and interview transcripts into qualitative analysis software (NVivo, 2010) to assist in identifying and organizing potential analytical categories. I used the constant comparison method for code and theme development from the data, wherein I generated and connected categories by comparing incidents in the data to other incidents, incidents to codes, codes to categories, and categories to other categories (Creswell, 2005), developing or grounding my identified themes in the data. The emergent

themes served as the basis for additional probes and checks for the following observations and interviews in the upcoming days.

I used three techniques to establish credibility: triangulation of data, peer debriefing, and member checks. Triangulation of data calls for using multiple types and sources of data from multiple participants by multiple collection methods (Maxwell, 2009). In this study, I triangulated data through the use of multiple data collection methods (i.e., participant observation & interviews) from multiple participants with different characteristics in a number of different settings (i.e., homes, education, associations).

Peer debriefing is a strategy of enlisting a peer, who is not immersed in the research but has some general understanding of the study, to discuss the study data. During my period of intense participant observation (the initial four months of the research), I sent bi-weekly memos to a colleague unconnected to, but familiar with, the study. These memos discussed what I was seeing, provided field note excerpts, and commented on emerging themes. My colleague would then reply to these memos with thoughts and impressions about the study direction. For the last three months of research, I sent memos every month. This colleague continued to provide input on developing themes after I had left the field and as I was conducting final data analysis.

I conducted member checks with study participants in order to decrease misinterpretation by asking participants to check for the accuracy of my data (Creswell, 2002). I conducted member checks by explaining my biases and expectations before each semi-structured interview, consistently asking for clarification from study participants to ensure their opinions are accurately understood and recorded, describing initial themes identified in initial observations and asking participants whether they agree or have experienced the same things, and seeking discrepant evidence and negative cases to determine if conclusions should be modified or

retained. At the conclusion of my time in the field, I presented a summary of my research activities and highlighted some of the emerging themes and salient quotations to my research participants. My research assistant and I invited all persons who participated in my research to attend this session; approximately 60 people attended (which represented an approximate 59% attendance rate). After I gave the presentation, I opened the floor for participant discussion and encouraged attendees to agree with, disagree with, or provide additional information about what I had just presented. I also provided paper surveys with open-ended questions for any written reactions to the presentation. Feedback on the preliminary findings was overall highly positive, and no one stated any major disagreements. A number of participants requested that I not focus too much on strengths and positives and implored me to ensure I also represent the sometimes harsh and negative realities of the lives of people with IDD in Kinshasa. Participants requested that I use study results for action toward the betterment of people with IDD in Kinshasa and expressed a desire for the research to lead to more concrete projects aimed at improved quality of life.

Confirmability in qualitative inquiry calls for determining whether the researcher's conclusions are reasonably traceable to the rich data sources. In this study, I established confirmability by triangulation of data, peer debriefing, and reflective practice and search for bias. Both my peer-debrief colleague and my academic advisors validated whether decisions made during the research process were plausible, i.e., whether they can identify or understand the source of the conclusions I am drawing. Meanwhile, throughout data collection and analysis I actively and continually searched for any bias (e.g., through field note reflections, discussions with my research assistant, and debriefing with my noninvolved peer) and made any such bias visible for further inspection to ensure conformability (Creswell, 2007). Particularly as it relates

to this study, I discussed my personal beliefs about the causation of IDD with my research assistant and noninvolved peer. We reflected together on how my bias may impact the way I ask questions, analyze data, and interpret responses. We discussed strategies for minimizing the impact that my own beliefs have on data collection and analysis, such as posing questions in a different way and having my research assistant evaluate my preliminary analysis of the data. I ensured dependability of my research by triangulation of data, close cooperation with a local research assistant, and constant comparison analysis to detect any discrepant evidence and negative cases. These methods have already been described above.

Ethical Considerations

This study was approved by the University of Kansas Institutional Review Board before I entered the field. Before commencing participant observation or interviews, my research assistant and I explained the study to potential participants and participants signed an informed consent form written in both French and Lingala. Participants were offered the option to either keep their identity confidential or waive this right to confidentiality. Those who chose to remain confidential (approximately 10%) had pseudonyms applied to their data. When explaining the study to participants, we requested that individuals with IDD repeat to us in their own words the information we had just given them. If they demonstrated understanding of all key aspects of the consent form, they would sign on their own behalf. If they were unable to demonstrate ability to provide informed consent to a level deemed satisfactory to my research assistant and me, we required a surrogate (the primary care provider) to sign the informed consent form on the individual with IDD's behalf; however we always sought and procured oral assent from all participants with IDD, regardless of who signed the consent form.

Findings

In Kinshasa, ambiguity around life occurrences is inconceivable. Indeed, “at the base of every problem, there is always a cause” (Papy, male, 26-35, no disability experience). Moreover, my research showed that most participants would not accept that IDD “just happened.” The cultural world of the Kinois is divided in two: The visible and the invisible. The visible world is what we can see and touch: you can look out the window and see cars; there is a president of the country, there is a physiognomy of the human body that we understand through modern medicine. There also exists an invisible world. This world also has a sort of organization, but it is not accessible. Or, at least, it is only accessible to those who are initiated. Thus, ancestors, chiefs, pastors, priests, traditional healers, and others all have the power to access this invisible world. Sorcerers are those who have access to the invisible world but who use it for evil, rather than for good.

Understanding distinctions around the visible and invisible worlds is important in understanding the construction of meaning around IDD and its effect on the personhood of individuals with disabilities in Kinshasa. Indeed, the causal understanding of IDD (whether from the visible or the invisible world) can have a great impact on both the individual and his or her family’s social standing or status and on support accessed and needed. In general, my study population understood the causation of IDD in biomedical (visible) or metaphysical (invisible) terms, or a combination of both.

Biomedical

The vast majority of respondents demonstrated an understanding of biomedical causes of IDD. Most families could trace the medical cause of their family member’s disability.

He had a normal birth. At 6 months, he was sick. He had malaria and when they tried to heal him, he fell into a coma. He spent a week in a coma. After they treated him [for malaria],

they saw that it wasn't working so they changed treatment, and they took liquid from his vertebral column. After this, they determined that he had meningitis. After the treatment [for meningitis] he was physically fine, like you see him. It was on the level of his head that we determined that things weren't right. (Justine, female, 36-60, aunt of person with IDD)

The family's narrative of sickness was sometimes passed along to the individual with IDD, who then integrated this narrative into his or her own narrative of self.

I was born with a handicap on the mental side. Everything started when I was 2 years old. One morning, I woke up well (normally), very well. Suddenly like that a little hot. Of one degree or two degrees. Fever. They give me medicine, and I take it. It went beyond fever. ... We went to the hospital, the university clinic, and that became something else. On the level of nerves. When they noticed, they did an operation. And when they did the operation, they remarked that it was a little... the sickness they call... (long pause) I forget. (Kalambaye, male, 18-25, adult with IDD)

Families spoke of illness in their children's early years, unsuccessful abortion attempts, medical incompetence during childbirth, inaccurate or lack of early diagnosis, and treatment of an illness that resulted in their family member's IDD. Most community members also demonstrated a knowledge that IDD can come about from various biomedical causes:

There are at least 200 causes today that are identified as causing mental retardation. This is according to the World Health Organization, and the research continues! There are at least 200 causes. (Oscar, male, 36-60, disability support provider)

The biomedical causes for IDD that community members most often cited were malaria, meningitis, chromosomal and/or genetic abnormalities, behavior of the mother during the pregnancy, and failed abortion attempts. When asked about what can be done for people with

IDD in society, adults, family members, and community members often spoke in terms of medical care and other sources of rehabilitation consistent with a medical model of disability, which focuses on the person with the disability as the problem and looks to cure the disability (Kaplan, 2000). Adults and family members also demonstrated this medical understanding of disability through their ongoing and often daily interactions with doctors, psychologists, physical therapists, and other medical rehabilitation professionals in the pursuit of healing or remediating the person with IDD. Some respondents asserted that IDD exists solely due to biomedical reasons; most respondents however, complemented their biomedical understanding with a metaphysical understanding of IDD.

Metaphysical

In Kinshasa, narratives of sorcery, *fétiche* (i.e., use of the occult and magical powers to protect or aid the user), and the breaking of taboos are employed on a daily basis to understand both fortune and misfortune. Community members, regardless of education level, age, or gender, vehemently asserted that oftentimes the true cause of a person's IDD was metaphysical.

Metaphysical causes of IDD come in a number of forms: (a) The person him or herself is a sorcerer, (b) a member of the family utilizes fetish, (c) an extended family member or member of the community has inflicted this family with disability through the use of fetish, or (d) the family has broken a social or ancestral taboo, or a combination of more than one of these causes.

Individual as sorcerer. Because those who practice sorcery are considered to be those individuals who are on this earth to inflict misfortune, suffering, and destruction; when any person demonstrates challenging behavior or acts outside of social norms, they are often considered to be sorcerers.

If he poops in his clothes, I just take off his clothes because I know that my child didn't do this on purpose. He did it because his head is sick. But when others see him do this, they say, "Ah! He pooped his pants! A child as old as him pooped his pants! He did it on purpose! You, you are a sorcerer or you are the devil personified!" ... I don't agree with this because I find that he does this because he isn't normal. His head isn't normal. He doesn't reason well, like us. (Agathe, female, 36-60, mother of a child with IDD, sister to persons with IDD)

Destructive behavior by individuals with IDD accused of sorcery often included such things as "deliberately" wrecking televisions, phones, and other household items or by "deliberately" creating work for the family through incontinence or uncleanliness. But individuals with IDD are sometimes seen as "deliberately" bringing destruction by causing family strife and discord or by causing the family to become poor because IDD can also require great amounts of financial sacrifice (e.g., for health care and medication). Even if there is not a direct link between the individual with IDD and the misfortune, such as a death in the family or the loss of the primary breadwinner's job, the person with IDD is sometimes suspected of being a sorcerer and bringing this misfortune to the family.

Individuals with IDD who were accused of being sorcerers were often thought to be "abnormal" and unfortunate during the day (e.g., lower intelligence, drooling, unable to communicate, different facial features) but holding desired traits and enjoying lives of extreme fortune at night (e.g., beautiful, rich, powerful, married, well-traveled). Illustrative of the night/day dichotomy and the ability to harm others, a member of the community explained:

Bitanga soyi (drooling) during the day, yes, the night he is no longer *Bitanga soyi*. He is a boss, at night he manages businesses. At night, he is rich. He is a boss, he travels a lot, all this during the night, but you see him during the day, he comes and begs me for 100 francs so

that I give it to him and then he has power over me and he can block me. He can block my business. *Na kopesa te*, I cannot give, ok, it's like that. (Benjamin, male, 36-60, disability support provider)

Many families told me of experiences with members of their extended family or wider community who encouraged them to neglect their child so that he or she would die as quickly as possible, effectively freeing the family from his or her destructive impact. For example, one mother of a girl with IDD said:

Here people say you should not go with your child [to seek help/support]. You are wasting money for nothing. These children will die. You must leave her. You must neglect her so that she will die. (Marte, female, 36-60, mother of child with IDD)

Adults with IDD themselves often told me how they are constantly accused of being sorcerers. "Ah! They insult me, that I touched the occult, that I am a sorcerer. There are many people who say this. Problems." (Nsimba, female, 18-25, adult with IDD) All of the adults with IDD with whom I spoke forcefully and disdainfully denied that they had any experience with sorcery or the occult. Although some respondents argued that people with IDD can be sorcerers, many other participants, although they believed that IDD can be caused by sorcery, did not believe that the individual him or herself (particularly if the individual in question was a child) was the sorcerer. According to many, children with IDD are the victims: Someone else caused them to be the way they are.

Family member use of fetish. Families who enjoy a certain amount of fortune in life, either through wealth, power, or success, are often seen as using fetishes and the powers of the occult to gain this level of fortune. One aspect of this use of the occult is the necessity of sacrifice. In

this study, fetish-related sacrifice was the sacrifice of a child's intellect. This mother tells a story from her childhood about a family who had four children with IDD:

They had four! And the parents had a lot of money. They had a two-story house. But many people said that it was [the father] who had sacrificed his children to have that money. Me too, I believed that! Yes! He had sacrificed his children. Why had he done that? If I saw those children, I would say "Why would he do that? All four children! He did that, but, that money, who will he eat with, since all his children have become like that? That is not good." I always said that. But when I had my own child with the same problems, I did not go [to the occult] to look for money. Even my husband said: "Me too, I thought that... we said that children came from people who go and look for fetishers so that they can have money. Why do I have a similar case here? Do I have a lot of money? Did I turn to fetishers to get money? How could this have come into my own home?" Voila. [Interviewer: So, having a child with IDD changed your mind about how it is caused.] Yes. It changed our minds. (Marte, female, 36-60, mother of child with IDD)

A number of families had similar narratives to that expressed above. Before they had their child with a disability, they looked down upon families who had children with IDD because they believed that the family had sacrificed their child out of greed. When a child with IDD then came into their own family, they began to reconsider their beliefs about causation of disability because they knew that they themselves had not done anything out of the ordinary, and they still had a child with IDD. It is interesting to note that no family in this study accepted that they personally used sorcery or fetishes; many vehemently and defensively argued they did not. However, they often accepted that others may have used fetish against them. In contrast with some who changed their minds after IDD came into their family, others would still argue that although it was not

true for their family, other families had surely used fetishes and caused the IDD. The stigma and suspicions surrounding the causality of IDD were particularly fierce when a family had money and treated the child with a disability with love.

[A person with IDD] is really maltreated, unless the father knows the origin of that disability there [he knows that he used fetish and sacrificed his own child]. You will see that father take care of that child. The father will take the child and clothe him well. He can even give that child a car and driver because he has money, and he can tell the chauffeur to take him to Kinkole [a place by the river where many families with means go on the weekend for amusement] and buy fish to make his child happy because the father knows the origin of the disability, and he wants to make it up to the child. Those are the times when fathers can spend money [on children with IDD], but if the family did not use fetishes, these children are not treated very well. (Jean, male, 60+, no experience with disability)

If the family is rich, they are often suspected of using fetish; but if the family is poor, one suspects the family's entourage (friends, neighbors, extended family):

For me, that's it, I don't have anything. How could I have traded her? How could I have sacrificed my child for nothing in return? Our extended family, our entourage, our friends, that's another way we live in Africa, we say when you have someone like that in the family, there was someone who is out to get you or you sacrificed your child. Because we have nothing, we turn the page. To think about someone who would want to do our family harm?

Who and why? I try not to think about that. (Anne, female, 36-60, mother of adult with IDD)

Fetish use from extended family and neighbors. IDD is often attributed to discord and jealousy in the extended family (e.g., in-laws, aunts, uncles) or with neighbors. So, for example, a neighbor is jealous of a particular family and uses fetish to inflict suffering on this family in the

form of a child with IDD. Or, an uncle of a bride is displeased about the size of (or his cut of) the bride's dowry and puts a hex on the new family that causes them to have a child with a disability.

As one mother (who did not believe in sorcery herself) explained to me:

Here, we cannot think that a child acquired a disability on accident. One aspect of this can be, there is someone who had bad intentions, who cast spells on you during the pregnancy and the child became disabled in the womb. Someone who is jealous of you will give you this child to make you suffer. So that is one aspect. People say "No, this child has a disability; there was sorcery in the family. Either it was an aunt or uncle or a nephew or even a neighbor who is jealous of us. They ruined the fetus inside the womb." This child will come out disabled. He will suck all your money so that you will become poor. (Salome, female, 36-60, mother of child with IDD)

Participants often expressed discomfort cooking on their open stoves outside in compounds that were shared with other families, because neighbors who had not had anything to eat that day, or for two days, may see them cooking their food and become resentful and jealous and cast a spell on the family to make them suffer as well.

IDD as a result of broken taboos. Related to the understanding of IDD as a result of social discord is the understanding that IDD can come about when individuals break various social taboos. For example, pregnant women in particular are often told to avoid eating certain foods or doing certain things while they are pregnant to avoid harm to their unborn child. Parents of children with IDD told me that pregnant women often avoided looking at their member with IDD or walking across ground that was wet from the water the member with IDD had used for bathing because they feared the disability being passed on to their own children:

When we come across a pregnant woman, she cannot look at you. She cannot, for example, touch [my son] Jeremy and that is why that sometimes causes us problems with public transportation. We get on a bus with our disabled child, if there is a pregnant woman, she will want to get off the bus because a sorcerer has entered the bus. “No, that useless child he will cause my own child to be a sorcerer.” (Salome, female, 36-60, mother of child with IDD)

Sometimes social taboos are related to marriage and family life and were determined along ethnic lines. For example, one community member explained to me that if a woman commits adultery, unless she undergoes various rituals (e.g., asking forgiveness of chiefs or elders, leaving the house completely nude, confessing the adultery, and suffering the humiliating stares of others), she will have a child with IDD. Others explained that if they do not give a dowry (or if the dowry is not adequate enough) or if they do not follow other traditional norms as related to such life transitions of marriage and death, they risk having a child with IDD as a result.

Both Biomedical and Metaphysical

With the exception of a handful of individuals who believed solely in biomedical causation or solely in metaphysical causation, most respondents believed that IDD is caused by both biomedical and metaphysical reasons depending on the situation. Sometimes, both the biomedical and metaphysical causes coexisted in participants’ understanding of IDD. One mother explained that before her child became terribly ill, she did not believe in sorcery but her own experience with illness caused her to believe. She told me that her daughter spent 12 days in intensive care and had enormous amounts of injections and transfusions, yet nothing seemed to help in lowering her daughter’s temperature. Doctors could not figure out why this child had such a high fever and why they could not get it to go down.

Then she went in a coma, and the nurse told me “you need to pray” because all the medical exams, there wasn’t... there was malaria, yes, but malaria couldn’t bring a person to that level, she told me “You need to pray, you need to pray” and from that time on, I started to believe in sorcery. And plus, ... one of my uncles called me and said “You see what happened to your daughter. It is because you refused to allow her father to give dowry money.” (Futfu, female, 36-60, mother of adult with IDD)

Futfu’s uncle confessed that he caused her child’s disability because he was unhappy with the father of the child, who did not pay a dowry to the mother’s side of the family. He admitted to leaving the house naked in the middle of the night and invoking the occult to cause the child to become ill with the intention that she would die. Because he was unhappy with the lack of dowry money, he wanted to impede his niece’s happiness as well.

That’s why my daughter has become the way she is. But if I had said to my daughter’s father to give my uncle the money, my uncle knows how to make my child become normal again.... So it was from that that I understood that sorcery exists. Before I didn’t believe, but from [the inexplicable fever] and plus my uncle himself told me... plus malaria could not paralyze her like that, never. If it was even meningitis [it wouldn’t have done this].

The above story illustrates that the mother accepted that her child’s disability came about because she had a high fever and was in a coma for 12 days. The cause of the disability was from true biomedical issues; however, the reason these biomedical issues came about was because her uncle had cast a spell to bring about family misfortune.

In sum, IDD is understood in Kinshasa in biomedical, metaphysical, or a combination of biomedical and metaphysical terms. However, as I discuss below, the different ways in which

meaning is constructed around IDD can have an important impact on the personhood of individuals with IDD.

Discussion

These data demonstrate how beliefs about the meaning of IDD can have a great impact on the personhood of people with IDD. Although people with IDD experience stigma and lack of opportunities in general in society (see Chapter 3), when IDD is thought about in terms of strictly a medical causation, there seems to be much less stigma, or more social understanding, experienced by the individual and his or her family. If, alternatively, the individual and his or her parents are seen as the (malevolent) source of the IDD due to sorcery/fetish use, people with IDD and their families are seen with particular disdain, as if “they got what was coming to them.” As Devlieger (1998) argues “if disability is associated with the incompetence of other individuals, the person who has the disability can reckon on sympathy; but if it is determined that his or her own wrong behavior is expressed in bodily difference, the person will not be pitied” (p. 59).

Indeed, families with whom I interacted in Kinshasa would often insist on using an explicit medical model to explain their member’s behavior, even if they did not believe their child was sick, “damaged,” or in need of medical intervention, simply so that they could avoid the blaming and social disdain often affiliated when someone suspects a malevolent metaphysical attribution to difference. Causation of disability can have an impact on a person’s exposure to society, as participants explained to me that a family may keep their member with IDD at home or out of sight out of fear of what others may say or think about this family and their use of the occult. This lack of exposure outside of the household reduces a person with IDD’s ability to participate in everyday activities (e.g., lucrative work, marriage). Participation in everyday activities is often

a requirement for the achievement of full personhood in Kinois society, as I explain in chapters one and three.

Causation and its implication for personhood will also have an impact on the support accessed and needed by families with members with IDD. For example, families who believe in a purely biomedical cause may see the individual with IDD as “damaged” and in need of healing and may seek support from the healthcare sector. Families who believe in a purely metaphysical cause may seek support from churches or traditional healers or may attempt to examine and heal damaged relationships rather than seeing the individual as “damaged.” Families who believe IDD to be a result of a combination of factors may engage in more pluralistic support-seeking patterns. Families who believe their member with IDD to be a sorcerer may not attribute full personhood to that member and may not believe that support to improve this individual’s quality of life is necessary at all. Certainly, how a family creates meaning around their members IDD will impact support-seeking practices.

If one type of support is not seen as effective, this may change the way the family creates meaning around IDD. For example,

Faced with bad luck, misfortune or disease, even when they understand the problem might be brought about by a microbe or an accident, people want to know more: why something happened to them, why now, and whose fault it is (who cast the spell)...The perceived need to understand the supernatural cause of health problems eventually led many Kinois to alternative health systems. This is particularly true when a problem persists after Western-style medical treatment has failed (Persyn & Ladriere, 2004, p. 74).

Families who do not get the desired results from biomedical-based support may then shift their understanding to the IDD having metaphysical causation and will then shift their support-seeking patterns accordingly. In this way, support can also shape meaning of IDD.

Limitations

Given that Kinshasa is one of the largest urban areas on the continent of Africa, it follows that this study, which sampled a population of just 102 individuals, cannot be representative of experiences in the entire city. Although I utilized theoretical sampling methods that aimed at wider representation, one limitation of this study is that it may not adequately represent the true diversity of socio-economic status, family background, ethnicity, and life experiences of the incredibly diverse inhabitants of Kinshasa. Indeed, one should not generalize the disability experiences and attitudes represented in this study to the entire city 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. Capturing the diversity of each separate neighborhood of Kinshasa was simply impossible with this study.

The attitudes represented in this study may have been affected by the positionality of the researchers. Participants may have been hesitant to express intimate details of their life to a foreigner for fear of judgment. For example, no families admitted to sorcery use, and few families admitted to even using traditional forms of healing in complement or instead of biomedical healing. This is in contrast to a vast amount of literature on traditional health and healing practices in Kinshasa (e.g., Corin, 1979; Devisch, 2005). Moreover, both my research assistant and I represent ideas and movements of disability rights and disability advocacy; thus, our position as people clearly identifying with the social integration of people with IDD may

have impacted the sort of information and attitudes that community members shared with us.

This aligns with Sabuni's (2007) observations of causation of illness in central Africa: "people tell one person one cause and another a different cause, and this depends on the background of the person being told, for example, a pastor, medical professional, or close friend. This is meaningful and reveals that communication is not good not only between health professionals but with any individual who represents outside culture in the village" (p. 1289).

Finally, given that metaphysical paradigms of disability do not align with my personal cosmological background, my interactions with participants and analysis of data may be impaired: I may not have been able to elicit as much or as candidly stated responses as I might otherwise have been able to elicit, and my interpretations of the data may be skewed by some tendency to interpret them according to my perspectives, not respondents'. However, this positionality may also be seen as a strength of the research, in that I may have been able to elicit more detailed explanations of a phenomenon than a researcher of the local culture for whom such paradigms are commonplace.

Implications

Research. This study's findings on causality of IDD in Kinshasa contribute an additional confirmation to the body of literature on beliefs surrounding disability in Africa. In addition to serving as a confirmatory study of non-Western disability understandings, this study may also serve to expand our understanding of family coping and resilience, a body of literature which, to date, has been dominated by studies in Western contexts. Research on family coping and resilience aims to understand why some families who face adversity can overcome this adversity and become stronger as a result, while other families faced with the same situations do not (Cowan, Cowan, & Schulz, 1966; Patterson, 2002; Walsh, 2006). Family resilience is a flexible

process indicating the family's strength in different circumstances and at different points during the life cycle. Walsh (2006) identifies three key factors which contribute to a family's resiliency: (a) making meaning of adversity, (b) affirming strength and keeping a positive outlook, and (c) having spirituality and a belief system. Indeed, findings in this chapter align with theory which suggests that seeking causal attributions for aversive experiences may help individuals to gain or re-establish a sense of control (Taylor, Lichtman, & Wood, 1984) or order in one's environment (Rothbaum, Weisz, & Snyder, 1982). Biomedical explanations may enable one to believe that healing or medical intervention can occur; metaphysical explanations may enable one to seek out the source (e.g., problems with a dowry, father used fetishes) and work to repair damaged relationships and right wrongs (e.g., pay more dowry money to disgruntled family members, go to church and pray for forgiveness for past fetish use).

Perhaps the strongest tie that these findings have to the resilience literature is through discussions of coping, which is an element of resilience. This study may have implications for future research on the continent of Africa as it relates to coping and resilience. Indeed, a wide body of literature from largely Western contexts demonstrate that families who draw from spiritual sources to understand causation of IDD may experience greater levels of positive coping skills (Bayat, 2007; DeFrain, 1999; Summers, Behr, & Turnbull, 1989). Taylor (1983) argues that when people experience personal tragedies or setbacks, they respond with cognitively adaptive efforts that may enable them to return to or exceed their previous level of psychological functioning. The themes around which such adaptations occurred may include (a) a search for meaning in the experience, (b) an effort to regain a sense of mastery or control, and (c) an attempt to restore a positive sense of self. Residents of Kinshasa, who place great importance in finding meaning in IDD and exhibit efforts to regain a sense of mastery (e.g., consulting pastors,

doctors, healers), may be displaying positive coping behaviors as it relates to IDD. Indeed, it is possible that residents of Kinshasa, often heralded for their astonishing resiliency in the face of adversity (DeBoeck, 2011; Trefon, 2011a), are drawing upon coping techniques (such as applying various understandings of causality related to the adversity often affiliated with IDD and engaging in ideas of the metaphysical to make meaning) to enhance resiliency in face of difficult situations. Future research should continue to explore the linkages between causation in light of theories of coping and its impact on the resilience of people with IDD and their families in Kinshasa. How might the permeating sense of metaphysical forces in Kinshasa and the importance of causation for Kinois' understanding of all instances of misfortune confirm or complicate theories on family coping and resilience?

Additionally, although ideas of causation and construction of meaning around IDD are important shaping factors of personhood of people with IDD in Kinshasa, it is important to understand that this is only one important piece of one's social identity. Indeed, as Whyte (1995) argues "the consequences [of impairment] depend on the person's social background, individual characteristics, and the severity of the condition as well as on the attitudes and possibilities presented by the local society" (p. 237). Future studies should be conducted to further explore other contributing factors to the plethora of factors that contribute to the construction of personhood of people with IDD in Kinshasa, such as gender, socio-economic structure, existence of extended family in the city, or discourses of healing (Devisch, 1993; Janzen, 1992).

Practice. This study provides reinforcement to the argument put forth by Devlieger (1995) that "whereas the concern of Western societies is to improve on the lives of people with disabilities, in some African societies, such as the Songye of Zaire, the primary interest is in explaining why they are the way they are" (p. 95). Ideas related to meaning will have an

important impact upon the types of support that are most useful for people with IDD in Kinshasa. In particular, support must move from being primarily focused on the individual to being focused on the entire family since these findings demonstrate that IDD in Kinshasa is often “made a relational problem between human beings” (Devlieger, 1995, p. 101). Indeed, one of the strengths of this understanding of IDD is the recognition that it is not simply an abnormality of the individual but also a disruption in the family. More attention should be paid to the “relational context in which the person with a disability exists, and greater efforts should be made to involve and support important others” (Devlieger, 1995, p. 104). Human service professionals and others must not only provide support to families rather than individuals, but they must also ensure that such family support involves an examination of key family relationships, problem solving with families, and interventions that work toward restoration of weak relationships. So, for example, in addition to simply providing physical therapy, medications, and special education services for a child with IDD, human service professionals should also seek to engage in counseling and social work with families, identify damaged relationships, and help the family to repair identified damaged relationships.

Families in this study cited information gained from medical practitioners as an important support. Once they were able to identify concretely the biomedical cause of the disability, some families reported an alleviation of tension and stress around trying to figure out the metaphysical source of the disability. Future informational support practices that provide families and communities the opportunity to learn about the biomedical etiology of the impairment may be an important form of support for some families. Although this sort of information may be useful in restoring relationships for some families, it is important to note, however, that trying to get families to recognize a solely biomedical cause is not realistic or relevant as a *sole* intervention

within Kinshasa society given the permeating beliefs grounded in the metaphysical. Rather, other interventions must be grounded in or integrate ideas of metaphysical meaning.

Emotional support that seeks to address metaphysical concerns may come through human service professionals and others assisting families to outline potential damaged relationships and work on rebuilding these relationships within the family and in the wider community. Within the relational context, one important way to reduce stress for families may be to create interventions that build relationships with those in Kinshasa who exploit metaphysical understandings of IDD at the expense of individuals and families affected by IDD. As Dowden (2006) argues, the new fundamentalist Christian sects, of which there are thousands in Kinshasa, make money out of identifying individuals as "witches." Increasingly parents bring "troublesome" children to the pastors and, for a fee of \$5 or \$10, the churches investigate a child and confirm he or she is possessed. A 2002 USAID report outlines, "in today's circumstances, self-made preachers can easily set up their pulpits and mete out predictions for those seeking an easy fix for their grief and misfortune. ... A family seeking the advice of their preacher might, for example, be told that their handicapped child is causing their continued misery, citing the child's disability as a clear indication that he or she is a witch" (Cripe, Curran, Lockett, & Verhey, 2002, p. 16). Family support interventions may target such pastors, seeking to create positive relationships and develop incentives whereby these pastors become sources of emotional and spiritual supports to families, actively helping them find both biomedical and metaphysical solutions to their problems in a way that does not harm the individual with IDD and that honors, rather than stigmatizes, the family.

Policy. There are a number of key implications of this study for policy. First, one may consider national poverty-reduction efforts as an important form of family support that has the

potential to address some of the negative aspects affiliated with metaphysical meanings of disability, particularly when the individual with IDD herself or the immediate family is accused of being at the base of the impairment. Accusations of sorcery have been attributed to a growing number of families who experience a great burden of care for their children or the children of their relatives while facing increasing economic difficulties. Families unable to cope with the care of the children in the household understand that sending the children to the streets would be culturally unacceptable and, thus, accusations of sorcery, particularly by a religious leader, provide an excuse for guardians to expel children from their homes (Human Rights Watch, 2006). Witchcraft accusations are often most prevalent in urban areas such as Kinshasa and “seem to take shape during African families’ often violent transition from traditional organisation to urban life. To pastors and parents, child witchcraft represents an ‘invisible order’ that acts according to its own logic and lives alongside the social world” (Aguilar, 2006, p. 15-16). Although metaphysical attributions of meaning to IDD are not always negative, when such attributions stigmatize and demoralize families, or are used by both families and the community as justification for the mistreatment, neglect, or abandonment of people with IDD, interventions that discourage this treatment are important. Poverty reduction work may provide various necessary emotional, financial, informational, and logistical supports to families to enable them to function in a society that attributes biomedical and metaphysical understandings of meaning to IDD while still striving to provide basic human rights, equal treatment, and social inclusion to their family member with IDD. Lastly, due to the fact that the DRC has not yet created or passed a national policy on disability, as promised in its constitution, the DRC is uniquely positioned to incorporate national understandings of disability into its future policy on disability. For example,

budget allotments should be made that allow for metaphysical and traditional support methods in addition to biomedical support options.

Conclusion

Causal understandings of IDD can have an important impact on the personhood of individuals with IDD in Kinshasa. With this study, I contribute to the literature on local understandings of disability in different cultures, and I introduce ideas related to causality and coping in a non-Western context. Researchers, support providers, and policy makers must take into consideration the various causal understandings of IDD and the resulting impact on personhood when creating and implementing relevant and effective interventions to improve the quality of life of people with IDD and their families.

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CHAPTER 3: Factors Contributing to the Construction of Personhood of Individuals with Intellectual and Developmental Disabilities in Kinshasa, Democratic Republic of the Congo

ABSTRACT

In order for support for people with intellectual and developmental disabilities (IDD) to be most relevant and effective, human service professionals, other support providers, and policy makers should consider the social and cultural construction of IDD when creating, providing, and funding support. In this chapter, I utilize 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. I 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.

CHAPTER 3: Factors Contributing to the Construction of Personhood of Individuals with Intellectual and Developmental Disabilities in Kinshasa, Democratic Republic of the Congo

In order for support for people with intellectual and developmental disabilities (IDD) to be most relevant and effective, human service professionals, other support providers, and policy makers should consider the social and cultural construction of IDD when creating, providing, and funding support. One method to gain this understanding is to examine the personhood of people with IDD, which according to O’Conner et al. (2007) includes subjective experience, the interactional environment, and the socio-cultural context. In this chapter, I draw upon the findings from a study that I conducted in Kinshasa, Democratic Republic of the Congo (DRC), between June 2012 and January 2013 to discuss factors contributing to the construction of personhood of individuals with IDD in Kinshasa. These findings are part of a larger qualitative study that explored the construction of personhood, that is, the social standing or status, of individuals with IDD and the innovative access of support in Kinshasa. Specifically, I 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?

I will provide a brief overview of the constructs of IDD and personhood. I will then utilize the O’Conner et al. (2007) 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 social identity of people with IDD in Kinshasa. I highlight the impact that this construction may have on creation or access of support. I conclude this chapter with suggestions for various future support interventions that may facilitate the achievement of full personhood for individuals with IDD in Kinshasa and in other similar contexts. Although

issues of causation and the metaphysical are important aspects of Kinois' understanding of personhood of people with IDD and implications for support, because I address this elsewhere (Aldersey, Chapter 2) this chapter will not include a discussion of causality.

For the purposes of this research, I define 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 originated 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). I have found the O’Conner et al. framework for personhood and dementia to be particularly helpful in framing my own findings around personhood and IDD, in the study to which I will now turn, because this framework 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

In this study I utilized a qualitative approach, that consisted of participant observation and semi-structured interviews. I engaged in participant observation in homes, on the streets, in schools and vocational centers specialized for people with intellectual disabilities, and during association meetings and outings. I conducted semi-structured interviews with 19 adults with IDD, 24 family members of a person with IDD, and 59 community members: 24 without experience with people with IDD (e.g. vendors, pastors) and 35 with experience with people with IDD (e.g. psychologists, teachers).

Sampling

Sampling of participants for all aspects of the study was theoretical: I chose in a strategic way the next people to interview to obtain data for comparison to those with whom I have already talked (Agar, 2008). As the research progressed, I selected participants strategically to test or elaborate on emerging themes. I strategically considered gender, neighborhood of residence (often an indicator of socio-economic status), type and amount of experience with intellectual disability, and family structure. To the maximum extent possible in light of the

varying abilities of the adults with IDD, I solicited responses from them. When they were partially able to respond, I also sought clarification or corroboration from surrogates in their families. When the individual was significantly unable to respond, I relied on a surrogate, generally their primary caregiver.

I 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 my research assistant, Delphine Assumani. My primary means for establishing credibility was through the engagement of my research assistant, Delphine Assumani, and the Association of Centers for People with Disabilities in Central Africa (ACHAC). Delphine is the secretary of ACHAC, a longtime advocate for disability rights, and a person with a disability herself. Delphine facilitated the initial contact with the majority of my study participants and enabled my entry as participant observer in the specialized schools and centers. My time and visibility in the above associations and institutions enabled me to gain the trust and interest of various potential study participants, many of whom I arranged to interview at later dates. I also recruited study participants when I spoke about my study on a national radio station on three different occasions, each time providing my contact information for individuals interested in being interviewed for my study.

Data Collection

I collected data through participant observation and semi-structured interviews. For the first two months, I engaged solely in participant observation in eight homes of families that had members with IDD and the wider community surrounding them. Although I spent an entire week with each of the eight families, I continued interacting with and observing these families after the initial week when I saw their children in the schools, participated in association meetings, and

paid social visits. I joined participants to do daily chores, visit their workplace, go to the market, and on various association-related activities and trips. I also observed in eight different schools that provide special education services to children with IDD. In all of these experiences, I observed exchanges relating to personhood and disability status, such as perceived ability or inability to participate in mainstream social activities. Broadly, both in the homes and schools as well as in my daily life in Kinshasa, I listened for and participated in informal discussions on topics such as intelligence, ability, disability, support, family roles, stigma, religion, and responsibility (i.e., of family, government, individual, society) to support individuals with IDD. I watched for situations that demonstrated the genuine inclusion or exclusion of a person with IDD in their surrounding environment. I attempted to study situations in which people without disabilities encounter persons with IDD, for example, one day the class in which I was observing took a trip to the local municipal office. I took detailed notes about how the other people conducting business in this office observed and interacted with the students. In a different occasion, I observed and took notes about the way in which a boy with Down syndrome interacted with other children without disabilities at a playground.

I wrote up field notes every evening or as soon as possible after an experience. My field notes included descriptions of people, places, interactions, and events; researcher reflections or rich points; preliminary analysis; and identification of issues for further exploration (Agar, 2008). To facilitate memory during the field note write-up process, I carried a notebook in the field and noted key terms and important quotations.

For semi-structured interviews, I used a separate protocol of questions adapted slightly for each category of person. I used semi-structured interviews to build upon themes I had already identified through participant observation and to explore issues related to personhood. In

interviews with individuals with IDD and their families, I gathered detailed information about multiple aspects of the participants' lives, including their day-to-day activities, stigma, disability generally, IDD specifically, strengths, and hopes for the future. For community members I asked about perceptions of people with IDD, willingness to live in the community with people with IDD, and available services for people with IDD. I used an audio recorder, and conducted roughly three-quarters of the interviews in French and one-quarter of the interviews in French and Lingala, with Lingala translation assistance.

Data Analysis

I 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 I wrote up my field notes and transcribed interviews, I engaged in preliminary analysis and noted observations I wanted to make in the future and new questions that I needed to ask. I organized and analyzed my data using techniques recommended by Creswell (2002): (a) preparing and organizing the data; (b) describing and developing themes; and (c) interpreting the data and reporting findings. I circled back through these phases to further check to ensure accuracy and trustworthiness.

Transcription of interviews began while I was in the field and enabled me to note key themes that were coming up and expand upon these themes in future interviews. I imported all field notes, memos, and interview transcripts into qualitative analysis software (NVivo, 2010) to identify and organize analytical categories. I generated and connected categories by comparing incidents in the data to other incidents, incidents to codes, codes to categories, and categories to other categories (Creswell, 2005). The emergent themes served as the basis for additional probes and checks for observations and interviews in upcoming days.

During my period of intense participant observation (the initial 4 months of the research), I sent bi-weekly memos to a colleague unconnected to but familiar with the study. These memos outlined what I was seeing, provided field note excerpts, and identified emerging themes. This colleague would reply to the memos with ideas and impressions about the study direction. This colleague continued providing input on developing themes after I had left the field and as I was conducting the final data analysis.

I conducted member checks with study participants by asking them to check for the accuracy of my data (Creswell, 2002). I did this by explaining my biases before each interview, asking for clarification from participants to ensure their opinions are accurately understood, describing initial themes identified in initial observations and asking participants whether they agree or have experienced similar things, and seeking discrepant evidence and negative cases to determine if conclusions should be modified or retained. At the end of my time in the field, I presented a summary of my research and highlighted emerging themes to participants. All persons who participated in the research were invited to this session, of which, approximately 60 people attended (which represents an approximate 59% attendance rate). After I gave the presentation, I opened the floor for discussion and encouraged attendees to agree with, disagree with, or provide additional information about what I had just presented. I 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.

Ethical Considerations

This study was approved by the University of Kansas Institutional Review Board before I entered the field. Before commencing participant observation or interviews, my research assistant and I 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%). When explaining the study to participants, we would request that individuals with IDD repeat to us in their own words the information we had just given them. If they demonstrated that they understood the major aspects of the consent form, they would sign on their own behalf. If they were unable to demonstrate ability to provide informed consent to a level that was satisfactory to my research assistant and me, we would require a surrogate (the primary care provider) to sign the informed consent form on the individual with IDD's behalf; however we would always procure oral assent from all participants with IDD, regardless of who signed the consent form.

Findings

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

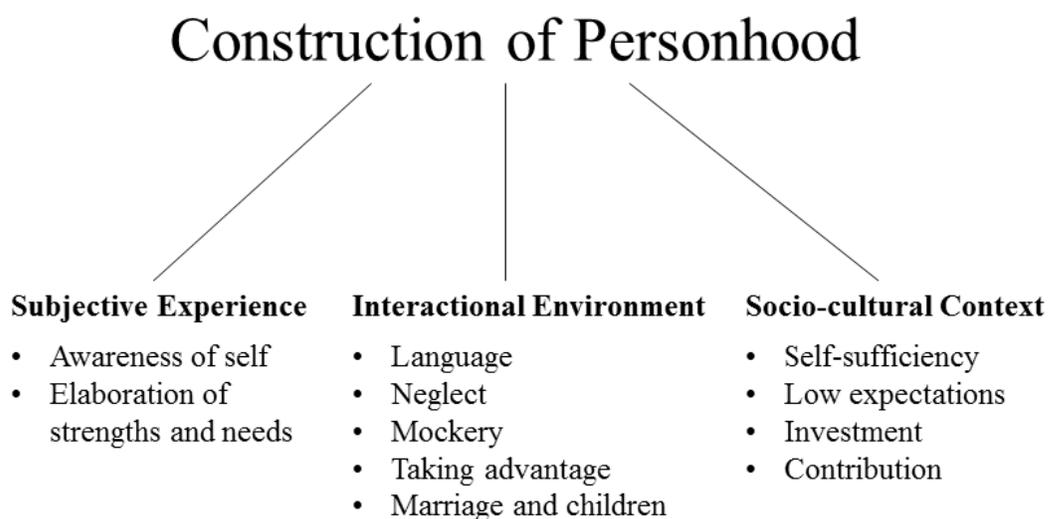


Figure 1. Summary of findings.

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. In my study, 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 I 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, female, 36-60, 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, female, 36-60, 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 I asked adults with IDD what they thought their best qualities were, they often maintained how well they clean the house, wash the dishes, wash clothes, cook, etc. Being able to contribute to household affairs was a source of great pride for many respondents. For example, Sandrine proudly told me a story about when she fought with members of her family: “I went out, when they saw that it was me that takes such good care of the house and that I wasn’t there, there wasn’t anyone to do it. As soon as I came back and they saw me, they apologized to me [because they regretted my absence].” (Sandrine, female, 26-35, adult with IDD)

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, e.g. “learn how to braid hair so that I can have a lot of money” (Sandrine, female, 26-35, adult with IDD); “I don’t want to ask father for money, because if I had a job that brought me some revenue, that would allow me to meet my needs” (Chantal, female, 36-60, adult with IDD); “I have always dreamed to be like others are. [Interviewer: How?], I want to become a boss. [Interviewer: Boss in what?] Boss in things like money.” (Mbiya, male, 36-60, adult with IDD) 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 other people 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.

In the church where I pray, I want to give donations. ... Like the last time the other day, during the service, they said, “Oh those who have the ability to help the church, if they could at least buy one chair.” There were lots of people who raised their hands [to commit to buying a chair for the church]; me, I could not raise my hand because I said “if I raise my hand I won’t have the money to buy even a chair” so that is why I didn’t raise my hand. I said in my heart that if I had someone give me money, I would take this money to buy a chair, and I would bring it to the church. If I had raised my hand, I wouldn’t have a clear conscience because I would think “I said I would buy a chair, and I can’t buy a chair”. If God gives me the ability, he will give me money so that I can buy a chair and leave it at the church. (Chantal, female, 36-60, adult with IDD)

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, on a whole, 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 I 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, male, 18-25, 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,

Kinois call those who do not have IDD *kizengi* as a way to insult them, much like the English use of the word “retard.”

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! So, all of this goes to show that they really are not very well considered. (Esperant, male, 36-60, service provider to people with IDD)

One member of the community without experience with IDD even admitted to insulting people with IDD: “People insult them! They really insult the *kizengis*, the *kizengis*, people really insult them. [Interviewer: Do *you* insult them?] Of course I insult them! [Interviewer: Why?] The *kizengi*, they make you lose your patience.” (Sophie, female, 36-60, no experience with IDD)

Neglect. In addition to negative language, I heard stories of neglect of people with IDD. Families and community members told me 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 told me,

Really, they are not treated well. Because even when you visit the family, the parents do not treat them well because... you will see, [the person with IDD] will have brothers and sisters who study. But for [the person with IDD], 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. It's sad. (Anne Mereille, female, 18-25, service provider to people with IDD)

Mockery. A number of special education teachers told me of many times they witnessed their students being mocked on the streets. "She is ridiculed. When she passes on the street, people throw rocks. She is dressed in a *pagne* (an African wrap skirt), people come and lift up her *pagne* to see underneath. They are ridiculed." (Marie France, female, 36-60, service provider to people with IDD)

Although participants gave me 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 my observations showed me. Much of the time, the adults and children with IDD with whom I interacted were clean, healthy, and well-loved in the family and community.

Taking advantage. Another aspect of the interactional environment described to me 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 me, with the help of his sister filling in the blanks, that he works in a flour mill, transporting the ground 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:

They are treated, they are crazy, people with IDD. They [people who exploit them] do not consider them to be sick, no they consider them as a machine. They consider them 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 ha 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, male, 36-60, no experience with IDD)

Another woman with IDD recounted an experience with a pastor who took her away from her home under the guise of “healing” her, but then actually took her to a nightclub and then to a hotel room and had sex with her. “He told me, we are going to be here like I am with my wife, mama Therese. Me, I said oh! How you are with mama Therese? Oh! I don’t know those things. And then he told me to shut my mouth [to not tell anyone]” (Nsimba, female, 18-25, adult with IDD) I also heard second-hand stories of sexual abuse of people with IDD from a number of community respondents.

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 or 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. She had three children, I think. [Interviewer: They didn’t make a problem?] No, no. 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, male, 36-60, service provider to people with IDD)

Marriage and children. Marriage and having children are important aspects of the interactional environment that contribute to full personhood in Kinois 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 often expressed a desire for their member to be married; however others, such as Esther's mother below, admitted that because of their members' IDD, they have lost hope that their family member will ever marry one day.

[Interviewer: Why did you smile like that when I asked papa if he thought Esther would marry?] When I smiled, it was because when Esther was born, we baptized her with the name Esther. I always called her "the king's wife" because I looked in the bible, and Esther became the wife of a king. I always called her that. The king's wife, Esther, the king's wife. Sometimes I would sing it to her "the king's wife." And bit by bit, when I saw her disability appear, I started to lose this song. And I completely stopped thinking like that! When you asked me that question, that is the moment that I remembered (laughs), I remembered that I called her the wife of a king. Referring to Esther in the bible, and then I said to myself, perhaps in her life, she will be the wife of a big man, and that was it. But now, I realize that I've lost that. That came back to me only when you asked that question! For the moment, I don't think at all that Esther will marry. (Lucie, female, 36-60, mother of child with IDD)

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.

They can marry, but I think it depends also on the degree of the disability. Because if it is profound, that would be a little difficult. But when it is light or moderate, they can marry but they must have assistance - people who can help them from time to time. Because they will have problems also. Because there is always a lack of ability. [Interviewer: Help them to do what?] I don't know; help him to take care of his wife, his children... help him to be responsible. Because a man is the head of the family, so he needs to be at least at the top... in the family he is responsible. (Anne Mereille, female, 18-25, service provider to people with IDD)

Many people, when asked if people with IDD could marry, responded in almost the exact same way: "Of course! They are people!" (Ralph, male, 36-60, service provider to people with IDD). 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. I met a few 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, female, 60+, 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 I highlight the most salient values, norms, and beliefs that emerged in my findings. These are related to self-sufficiency, low expectations, investment, and contribution.

Self-sufficiency. People with IDD were considered in a more positive light (and more like non-disabled members of society) when they experienced high levels of independence or self-sufficiency. Indeed, most special education teachers that I interviewed cited self-sufficiency as an overall goal of their work:

We say these children are people like everyone else. But because they have a mental delay, we have our methods that help us put something in their heads, and to valorize them also, so that these children are independent in their lives. [Interviewer: And what does that mean, to be independent in life?] Independent in life, that means that when you bring a child [to school], he doesn't even know how to put on shorts; but me as his educator, I will do everything to show the child everything, how he can put on shorts on his own, how he can go to the bathroom on his own, with our techniques. If a child doesn't know how to walk, me as an educator, I am going to find people who can help the child. Physiotherapists, psychologists, they can help our children. (Emilie, female, 26-35, service provider to people with IDD)

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.

To be useful, one must take care of oneself. Take care of yourself and play your role. If it is a woman, she must get married. If it is a man, he must be responsible and get married and work somewhere. Take care of yourself and eat according to your taste, dress according to

your taste; because right now people who beg can eat something that they don't like because it was given to them, he is obliged to take it. (Michel, male, 36-60, no experience with IDD)

Conversely, when people with IDD were significantly dependent on others, they were seen as a burden on society and less worthy of full personhood.

It is a burden; it is a burden when child can't take care of herself. So parents have the obligation to help their children when they are young, up to a certain stage in life, ok. After this stage, the child needs to look out for herself and evolve by her own means. She needs to detach herself from the daily assistance of her parents. And now, at this moment, the child becomes independent, and she will also, in turn, help her parents who raised her, you see. But a child that needs to depend on her parents 100%, let's take the example of the child who cannot go to the toilet by herself, it will always be a constraint to have to have someone at her side to help her. ... So, sometimes this person becomes a source of contempt. The child already pooped, it's been a long time, but instead of cleaning her up, one leaves her to sit in it for more than an hour, and you understand that can create infections and other things. So, it's an obstacle. (Robert, male, 36-60, no experience with IDD)

For most of the families I interviewed, self-sufficiency, particularly self-sufficiency through education and ultimately paying work, was seen as their major dreams 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.

I have always had that idea. The child must start to study because she needs to be independent, she cannot just sit there like that. The day that I will no longer be here, what will she do? That is why I always think about this. When I look at the child, "hmmm what

can I do?" [...] She has brothers and sisters, but they need to take care of themselves! They shouldn't have to take care of Sephora too! They can take care of Sephora sometimes, occasionally, financial help, but the other things, she needs to be able to fend for herself! That she is also independent. That is why I always think of her studies. I even spoke with her sisters and brothers, and I said "Look at your sister, do not leave her like this. She needs to study." (Marte, female, 36-60, mother of child with IDD)

One family of a young adult with IDD even cited self-sufficiency acquired through work as a way to combat some of the aspects of ID that make one different in society (in this case, being taken advantage of)

Mother: My first dream, she is a girl, but I always wished that she can have training, that she finishes her training in sewing there. That way she will be good at something, rather than staying at the house with nothing to do. Even when she is at the house, even when she moves into her own home, she can sew something that can help her earn an income. [...] This can help her, instead of following after men, because I fear, because she is not very intelligent, she can be taken advantage of.

Uncle: That is to say, with her intellectual development, a boy could easily take advantage of her, use her, and abuse her. (Jeanne, female, 36-60, mother of an adult with IDD; Marc, male, 36-60, uncle of adult with IDD)

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 [because she is both blind and has IDD], 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, female, 36-60, mother of adult with IDD)

If I never bring him out of the house it is because when you bring him out the children will tease him. That is why. When they tease him, this will hurt me, and that’s why it is best if I leave him in the house. If we ever close our compound [put walls around the house], I will start to bring him out of the house. (Koko, female, 60+, grandmother of child with IDD)

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.

Others demonstrated the existing societal stigma around IDD. For example, a woman who sold doughnuts on a street corner for a living insisted that she would never allow a person with IDD to do her job. She argued, in addition to the fact that they cannot count money and they would make her business lose all the profits, that “people are going to notice that there is an idiot who is selling things, because there are some idiots who, ohhh, they drool! Ohhh. If for example, with doughnuts, the clients will refuse, they won’t buy from me anymore, and they will start to avoid [my business].” (Safi, female, 36-60, no experience with IDD)

Investment. In Kinois 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. One mother told me that the community around her tried to influence her to abandon and neglect her child because they saw him as a poor investment:

[They told me] "You must leave him, throw him somewhere, wake up in the morning at 4 am and get rid of him." I said, "This is a child that I carried for nine months in the womb, and plus we like him at the house!" Like I am just going to wake up one morning and go get rid of Jeremy – people told me to do this! 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, female, 36-60, mother of child with IDD)

Special school administrators told me 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, with the idea that the education of their 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. A few 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. For example, one mother told the story of another family that she knew who had a child with Down syndrome who became much more severely impaired due to an illness that a doctor refused to

treat: “I touched the child: very, very hot! Her fever was 40 degrees [Celsius], and the child had already started to convulse.” (Salome, female, 36-60, mother of child with IDD) When Salome asked the child’s mother what happened, the mother told her: “The doctor told us to leave the hospital. He said it was a waste of money [to try to treat the illness] and that we should just return home so that our child would die.”

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, male, 26-35, 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 ambiance. The ability of an individual with IDD to contribute to society in these three categories will have a great impact on the ways in which he or she does or does not experience full personhood in society.

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 multinational corporation. 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. Below, a special education teacher notes the transformative power of work for one of his former students:

Each week, the agropastoral center paid the child. You know that the child with an intellectual disability didn't know how to manage his money, so he needed to be accompanied by one of his parents to help him manage his money. I assure you it was marvelous! You understand that the child was considered as a good-for-nothing, and he starts now to work, and at the end of the week they give him something and his parents are there. Every Saturday his parents are there to get something. [Interviewer: They are proud?] Very proud of the child because now he contributes something to the household. That valorizes him. (Oscar, male, 36-60, service provider to people with IDD)

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 normal 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.

So before, he wasn't very highly regarded, when he was still little, but since he has grown up and he works, well everyone likes him a lot because when he is around others, he makes himself useful. He can see things and start to sweep the house. He starts to help others in their household chores. That's why everyone loves him. Plus, my big sister, she sells drinks in a bar. She was trying to find someone that she could pay so that he stacks the cases of

drinks. She was looking for someone and then, you see, spontaneously, Nego [my son with IDD] grabs a case and starts to stack them and organize them. And my big sister said, ‘You see, in life you should never neglect people. Me, I thought that he was useless, but look how he has started to really help me. That is why it is not good to neglect people. It is always the people we neglect who have value in the eyes of others. (Sylvie, female, 36-60, mother of a child with IDD)

Moreover, when I 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. As one mother explained, her daughter is a great contributor to the family; for example, she is the only one in the household who likes to prepare manioc leaves for cooking:

You see, when we need to do the manioc leaves [pick them off and grind them for cooking], they will say “Big sister Ndine! Big sister Ndine! Come do the manioc leaves!” Everyone asks her “Big sister Ndine ! Why aren’t you working?” and Sandrine will joke, “The day that I die, will you come wake me up at the cemetery to come prepare your manioc leaves!”
(Laughs) (Edith, female, 36-60, mother of adult with IDD)

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, male, 36-60, adult with IDD)

People who worked with 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.

David is a big comedian! Sometimes he goes to see friends. He helps them with their work. He is really social! [Interviewer: Yes, I see he loves to joke. He teases his grandmother...]
(Laughs) He is a comedian! He even likes to tease you! ... Even people at church tell me “Ah! David is animated!” Even to dance, get everyone in a festive mode, he lowers the tension of everyone. (Blandine, female, 36-60, mother of child with IDD)

In sum, even if people with IDD are considered “different” and treated negatively because of their 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 this social value and to combat the 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, I summarize the findings from this study. I also complement these findings with a brief discussion of causality as it relates to the personhood of people with IDD. Finally, I 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 I 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 the 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 particularly 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 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 my 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, Chapter 2) of the impact of causality on the personhood of people with IDD in Kinshasa. In this study I 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. Depending upon 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 chapter. For example, when there is a metaphysical causation attributed to personhood, people with IDD may be subject to greater degrees of mockery or neglect. Causation 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 chapter.

Limitations

In this section I highlight three major limitations of this study. One limitation is that it was much easier to find individuals with IDD who were not neglected and families who tried their hardest to love and support their members with IDD. Thus, although I heard many second-hand stories of neglect and negative treatment, I was personally unable to observe such neglect and treatment or to interview people who had actually abandoned their family member with IDD. That was so, even though I 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.

It is also clear that there is a continuum of treatment of people with IDD in Kinshasa, and I 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. The fact that I could not gain insight from families who neglected or abandoned people with IDD is a potential limitation in the population represented in my sample.

Further, 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; she disproved the widespread myth that most people with disabilities are hidden in Botswana, rejected attitude surveys as a foundation for rehabilitation work, and deplored the tendency of rehabilitation professionals to “generalize abusive cases as images of the way of treating disabled people in developing countries while similar examples are seen as exceptions in the so-called developed part of the world” (p. 261).

Additionally, a second limitation is that, although I sought diversity in sampling, my study population likely 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, a third limitation is that it is very likely that participants often opted to focus mainly on deficits and needs when speaking with me, even when I searched for strengths and positive experiences. I believe that they did this in the hope that I would return and offer development

and financial aid for their identified problems or that other foreigners would read my study and be motivated to help them. Even though I made it very clear that I was not able to provide assistance, I still got the impression that many participants hoped that this was what would be a probable outcome of this study.

It is important to understand the limitations such as these that often accompany studies of disadvantaged populations from the global South by researchers from the global North. In spite of its limitations, the findings of this study on factors contributing to the construction of personhood of people with IDD in Kinshasa raise a number of important issues for research, future support interventions, and policy.

Implications

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

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, we 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. Finally, this study primarily represented participants who expressed positive personal sentiments toward people with IDD and families who often organized in support for their member with IDD. Future studies should seek to involve families who admit to having neglected or rejected their children with IDD, community members who actively reject

people with IDD (e.g., pastors who accuse them of being sorcerers), and adults with IDD who have been rejected by their families. If families do not readily admit to neglect, it would be useful to have the assistance of social service agencies to help identify families suspected of neglect. If it is impossible to find such participants, this may be an indication that the widespread neglect and rejection of people with IDD that was often reported to me second-hand by participants is actually a myth.

Services. 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 for people with IDD should be targeted not only for the individual but also for their families and other interpersonal relationships (e.g., friends, neighbors). Support consists of resources and strategies that aim to enhance individuals’ functioning and to promote the person’s development, education, interests, and well-being (Luckasson, 1992). When there is a mismatch between the person’s individual capacity and environmental demands, the result is a need for support (AAIDD, 2010). Support can be provided to enhance physical, mental, behavioral, emotional, social, environmental, and spiritual wellbeing of people with IDD.

Support can also be related to the interactional environment domain. Key themes from this domain showed that personhood is negatively affected by insulting language, neglect, mockery, and taking advantage. 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:

We could put them in films to show how a child with IDD started his academic life and then progressively, progressively, just to the point where he becomes a big [important] man or a big woman, thanks to the support. That must go on the television like that. That will cause people to understand (Benjamin, male, 36-60, support provider for people with IDD)

We could educate, if a show goes on television that shows children and demonstrates signs of IDD and uses testimonies to show how a child with IDD has evolved. We take an image, for example, of a child at school, who is participating in a game with other children without disabilities. That is the moment when even those who hide their children with IDD in the house will say “Oh! He can also go to school!” (Salome, female, 36-60, mother of child with IDD)

Instances of neglect will also likely decrease if families are given appropriate support (i.e., emotional, financial, logistical, informational) to meet the needs of their member with IDD, along with the needs of the rest of their family. 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. The television public education campaigns mentioned above would also be useful in combatting negative social-cultural context factors on the personhood of people with IDD. For example, public education may show the contributions that people with IDD can make to society even if they are not fully self-sufficient. These campaigns may also show successful and thriving people with IDD and testimonies from families with members with IDD both to combat low expectations and to convince families that it is worthwhile to invest in their members with IDD. The findings from this study demonstrate that a person with IDD who is self-sufficient and able to work and make money is more likely to achieve full personhood. 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 social 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 (Aldersey, Chapter 4).

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, in press). 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.

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. There are a number of various mechanisms, such as public awareness campaigns, family support, and national policy that 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.

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CHAPTER 4: Support Availability, Innovation, and Needs of Families who have Members with Intellectual and Developmental Disabilities in Kinshasa, Democratic Republic of the Congo

ABSTRACT

Support is an important means for ensuring the social integration of people with intellectual and developmental disabilities (IDD) and their families, but only if it is relevant to their needs and useful for achieving their goals. Here, I discuss the findings of a 7-month, qualitative study that explored the availability of support for families who have members with IDD in Kinshasa, Democratic Republic of the Congo. I highlight a self-help association as a particularly strong and innovative source of support, especially in a nation where the federal government is relatively absent in providing the support required to meet the needs of people and families impacted by IDD. I discuss how self-help associations have affected and may continue to affect the personhood of people with IDD through support and offer suggestions about how researchers may continue to investigate self-help associations as sources of support and the strategies policy makers and support providers may adopt to ensure future family support in Kinshasa.

CHAPTER 4: Support Availability, Innovation, and Needs of Families who have Members with Intellectual and Developmental Disabilities in Kinshasa, Democratic Republic of the Congo

In this chapter, I discuss the findings of a 7-month, qualitative study that explored support availability and needs for families that have members with intellectual disabilities in Kinshasa, DRC. I highlight the experiences of a parent association that I found to be particularly effective in meeting family support needs. Finally, I discuss the ways in which support may impact the personhood of people with IDD, and I suggest how future support providers may build upon existing strengths of individuals and organizations in Kinshasa in order to better meet the identified support needs of this population.

Introduction

In this section I outline literature pertinent to support and associations in Kinshasa.

Support

Support, defined as “resources and strategies that aim to promote the development, education, interests, and well-being of a person and that enhance individual functioning” (Luckasson, 1992, p. 151), can be an important tool for ensuring the social integration of people with intellectual and developmental disabilities and their families (AAIDD, 2010). However, support must be relevant to the needs of people with IDD and their families in order to be useful for achieving their goals. Oftentimes, when developing countries do not have a strong governmental system of national support, support is delivered by entities, such as religious entities or international NGOs. Support is a crucial aspect in the lives of people with intellectual and developmental disabilities (IDD) and their families. Indeed, the degree and type of support often determine whether a person may be classified as having IDD at all (AAIDD, 2010). When there is a mismatch between the person’s individual capacity and environmental demands, the

result is a need for support (AAIDD, 2010). Put another way, support is “the bridge between ‘*what is*’ (i.e., a state of incongruence due to a mismatch between personal competency and environmental demands) and ‘*what can be*’ (i.e., a life with meaningful activities and positive personal outcomes)” (Thompson et al., 2009, p. 136). The American Association on Intellectual and Developmental Disabilities recommends systems of supports to improve the personal outcomes of a person with IDD. Support can be provided to enhance physical, mental, behavioral, emotional, social, environmental, and spiritual wellbeing. Outcomes of support “may include more independence, better personal relationships, enhanced opportunities to contribute to society, increased participation in school and/or community settings and activities, and a greater sense of personal well-being/life satisfaction” (AAIDD, 2010, p. 112). Table 6 provides examples of the various types of systems of supports that may be available to persons with IDD.

Table 6

Systems of Supports (AAIDD, 2010)

Systems of Supports	Examples
Organizational systems	Laws, funding systems, regulations affecting the supports organization
Incentives	Compensation and income, feedback on performance, recognition and encouragement
Cognitive supports	Documentation of service functions, knowledge relative to the assessment of ID
Tools	Technical aids, information and communication technology, transportation

Physical environment	Quality of home, work, and leisure settings, accessibility of services and settings, safe and secure environments
Skills/knowledge	Competencies and skills, training, teaching, and study activities
Inherent ability	Health, physical vitality, matching tasks to an individual's relative strengths and interests, maximizing intrinsic motivation

Although not as widely discussed as support for individuals with disabilities, there has also been a recognition of the necessity for families of individuals with IDD to receive support at a family level (Kyzar et al., 2012). Evolving across a series of national meetings of family leaders (H. R. Turnbull et al., 2007), family support is defined as:

A set of strategies directed to the family unit but that ultimately benefit the individual with ID/DD. Family Support strategies are intended to assist family members, who have a key role in the provision of support and guidance to their family member with ID/DD. These strategies are designed, implemented, and funded in a flexible manner that addresses the emotional, physical, and material well-being of the entire family (Hecht, Reynolds, Agosta, McGinley, & Moseley, 2011, p. 12).

High quality, effective family support is critical in meeting the needs of families who have members with disabilities (Dunst & Trivette, 2009; Singer et al., 2009) and is an important factor in achieving positive family outcomes for families who have children with disabilities (Kyzar et al., 2012). Support is typically provided by a wide range of individuals and institutions, including family, friends, professionals, neighbors, other parents, co-workers, social groups/clubs, church members/ministers, services, and schools (Kyzar et al., 2012).

Family support may pertain to reducing stress and improving positive feelings (emotional); improving knowledge on how to address family needs (informational); assisting with practical tasks such as transportation to medical appointments, childcare, and access to community resources (logistical); or obtaining economic resources to cover family needs (financial) (Kyzar et al., 2012). Examples of emotional support are someone to talk with or family acceptance of disability. An example of informational support is having further information about the etiology and typical treatment of the child's specific disability. Examples of logistical support are assistance changing diapers or bathing the individual with the disability. Examples of financial support are finding resources to meet basic needs, visit a doctor, or pay for transportation to appointments.

Just as support to the individual with IDD is provided with the eventual goal of improving positive outcomes, family support is also provided with improved outcomes as the overall goal. Family outcome domains may be related to family interaction (spend time together, talk openly with each other, solve problems together), parenting (help children, teach children, take care of individual needs), emotional well-being (have friends who provide support, have time to pursue individual interests, have available outside help to take care of special needs, feel safe),, physical/financial wellbeing (get needed medical care, opportunities for recreation and leisure, have available transportation, have a way to take care of expenses, family income), and disability-related support (support at school/workplace, support to make progress at home, support to make friends, or have a good relationship with a support provider) (Park et al., 2003). Although specific family support needs will vary depending on the individual family situation as well as the context in which the family lives, family support in the general sense applies to all families. In the context of Kinshasa, one of the strongest locally-created sources of family

support that I identified in this study was a parent self-help association. Accordingly, much of this chapter will focus on examining roles of this association in providing support to families with a member with IDD.

Associations in Kinshasa

Kinshasa, the capital of the DRC and the location of this study, is one of the largest cities in sub-Saharan Africa. Kinshasa is a rapidly growing urban center with a population of over eight million - over 12% of the population of the entire country (De Herdt & Marivoet, 2011). The majority of Kinshasa residents live on less than \$50 per month, which is barely enough to cover food expenses (Trefon, 2004). Kinshasa has been described as a city that, in the context of an absent state, has residents who have developed creative solutions to meet their daily survival needs (DeBoeck, 2011; Trefon, 2002).

An important strategy for meeting one's everyday needs in Kinshasa is to participate in an association, a group of people where the basis of participation is based on kinship, ethnicity, gender, religion, profession, or other commonalities, such as disability (De Coster, 2012). Kinshasa associations have long been shown to have an important role in fostering social cohesion and belongingness (Devisch, 2005). Often, these associations draw upon members to provide emotional, informational, logistical and financial support. For example, when providing financial support, associations (in Kinshasa often called 'muzikis' or 'tontines') "allow members to collect finances that can serve as a reserve when one of [the members] goes bankrupt or faces other financial troubles. The money is also used as funding for funerals, marriage or birth celebrations, or school funding. The reserve money acts as credit that must be repaid" (de Coster, 2012, p. 6).

In the years following the decline of its charismatic leader, Mobutu, the DRC experienced an explosion of civil society organizations, non-governmental organizations, and community-based solidarity networks (“associations”) in Kinshasa (Trefon, 2004). These entities are important components in the myriad of survival strategies (survival in both the literal and figurative sense) invented by the Kinois (Kinshasa residents) to replace the state in many areas of public life. Trefon (2004) argues this explosion happened when, in response to a lost hope in Mobutism and frustration with the fiction of democratic transition, Kinois were forced to invent new means of support responsive to their needs – solutions that were and continue to be based primarily on friendship, trade and profession, neighborhood ties, and religious affiliation. These new associations, Trefon argues, are “a clear example of people-based social organization driven by pragmatism and the will to survive” (p. 11). There are a great number of associations for people with disabilities in the DRC. For example, the *Association des Centres pour Handicapés de l’Afrique Centrale* (ACHAC), an umbrella association for disability-focused centers and NGOs in the DRC, has over 100 active member associations (Personal communication with Delphine Assumani, 2012).

Literature on disability associations in Kinshasa demonstrates that people with disabilities are innovative and active agents in Kinois communities (deCoster, 2012). In commencing this study, I hypothesized that the innovation demonstrated by everyday Kinois and Kinois with physical disabilities would also be demonstrated among families of people with IDD. In both popular media and academic literature, perhaps the most prevalent example of innovation linked to disability is the situation of cross-border traders between the cities of Kinshasa and Brazzaville. As De Coster (2012) describes, persons with disabilities (most often people with physical disabilities but also people who are deaf or blind) defy traditional and widely held ideas about

the roles and abilities of persons with disabilities because support enables them to dominate the economic niche of the borderland. This rare showing of governmental support comes in the form of a law that allows people with disabilities to cross the border every Monday, Wednesday, and Friday at a discount, with fewer or no taxes levied on transported goods, and the ability to travel with a helper at a cheaper passage rate (De Coster, 2012). Because of governmental support for easier cross-border passage for persons with disabilities, people with disabilities are able to hold gainful (and often lucrative) employment, provide for their families, and have come to dominate this economic niche, even garnering the title “the kings of commerce” from journalists (Zajtman & Rabaud, 2010). Due to this interaction with the community as the kings (and queens) of commerce, these individuals have banded together to create cooperatives to (a) ensure the continuation of disability laws, (b) formalize systems (e.g., registration of ‘helpers’ for less hassle with border officials), and (c) collectively raise money for tricycles and prostheses (De Coster, 2012). Given that personhood in Kinshasa is often linked to contribution (Aldersey, Chapter 3), associations provide opportunities for Kinshasans with disabilities to contribute. This demonstrates the symbiotic relationship that may exist between personhood and the access of support, personhood (e.g., being viewed as a leader in commerce) may influence the creation and access of support (e.g., associations) for Kinshasans with disabilities, and alternately associations (support) help to reinforce and maintain one’s social standing as a leader in commerce (personhood).

Support to families that ultimately increases family quality of life also may have an indirect impact on the personhood of the individual with IDD: When families are able to better support their member with IDD, that person may experience increased opportunities for social inclusion or societal understanding.

Methods

The overall goal of this study was to answer the question: What support do families with members who have IDD need and/or utilize to navigate daily life in Kinshasa? This study took place over a period of 7 months between June 2012 and January 2013.

Sample

To collect the data outlined in this chapter, I interviewed 19 adults with intellectual and developmental disabilities, defined as someone whose intellectual function and adaptive behavior (everyday social and practical skills) is significantly limited from what is normative in his or her society; and this difference originated before the age of 18 (AAIDD, 2011). I also interviewed 24 family members of people with IDD and 36 support providers to people with IDD (e.g. special education teachers, physical therapists, psychologists). Table 7 provides more information about the demographics of this study's respondents.

Table 7

Participant Sampling Grid

Demographic	People with IDD	Family Members	Community Members
Gender	Male	Male	Male
	Female	Female	Female
Neighborhood	City Center (e.g., Gombe)	City Center	City Center
	City Outskirts (e.g., Kimbanseke)	City Outskirts	City Outskirts
Family	Nuclear (mother/father)	Nuclear (mother/father)	N/A

Structure	Single parent	Single parent
	Grandparent-headed	Grandparent-headed
	Extended family-headed	Extended family-headed

Data Collection

Interviews lasted about an hour, with a specific semi-structured interview protocol for each segment of the respondent population. Table 8 includes a listing of interview questions.

Table 8

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? • 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 your daily life do you often need help doing? • What kind of help is most useful to you (discuss emotional, physical, financial, informational support)? 	<ul style="list-style-type: none"> • Please tell me about your family. <ul style="list-style-type: none"> ○ 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? • Where do you go for help when you need it? • What kinds of things in your daily life do you often need help doing? 	<ul style="list-style-type: none"> • Do you believe people with IDD 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 having/avoiding responsibility to support a person with IDD and the person's family? • If you found out that one of your children had IDD, what are the first thoughts that would run through your head? <ul style="list-style-type: none"> - Where do you think you would go for support? • What is your understanding about what goes on in various settings of support

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| <ul style="list-style-type: none"> • 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 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 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?) • If you were president of the DRC and you had no constraints, what support would you create for people with IDD? • What are your dreams for the future? • Is there anything that I have not yet asked but you think is important? | <p>[society, family, government]?</p> <ul style="list-style-type: none"> ○ Do you think such settings are useful? ○ Why or why not? <ul style="list-style-type: none"> • If you were president of the DRC and you had no constraints, what support would you create for people with IDD? • Do you have any other thoughts about support for families that have members with IDD that I have not yet asked you but you would like to share? |
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I conducted the majority of interviews in French, but when a person was more comfortable speaking in Lingala I would conduct the interview in Lingala with the assistance of a translator. I complemented interviews with observation in eight special education schools, eight homes of families that had a member with IDD, during association meetings, and in daily life in Kinshasa.

I used an observation guide to shape my observations and wrote up field notes at the end of the day or as soon after the event I observed as possible.

Whenever I observed or heard about a system or setting of support (e.g., association meetings, hospitals, foundations offering financial support) in my daily interactions, participant observation, or interviews, I tried to understand how and if these specific settings of support facilitate the ease of daily living and societal integration of individuals with IDD and what type, usage, and attitudes exist with regards to the support being accessed in the DRC. As I mentioned above, I attended meetings related to disability support, and I frequented other settings where I was able to interact informally with study participants, other persons accessing the same support, and the providers of the support (e.g., teachers, physical therapists, and social workers). I paid particular attention to the characteristics of social relationships created and maintained, as well as the variety and frequency of people with IDD and their families' practices in the sites (e.g., number of physical therapy sessions that families attended per week, interactions with other families also at the sessions). I took note of how people with IDD and their families are recruited to these various sources of support and the ways the support is described and understood by those who access it. I paid particular attention to how people with IDD and their families interact with one another and with the support providers and how the support providers interact with people with IDD and their families.

Data Analysis

I analyzed data using the constant comparative method (Charmaz, 2006; Patton, 2002), identifying themes as they emerged. With the help of my research assistant and a hired Congolese transcription assistant, I transcribed all of the semi-structured interviews in full. The transcription of interviews was an important aspect in preparing and organizing the data. Each

transcript went through three iterations. I always personally conducted two of the three iterations. This transcription process began while I was in the field, thus enabling me to note key themes that were coming up in the interviews and expanding upon these themes in future interviews. I imported all field notes, memos, and interview transcripts into qualitative analysis software (NVivo, 2010) to assist in identifying and organizing analytical categories. I generated and connected categories by comparing incidents in the data to other incidents, incidents to codes, codes to categories, and categories to other categories (Creswell, 2005).

I established trustworthiness through triangulation of data (using multiple types and sources of data from multiple participants by multiple collection methods), peer debriefing (enlisting a peer who was not immersed in the research but had some general understanding of the study to give bi-weekly feedback on data collection and analysis), and member checks (consistently asking for clarification from study participants to ensure their opinions are accurately understood and recorded, describing initial themes identified in initial observations and asking participants whether they agree or have experienced the same things, and seeking discrepant evidence and negative cases to determine if conclusions should be modified or retained).

Findings

In this section I will outline basic support availability for families who have members with IDD in Kinshasa. Next, I will describe in depth one aspect of support, self-help associations, which I have identified as particularly strong in providing family support of all types: emotional, financial, informational, and logistical. I will then highlight identified needs for increased and improved support.

Basic Support Available

Families with members with IDD in Kinshasa are accessing a range of support to meet their daily needs. Table 9 outlines the major providers and types of support that I identified through 7-months of observations and the support that participants and providers identified to me in interviews. This table does not provide an exhaustive list of all support and support providers in Kinshasa but rather it demonstrates the type of support that study participants were accessing and providing. This table identifies the major provider of support and gives examples of the type of support provided. It also provides quotes that are illustrative of the provider (but are not necessarily directly aligned with the examples).

Table 9

Existing Family Support in Kinshasa

Examples	Quotes
The Catholic Church	
<ul style="list-style-type: none"> ● CARITAS <ul style="list-style-type: none"> ○ Community Based Rehabilitation (CBR) ○ Summer Camps ○ Financial contribution for medical and educational expenses ● Centre de Rééducation pour Handicapés Physiques <ul style="list-style-type: none"> ○ Healthcare ○ Special education ● Telema Medical Center for Mental Disability <ul style="list-style-type: none"> ○ Healthcare ○ Vocational training ● Church <ul style="list-style-type: none"> ○ Charity 	<p>“We have a social service where from time to time we hold meetings with parents. We try to inform them and help parents understand that it is a person created in the image of God; our brother in Christ; he has a right to education. He also has a right to instruction. He can always learn something, but he has his limits. There are parents who understand and apply themselves. You get the sense that parents now hold their child in their hearts from this experience with us.” (Oscar, male, 36-60, disability support provider)</p> <p>***</p> <p>“Soap, at the parish they give <i>pagnes</i> (cloth), shoes.” (Nsimba, female, 18-25, adult with IDD)</p> <p>***</p> <p>“I often ask the social worker or the religious Sisters, the Sister directors of his center. ... They gave me advice to send him [to run errands] often. Sometimes he doesn’t know</p>

<ul style="list-style-type: none"> ○ Spiritual and emotional support ● Villages Bondeko <ul style="list-style-type: none"> ○ Education ○ Physical therapy ○ Social work 	<p>how to brush his teeth on his own. One day, when I went to tell this to his social worker, she counseled me “Oh no, you need to always make him do it. He will brush his teeth on his own.” To write. Because sometimes I help him, even his big sister, she helps him... vowels and numbers. He tries but... when I told them the problem at the school, they told me to always give him the opportunity to write [on his own].”</p> <p>(Blandine, female, 36-60, mother of child with IDD)</p>
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Religious entities other than Catholic (e.g. Protestant, Pentecostal, home-grown churches)

<ul style="list-style-type: none"> ● Koli school <ul style="list-style-type: none"> ○ Education ● Local churches <ul style="list-style-type: none"> ○ Charity ○ Spiritual and emotional support 	<p>“Ah! Church! People come, we go there to sing, they help me and they give me bread.” (Michel, male, 36-60, adult with IDD)</p> <p>“The other time she fell sick, we had her at the pediatric hospital. They came to see us. The church and the choir where we sing came to see us. Others, other pastors came and prayed for her.” (Lucie, female, 36-60, mother of child with IDD)</p> <p>“When I have a problem, I have my teacher at church. If I have a problem, I go to her. She is the pastor’s wife. I talk about the problem, she gives advice.” (Marte, female, 36-60, mother of child with IDD)</p>
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Family

<p>Nuclear family</p> <p>Extended family</p>	<p>“Big brothers. [what support do you get from them?] Money. [Is that it?] Clothes.” (Cynthia, female, 18-25, adult with IDD)</p> <p>“My uncle helps us. If I go there, he gives me money. Go buy rice, chicken, food. He gives me money to eat.” (Mbiya, male, 36-60, adult with IDD)</p> <p>“With my son, sometimes if I am in difficulty and in need of money, I need to go speak with the people at Caritas, at [the commune of] Limete. To go speak with them my son gives me the money for the bus.” (Koko, female, 60+, grandmother of child with IDD)</p> <p>“If [the nanny] doesn’t come, if she is blocked somewhere, I am paralyzed. I can’t go to work and that creates problems at work. I need to be there, so I arrange so that the nanny is</p>
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always there. Even if there isn't a nanny, from time to time I try with the children. Jeremy's big sisters, papa's nieces, especially papa's nieces, they can come in the morning." (Salome, female, 36-60, mother of child with IDD)

Community Members

- Neighbors
 - Employers
 - Other community members
- "Speaking with others, they counseled me that I must also live. That I cannot smother myself, that I need a life for myself also. And also for her. So this made me change my ideas, I told myself I can also; I can live a normal life like everyone else." (Futfu, female, 36-60, mother of adult with IDD)
- "No, the company will support the hospital bills. That is how I got the money, I went with the child to physical therapy, I paid, but I can't forget the receipt." (Marte, female, 36-60, mother of child with IDD)
- "People call me to wash their clothes and they pay me. If no one calls me, I go to bed hungry." (Angele, female, 36-60, adult with IDD)
- "I call nurses I know to come here [to the house] for consultation [so that I don't have to take her on public transportation]." (Futfu, female, 36-60, mother of adult with IDD)
- "[And the child who comes to take Reuben to school, do you pay him or does he do it for free?] No, I don't pay him. But when he takes Reuben to school I pay for his transport also. I pay two tickets. He takes Reuben." (Isabelle, female, 60+, grandmother of child with IDD)

Private Schools or Health Centers

- Bon Depart school
 - Education
 - Healthcare
 - Information to parents
 - CEIEHMA center
 - Education
 - Healthcare
 - Information to parents
- "After the birth, after the advice of the doctors and all the information that we had from the doctors, this reassured us that it wasn't the fault of my wife or of her family; that it was purely a clinical problem, I got my head back on track, we got back to the house, and we said lets fight together for one united victory, and that victory is [our daughter] Avertie." (Geoff, male, 36-60, father of child with IDD)
- "I trained educators, I had six I think, and we went to

<ul style="list-style-type: none"> ○ Parent support groups ● Kikesa <ul style="list-style-type: none"> ○ Education ○ Healthcare ○ Information to parents ○ Parent support groups ○ Vocational training & placement ● Private health clinics <ul style="list-style-type: none"> ○ Healthcare 	<p>families to help children. The children received a diagnosis and had to learn how to dress themselves, how to eat, how to wash themselves, and then cognitive activities like ‘how to play’.” (Joaquim, male, 36-60, support provider)</p> <p>“Another doctor told me that this child, if she is 20 years old, she will have the intelligence of a child of 10 years old.” (Jeanne, female, 60+, grandmother of an adult with IDD)</p>
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Associations

<ul style="list-style-type: none"> ● ANAMPEMCO ● ACHAC ● Parousia 	<p>“I often respond to invitations ... [of parent organizations] because when you don’t see other children, you think that you are really alone or the last to have an accident. But when you see other children, you tell yourself “Hey! We’ve got it easy!” For example I saw another child, I saw that child compared to our child, I would have said [our daughter] was normal, and I tell you that consoles me a little. When you don’t go out, you don’t see the misfortune of others, you can’t imagine that there are other people who suffer as much as, even more than you.” (Seki, male, 60+, father of adult with IDD)</p>
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Government

<ul style="list-style-type: none"> ● CRHP ● CNPP <ul style="list-style-type: none"> ○ Healthcare ○ Information to families ● Kikesa ● Villages Bondeko 	<p>“Churches have constructed the schools but it is with the consent of the state. [In partnership with the state?] Yes, in partnership with the state. Because this school here, it is the project of the archdiocese but it is a state school. [The state pays your salaries...] Yes, it pays our salaries. It is the state that pays us. We have a salary, despite the difficulties we have with the [low] salary.” (Marie France, female, 36-60, support provider)</p>
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International Non-Governmental Organizations (NGOs)

<ul style="list-style-type: none"> • CBM 	<p>“[Fondation Liliane] paid for physical therapy. She got pharmaceutical products, consultations.” (Belinda, female, 26-35, mother of child with IDD)</p>
<ul style="list-style-type: none"> • Fondation Liliane 	
<ul style="list-style-type: none"> • Handicap International 	<p>“There was an expert from Handicap International who came to our house. [...] they found that food was going into his respiratory system. It hurt him a lot. Now he doesn’t snore. So they helped me. [...] They told me that to feed him, he needs to be in a sitting position.” (Solome, female, 36-60, mother of child with IDD)</p>

Existing Support Strengths: Self-Help Associations

Created in 2006 by parents of children with IDD, ANAPEHMCO, the National Association of Parents of Children Living with Intellectual Disability in the Democratic Republic of the Congo, is one example of a local, innovative approach to family support in the absence of a strong state support structure. Members originally came together when they decided to formalize their get-togethers as they waited for their children at physical therapy sessions. Over the years, ANAPEHMCO has organized conferences, television public awareness campaigns, and monthly parent get-togethers where parents share stories and exchange ideas for solutions to one another’s problems.

All of the association members consider themselves ambassadors and often recruit new members simply by approaching people on the street when they are with a person with visible intellectual and developmental impairments. New members are also recruited when health workers, particularly a physical therapist at one of the major disability care centers, informs the association’s leaders that a new parent has started coming to physical therapy and could benefit from the support of the association.

As the secretary of the association explained ANAPEHMCO to me, the association is an important source of comprehensive family support:

Before, it was impossible to separate myself from Jeremy. I couldn't even go to a party, even to church. The rare times I would try to go to church with Jeremy, everyone was curious. I put Jeremy in a wheelchair, and I asked myself "is everyone going to treat him like they should?" I don't know. There were some who would approach Jeremy with courtesy and sincerity and say hello, but there were others who had a mean look and would say "Look, a sorcerer, look at that sorcerer." That's what often stops us from going out in public. But when you are with the others from the association, you know that they are going to be sincere. They understand your problems, and they have the same problems with their own children. Parents who can't buy medications, sometimes we all contribute and buy it for them. A parent who is hospitalized with her child, we go and visit, and so on. If we discover that a child is not loved in the family, we go with four or five of our children into that family home. They see us with our children with significant disabilities, and they say "Well our case isn't so bad! Her disability is much less severe than Jeremy's!" And the parents start to love their child. (Salome, female, 36-60, mother of child with IDD)

The above quote highlights a number of types of family support: First, the association provides *emotional support* to families in a number of ways. Members often told me of the great relief they obtained when realizing that they were not alone – that there were other families struggling with similar problems. This emotional support was complemented by the group sharing and problem solving that occurs during monthly association meetings. Oftentimes, association members will go and visit the homes of other families who may be having difficulties. Just the presence and camaraderie of these other parents can be an important emotional support.

Second, ANAPEHMCO provides *informational support* to families through the provision of conferences to which speakers are invited to talk about thematic issues of relevance to the members. ANAPEHMCO members also represent the organization on national television to discuss information related to identification of and appropriate responses to IDD.

The association, sometimes we organize learning sessions, doctors teach us how to take care of our children. How to love our children. How to protect them. And us also, in the association we give advice to other mothers who hide their children in their house. Doctors often teach us when we organize. (Lucie, female, 36-60, mother of a child with IDD)

Third, ANAPEHMCO provides *financial support* to its members in a number of ways. Members contribute to assist needy families to pay for medications, healthcare, or funeral costs. Given that members often were dealing with situations of poverty and could not often contribute much to the organization, ANAPEHMCO wrote a project with the Food and Agriculture Organization, which provided them with 200 ducks to finance small-scale family agriculture and income generating projects.

We gave four females and males for families that had a child with a disability. But we had families that couldn't farm because they were renters. So we did a community farm at my house. With this farm, there is a distribution. When a parent tells us "I have space," we give them a male and female duck. We can give to another family and so on. Before, we had a lot of ducks. We sell them to help the organization and to buy the ducks' food. We can sell the eggs for example to give money to buy medications. That little girl here in the photo, we bought medications for her with the money from the ducks. (Salome, female, 36-60, mother of child with IDD)

Finally, this association provides important *logistical support* to families, such as providing families with lifesaving healthcare for their member with IDD, helping families go where they need to go to get support, or assisting in the procurement of needed equipment.

One day I called the secretary with urgency. She came quickly in the middle of the night. She looked at him and because she is a nurse, she sent his big brother to go and buy medications. She prepared rehydration salts and porridge and gave it to him. (Koko, female, 60+, grandmother of child with IDD)

My wife would carry her on her back, and she started to have pain in her back. We needed a wheelchair. The money I had was really inadequate, very inadequate in relation to the price. We tried to negotiate but they said, ‘No, it is at least \$350’. We came home and the president of our association, mama Samuel, she said “No, no, when you have a problem with wheelchairs, come, Samuel doesn’t use one chair anymore, and you can repair it and use it.” (Geoff, male, 36-60, father of a child with IDD)

Oftentimes, the support provided to families through the association is so transformative that it can change societal attitudes and ideas about the worth of an individual with IDD, as is demonstrated when there was the death of Charlotte [name changed], a girl with IDD whose parents were a part of the association.

When Charlotte died, her parents called me. Since I’m secretary of the association, I called other parents and I said we have a funeral in the association. We all went the morning before the funeral, and the neighborhood ladies who were there were saying to Charlotte’s parents that they should not cry. They said “don’t cry, if you do, Charlotte is going to return and she will make you have another disabled child.” I said, “where is Charlotte’s body?” they pointed

and said “in the kitchen over there.” I went in and I found the body on the ground. The ants were already on the corpse. I cried, I cried, and the other mothers from the association came in and they cried, and Charlotte’s father and mother saw everyone crying. Charlotte’s father’s side of the family started to criticize Charlotte’s mother. “Why are you crying? Didn’t you understand what we said? Do you want to bring another disabled child into our family? Why must you cry for Charlotte? She was bad luck for our family.” I told them to leave her alone. They continued, and I said leave the mother alone to grieve. She cried, and after a while, she stopped. So I asked Charlotte’s father if we could prepare the child’s body, he said “mama, that is exactly what I need. I was waiting for you to come.” I went and bought the products, I cleaned Charlotte’s body, and the father gave me her clothes. He had gone and bought an outfit, a beautiful outfit for Charlotte. We dressed her, put some baby powder on her, arranged her body, put it out in the living room, we pushed the chairs aside. Her father had gone with another father from our association to buy a casket. We put Charlotte properly in the casket and we went to bury her. (Salome, female, 36-60, mother of a child with IDD)

In sum, ANAPEHMCO is an example of a local and innovative response to the provision of support to families that have members with IDD in Kinshasa.

Support Needs

Although a number of individuals and organizations are providing a range of crucial supports, especially emotional support, to families, there still remains an enormous need for additional and improved support for families in Kinshasa. In this section, I outline some of the support needs identified by study participants.

Financial support. A fundamental issue that one must address when discussing family support needs in Kinshasa is the undeniable fact that most families in the city are experiencing

debilitating levels of poverty. Unable to meet their basic daily needs, families with members with intellectual disabilities in situations of poverty often have to make hard choices when it comes to use of precious resources and access of support. Families who cannot even meet their most basic requirements for survival (e.g., shelter and sustenance) are certainly going to be unable to meet other important support needs for their member with IDD.

Medical care. Medical care is too expensive. One consultation, that's ten dollars. Just to go see a doctor, to look, touch like that, ten dollars, ten dollars. That's ten dollars at the house that you won't eat. All is done. After, you risk getting a prescription there. You will buy [the medication] with what? Then, with the medication he takes, he also needs to eat well.

(Isabelle, female, 60+, grandmother of child with IDD)

We may have a need for something for Esther, for example before we needed a stroller because she was getting bigger, and we couldn't put her on our backs. But a stroller costs around \$80-\$100. What I have every month [as salary] doesn't even meet that cost. There are other children who need to study. I have 5 who study.... And plus to eat. You think you have made it through another day, but you arrive home and... "Ah! Papa! I haven't eaten, I haven't eaten." They don't even know, does papa have money or not? That is my constraint.

(Emmanuel, male, 36-60, father of child with IDD)

In addition to families' needs for financial support simply to meet basic family necessities, disability service providers are also in need of sustainable funding so as to continue to be able to provide services to families. They often see the government as the only true entity that can provide the necessary sustainability of financial support required for the longevity of quality services.

There are certain partners who can help you for five years only or they come to you just to build the building. Give salaries and other materials, no. They construct the buildings and put in furniture, and that's it, they go away. But the people that need to work there need to get paid. And if you aren't affiliated with the government so you're a private institution, there you need a way to pay the teachers or the personnel. So at that moment, parents now have to pay school fees. And generally it is not a small amount of money; it is a lot of money." (Jose, male, 36-60, disability support provider)

If the Congolese government could, for example, give a subsidy, then parents could have money to say, "OK we will pay the transportation so that our child studies in this or that school." If the state took into consideration the planning, to say, "No, we want that people with intellectual disabilities must also be educated." Then they make a law for their education. That's how it normally is in the west. That is the mentality. You say, from now on, every child must study where he can study and it's finished. I say that would be a good thing but give a little to the family to facilitate this, to help the family. (Sacrifice, male, 36-60, disability support provider)

In sum, financial need is great for most residents of Kinshasa, not least for families who have members with IDD who may require higher levels of expenditures for such things as healthcare, adult diapers, medications, and supervision (e.g., nannies).

Informational support. In spite of the important work being done by ANAPEHMCO and other associations, informational support is also an ongoing need. Many participants specified that television campaigns may be the most effective way to begin to meet this need for the wider

population of Kinshasa, given the pervasiveness of television in many family homes and daily activities.

It is like that in Kinshasa. We need a lot of public awareness campaigns. There are a lot of mothers who have children with disabilities who don't know where to go or who to ask. Us for example, I know where to go; I can go and knock on doors. But people who know nothing, they are there with their children. And then the disability gets worse. (Solonge, female, 36-60, mother of adult with IDD)

We could educate [the public] if a show goes on television. Show the children, talk about signs [of disability], and give testimonies of how the child has evolved. We could take, for example, the image of a child at school, participating in a game with other nondisabled children. At that moment, even those who keep their child in the home will say "Oh! He can also go to school!" (Salome, female, 36-60, mother of child with IDD)

Informational support needs included information for parents to identify signs of IDD, information for families about how to treat their family member with IDD, and information for society, intended to decrease the level of stigma and increase public understanding around people with IDD. Support-providing agencies (e.g., healthcare, education) could also benefit from informational support about the characteristics of IDD, appropriate interventions, family experience with IDD, and the best ways to inform and collaborate with families.

Logistical support. One of the major existing logistical support needs was improved systems of transportation. Families regarded transportation as expensive, inefficient, and inhibitive to accessing other support (such as getting to charities for donations or going to physical therapy appointments). Families reported that they encountered stigma from other members of the

community when sharing public transportation, and they described denying their member education or healthcare because transportation was too inhibitive.

Father: There are some Sundays, she doesn't go to mass because I am not here, and her mother is busy. So she regrets this a lot, if she doesn't go to mass. Mother: Because we don't have a method of movement, there are times we need to go, for example to a family party, we are obliged to go, but there isn't a method to take her." (Mr. and Mrs. Seki, 60+, parents of an adult with IDD)

You will see that there are many children that come to school late, simply because there is not a way for parents to be able to bring their children to the center and come and get them again. So under other skies they would at least have a bus. This really necessitates a bus to pick them up and drop them off, and it's that simple. We have 30 years of Village Bondeko, more than 2000 students and not even one bus. (Oscar, male, 36-60, support provider)

Families identified the difficulty in coordinating all of the various support available and noted that increased coordination of services is a major logistical need. Families overwhelmingly expressed a desire to create a center where all support for people with IDD may be found in one central location.

There are difficulties. The care, really, it is complex. There are medications, physical therapy, consultations; it's all difficult to take. The first difficulty is the disbursement of all the services. I can say, you go somewhere; you go... it's not all done at the same place. I need to go to the neurologist. I need to go to CNPP [the neuropsychiatric hospital run by the government]. The neurologist gave care to Jeremy but then the doctor changed, and I need to go to Village Bondeko. I told myself "Why change?" There they don't have physical therapy.

One moment they told me to avoid deformations I needed to get a corset for Jeremy. I need to now follow the orthopedists. I need to pay a consultation fee. I need to travel. So, it's that that bothers us. (Salome, female, 36-60, mother of child with IDD)

If there is a center where you would have to pay, and I could put her there, I tell you I would do it! I won't say no, I would put her there because there are medications there. Personnel that would do all, but I won't leave her, I will stay with her.... If I find a place where I could put her, even if they ask me to pay a little, Mama! I will pay! (Sarah, female, 60+, grandmother of adult with IDD)

Even myself, I said if we could construct houses [where we could put people with IDD], I would be the chef. I would start to come and cook. I would start to work at that house there. (Koko, female, 60+, grandmother of a child with IDD)

Discussion

The data in this study show that there are a great number of entities presently providing family support in Kinshasa. Table 9 explains those entities and the support they provide. Among them are the government, religious entities, international and national NGOs, private agencies, extended family systems, and associations.

In spite of the existing family support, there remains a great need for increased and improved support in Kinshasa. Perhaps the greatest support need identified by families was financial; many families simply need to get out of poverty. When families cannot even meet the most basic food, shelter, and healthcare needs for their family, any other sort of higher-level support targeted specifically at helping the individual with IDD (e.g., specialized training, specialized medical or

communication devices) is out of the question. Because of the inability for most families to simply “get by,” financial support is the most important need for families at this time.

In addition, informational support to help families understand the nature of their member’s disability and where they might go for support, as well as to diminish stigma in the wider community is an important need. Finally logistical support, particularly that support which would assist in transportation and getting around, was often identified as an existing and important need for families as well.

ANAPEHMCO, a parent self-help association, emerged in my research as a particularly effective and locally-created source of support for families in all of the domains of family support (i.e., emotional, financial, informational, logistical). In the absence of more formalized systems of support for families, self-help associations such as ANAPEHMCO may be the most realistic and sustainable way to meet many identified family support needs.

This study’s findings demonstrate the symbiotic relationship that can occur between ideas of personhood (social identity) and support. In the instance of ANAPEHMCO, emotional support enabled people with IDD and their families to experience a sense of belongingness in society; they understood that they were not alone in their experiences. Financial and logistical support provided by ANAPEHMCO enabled a family to meet basic needs and to better navigate and integrate into the wider community. Informational support, such as ANAPEHMCO-sponsored television public awareness campaigns, served to increase community awareness, decrease stigma, and encourage the community to make efforts to welcome members with IDD and their families into society. All of these aspects of support likely have an impact on the social belongingness experienced by people with IDD and their families.

Similarly, in the absence of such support, families are likely to be less able to provide an optimal environment for their member with IDD. This could result in people with IDD who are more isolated and less integrated in the community. This could lead to increased stigmatization and may cause a lowering in personhood status for that individual. For example, when a family experiences difficulty getting around in daily life, this often decreases the opportunity that the member with IDD has to interact with others in the wider community. This decrease in contact with others in society could have an important negative impact on personhood. Alternately, the sense of social exclusion often experienced by families who have a member with IDD may motivate families to seek and create support such as that found in associations like ANAPEHMCO, in order to increase social belongingness, better provide for their member with IDD's needs, and effectively elevate his or her personhood status. If families believe that their member with IDD has a right to social belongingness and quality of life, they may be more likely to organize and advocate publicly for increased family support.

Limitations

It is important to note that much of the support demonstrated in this chapter is available because Kinshasa is a major urban location. Most other locations in the DRC are unlikely to have the same types of support availability; and indeed needs and priorities of families may be different, depending on if the family lives in an urban or a rural setting. Moreover, even though I aimed to get as comprehensive of a picture as possible of support availability and needs, I do not purport for my study's findings to be exhaustive of what is available and needed in 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. Capturing the diversity of each separate neighborhood of Kinshasa was simply impossible with this study.

Implications

This study of support for families who have members with IDD in Kinshasa has a number of implications for research, policy, and practice.

Research. Future research should seek to establish a more exhaustive list of family support needs and availability. For example, researchers may undertake large-scale quantitative studies to better assess support needs and availability for all disability-affected persons and families in Kinshasa. Additionally, future research may seek to understand more fully the impact that an urban environment can have on the availability and access of family support. Finally, even if support exists, it does not mean that it is effectively meeting the needs of families in the way that is intended. Because it was beyond the scope of this study to measure effectiveness of support, future research might measure the actual effectiveness of existing support in Kinshasa.

Policy. There are a great number of policy implications of this study, the first being the dire need for government assistance to families. The DRC does not presently have a national policy on disability; however, there are efforts to create one, in line with promises made in the 2006 constitution (Aldersey, in press). Writers of the national policy on disability should ensure that, in addition to affirming rights of people with disabilities, they also affirm the important role that families play in ensuring the quality of life of people with disabilities. This can come through the provision of family support as an aspect of national disability policy. Moreover, disability advocates are pressing for their government to sign and ratify the United Nations Convention on the Rights of People with Disabilities (CRPD) (Aldersey, in press). By ratifying the CRPD, the Congolese government would affirm that “the family is the natural and fundamental group unit

of society and is entitled to protection by society and the State, and that persons with disabilities and their family members should receive the necessary protection and assistance to enable families to contribute towards the full and equal enjoyment of the rights of persons with disabilities” (United Nations, 2006, p. 3).

Many support interventions must be offered with a continuity that is often only available when endorsed and provided by government entities: NGO priorities may shift and private agencies may choose to go more lucrative directions, but the government should always provide a social security net for families in need. Future policy may seek to provide for families through the improvement or creation of state-sponsored centers of support. Future policy efforts may also seek to create ways to identify and track families who have members with IDD. Once identified, families should be informed of support availability. Financial assistance in the form of a national family allowance for families that have members with exceptional needs would also be an important form of support for families.

The government is a necessary partner in best assuring family support quality, availability, scale and sustainability. Non-governmental support providers, such as associations like ANAPEHMCO, could become engaged in public policy and advocacy networks to ensure that the government meets support needs. Or, in the absence of government support, other funders, such as international NGOs may look to local associations to help determine their priority funding areas. Indeed, when looking for solutions to problems that concern people with IDD and their families, the government and international funders could put associations such as ANAPEHMCO in a consultancy role, wherein families take the lead in determining the policy and practice agenda.

Practice. In future practice with families who have members with IDD in Kinshasa, it will be important to use existing family support strengths in order to chart the way forward. Associations such as ANAPEHMCO could lead the way in improving the quality of life of people with IDD and their families in Kinshasa. International funders would be wise to work on building the capacity of local organizations to continue the important work they are already doing. For example, ANAPEHMCO should be supported to increase its television public awareness campaigns in order to increase its reach to more families nationally. Currently, ANAPEHMCO does not have an official office or paid staff. If family members could be engaged as full-time staff members, similar to many different parent-run organizations in other nations, many of the activities of the organization could grow in scale.

Conclusion

This chapter examined the availability and innovation of as well as the need for support in Kinshasa, DRC. This chapter also looked at support through the lens of personhood, examining the impact that support may have on personhood and vice versa. Although theoretical understandings of personhood and support are important, it is equally important to gain a practical understanding of the provision of support, which is what I argue is the key contribution of this chapter. The provision of family support is one important way to ensure the quality of life of people with IDD in Kinshasa. This is in the interest of all Congolese society, as people with IDD who are supported can better contribute, through work and social interactions, to improving society as a whole. Families themselves are an important key to creating and providing support, particularly when they organize into associations. Government and international funders should build on the strengths displayed by innovative families and provide them with the means and

power to organize to meet the needs of their family, improve the life of their member with IDD, and assist other families to do the same.

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