**Article**

# Stigma experienced by families with members with intellectual disabilities in Kinshasa, Democratic Republic of the Congo

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## Abstract

**Introduction:** This article outlines the results of a participatory action research project to (a) understand stigma experienced by family members of people with intellectual disabilities (IDs) in Kinshasa, Democratic Republic of the Congo and (b) identify strategies used by these family members to mitigate or cope with stigma. **Methods:** We conducted 20 semi-structured interviews with family members of people with ID. **Results:** All participants in this study discussed experiencing stigma. This stigma was most commonly felt when people directed negative looks, used negative language and names, or refused to touch their family member with ID. Stigma was also directed at the family members as being the 'cause' of the ID. Family members noted engaging a range of coping mechanisms or strategies to minimise the stigma. **Conclusion:** Insight from this study could be used to develop interventions benefiting families affected by ID. A sample of suggested interventions include creating opportunities for targeted, local contact with stigmatised persons; reducing or eliminating use of negative and stigmatising names (e.g. kizengi) for people with ID; and promoting self-help and self-advocacy groups for people with ID and their families.

**Keywords:** Democratic Republic of the Congo, intellectual disability, participatory action research, stigma

### KEY IMPLICATIONS FOR PRACTICE

- Families of people with intellectual disabilities in Kinshasa, Democratic Republic of the Congo experience personal and family-level stigma
- Family members use a range of coping strategies, such as referencing religion; educating others; and participating in self-help associations
- Future interventions might create opportunities for targeted, local contact with stigmatized persons; reduce or eliminate negative and stigmatizing names for people with ID; and promote self-help for people with ID and their families.

## INTRODUCTION

Globally, people with intellectual disabilities (IDs) and their families suffer high levels of discrimination, marginalisation and stigmatisation (Abbott & McConkey, 2006; Siperstein, Norris, Corbin, & Shriver, 2003). Stigma is a set of prejudices or stereotypes, discriminatory behaviours and biased social structures promoted by a sizable group about a discredited subgroup (Corrigan, 2000). Researchers often classify stigma experiences into four distinct types, depending on who experiences the stigma and how it is enacted. First, the term public stigma describes the attitudes of the general population towards a stigmatised person (Phelan, Bromet, & Link, 1998). Second, the term self-stigma describes individuals' internalisation of society's negative views about themselves (Corrigan & Watson, 2002). Third, stigma by association or family stigma describes stigma that affects those closely affiliated with the stigmatised individual (Goffman, 1963; Larson & Corrigan, 2008). Finally, the term affiliate stigma describes, when those closely affiliated persons internalise

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and have psychological responses to the stigma by association (Mak & Cheung, 2008). This article outlines the results of a participatory action research (PAR) project with an aim to (a) understand stigma experienced by family members of people with ID in Kinshasa, Democratic Republic of the Congo (DRC) and (b) identify strategies used by these family members to mitigate, avoid, or cope with stigma.

Stigma can lead to a number of negative outcomes. In a systematic review of stigma related to people with ID and their families, Ali, Hassiotis, Strydom, and King (2012) found evidence that stigma *'affects psychological wellbeing in parents and can lead to parental stress, increased care giving burden and a lower quality of life'* (p. 2138). Families of people with ID may be shunned by other family members friends and the general public (Pryor & Reeder, 2011). Experiences of stigma may lead to impaired self-esteem and low levels of help seeking (Dagnan & Waring, 2004; Hatzenbuehler, Phelan, & Link, 2013; Jahoda & Markova, 2004). Some argue that stigma is a fundamental cause of population health inequalities and can be a central driver of morbidity and mortality at a population level (Hatzenbuehler et al., 2013). Although there have been extensive research efforts and theoretical advancements in the study of stigma towards individuals with mental health disabilities, the stigma related to being a family member of a person with ID has received only limited attention (Ditchman et al., 2013; Werner & Roth, 2014) and few interventions have attempted to tackle ID-related stigma among the general public (Walker & Scior, 2013).

Researchers widely accept that stigma is a universal phenomenon, but they have also highlighted the importance of culture because it relates to stigma, arguing that stigma can be subject to the influence of local and cultural factors (Murthy, 2002). Yang and colleagues (2007) argue that *'across cultures, the meanings, practices, and outcomes of stigma differ, even where we find stigmatisation to be a powerful and often preferred response to illness, disability, and difference'* (p. 1528). Semrau, Evans-Lacko, Koschorke, Ashenafi, and Thornicroft (2015) identify explanatory models (e.g. attribution of disability to supernatural forces), cultural meanings of impairments and the manifestations caused by the disability (e.g. impact of stigma on marriage prospects will have a differing impact on the person depending on how important marriage is in the society), and concepts of self and personhood as the key domains, through which culture may shape the manifestation of stigma. In addition to cultural factors, socio-economic factors, such as poverty or access to health, can also affect how stigma is displayed or felt (Evans-Lacko, Knapp, McCrone, Thornicroft, & Mojtabai, 2013; Switaj, Wciorka, Smolarska-Switaj, & Grygiel, 2009; Thornicroft et al., 2009).

Kinshasa, the location of this study, is the vibrant capital city of the DRC. The DRC is an African nation that experiences high levels of poverty and limited state-sponsored health and social support mechanisms for people with ID and their families. The DRC consistently ranks at the bottom of the Human Development Index, a composite measure of life expectancy, education and per capita income indicators (United Nations Development Programme, 2014). This poor rating suggests that families in the DRC experience incredibly low life expectancy and education rates and high rates of poverty. Congolese families, who have a family member with ID are often faced with additional hurdles that could push them further into poverty, including increased health and education costs, debilitating caregiving burdens and decreased opportunities to work outside of the home (Aldersey, 2013b; Aldersey, Turnbull, & Turnbull, 2016).

Although there are no recent official estimates of disability prevalence, researchers use global estimates to predict that there are approximately 10.5 million people with disabilities in the DRC (Lobe & Mubaya Kiwele Kya Bantu, 2013). Specific to ID, global prevalence estimates of approximately 1% of the total population (Mckenzie, Milton, Smith, & Ouellette-Kuntz, 2016) suggest that there may be around 800,000 people with ID in the DRC. Among Congolese, the nuclear family is often only one part of a larger network of extended family that can include grandparents, uncles, aunts, cousins, nephews, nieces and even those not biologically related (Ranard, 2013); thus, the potential for stigma by association to persons with disabilities in the DRC is substantial.

Researchers have argued that people with ID in nations with high levels of poverty, such as the DRC, are more likely to experience stigmatisation than those in higher income countries (Jones, Weil, Coreil, & Shoush, 2004). Researchers have also acknowledged that people with ID may be one of the most highly stigmatised populations globally, yet little attention has been paid to them in the literature to date (Scior et al., 2016). It is for this reason, we have decided to study stigma towards ID specifically, rather than stigma towards disability more generally in the DRC. Although there have been no explicit studies focusing on stigma in DRC for people with ID, studies on different topics have indicated that stigma is an issue facing this population and warrants further study. For example, researchers studying people with ID and their families in the DRC affirmed that stigma related to ID is highly prevalent (Mukau Ebwel, Roeyers, & Magerotte, 2013). Others noted that it might be a key factor inhibiting the achievement of social inclusion for people with ID and their families in Kinshasa and, thus, warrants further study (Aldersey, Turnbull, & Turnbull, 2014). Accordingly, this study attempted to answer the following questions:

(1)  How do family members of people with ID experience stigma in Kinshasa?
(2)  What strategies or coping mechanisms do families with a member with ID utilise to attempt to cope with, mitigate or avoid stigma in Kinshasa?

## METHODS

### Research approach and preparation

PAR is an approach to research that involves an active collaboration of stakeholders, leading to a blurring of roles defining 'researcher' and 'researched' and to an equal partnership between researchers and community stakeholders (Grant, Nelson, & Mitchell, 2008). The research team conducting this study included five individuals who

are Congolese parents of children with ID along with a Canadian researcher who specialised in supporting families with members with ID in low- and middle-income countries. Collectively, we have worked together on research projects since 2011. In alignment with key values of PAR, the Congolese team members were actively engaged in all components of conducting the research, including study conceptualisation, tool development, data collection, data analysis and dissemination of results. The five Congolese family researchers were not, themselves, participants in the study; rather, they collected responses of other family member participants. Prior to commencing the interviews, we obtained ethical approval from the Queen's University Health Sciences Research Ethics Board.

## Data collection

Congolese research team members conducted 20 semi-structured interviews with family members (10 mothers, seven fathers, one sibling, two grandparents) of children and adults with ID. We, Congolese research team members, operationalised the term ID to be someone, whose intellectual function and adaptive behaviour (i.e. everyday social and practical skills) differ significantly from societal norms, and this difference originated before the age of 18 (AAIDD, 2010). Although a richer discussion of defining ID in a Congolese context goes beyond the scope of this manuscript, further discussion of this issue is provided elsewhere (Aldersey, 2013a). Given challenges in obtaining a formal diagnosis of ID in Kinshasa as well as a desire to leave 'family' open to cultural understanding of this term, any person who self-identified as a family member of a person with ID was welcome to participate in this study.

All interviewers followed a semi-structured interview guide that the team developed collaboratively, with questions that probed everyday experiences in the community, experiences of discrimination, affective reactions to experiences of stigma and strategies for avoiding/mitigating stigma. Interviews were conducted either in French or Lingala and were transcribed and, as appropriate, translated into French. At transcription, all participants were assigned pseudonyms to protect confidentiality.

## Data analysis

We analysed qualitative data concurrently and recursively within and across interviews to identify themes as they emerged (Charmaz, 2006). The concurrent team analysis of interview transcripts (the team met either in person or by Skype approximately every 2 weeks for the 6 months of intensive data collection) enabled the team to reflect together on emerging themes. The reflections of the team during these meetings then shaped subsequent interview questions and probes to confirm or expand upon emerging themes or concepts (e.g. getting participants to comment on stigma mitigation strategies identified by others in previous interviews). Once we completed data collection, we developed a coding guide and coded the dataset based on our initial group discussions. All the members of the team coded the same five transcripts individually and then came together as a group to discuss the codes and coding process.

We discussed themes identified and came to consensus on discrepancies or disagreements. The remaining transcripts were then assigned final codes by the first author, using the collaboratively determined themes. The second author then coded five transcripts also coded by the first author for further confirmation of agreement.

## RESULTS

Families in this study expressed experiencing stigma on two levels: (a) stigma directed at the individual with ID that then influences the emotional well-being of the family member; and (b) stigma directed at the family member for being affiliated with the person with ID.

## Stigma directed at the individual with ID and influence on family member

Family members expressed distress and negative feelings arising from witnessing negative reactions to their family member with a disability. Participants noted that these reactions came from extended family members (e.g. sister-in-law; cousins) as well as from neighbours and strangers within the wider community. The experiences that had a negative psychosocial influence on family members most often cited were (a) degrading looks and names directed at the person with ID and (b) refusal to touch the person with ID. It is important to note that although all participants noted experiencing stigma at some point (and many experience it frequently), most participants shared that while some people performed the stigmatising actions described below, others in the community did not treat their family member in a stigmatising way, and instead accepted and loved the individual with ID just like any other. Thus, there was recognition that not everyone in the community treated their family member (or them) in the ways described below.

### Degrading looks and names

Many families demonstrated degrading looks that they saw directed at their family member with ID, when he or she is out in the community. These looks included sneers, sideways glances and signs or whistles through the teeth. Participants said that when people would stare at their family member with ID that would make them feel uncomfortable, ashamed, embarrassed, or sad. A few participants reflected that they have stopped going out into the community with their family member with ID to avoid these feelings.

*The way she is always breaks my heart, to the point where, I cannot walk around with her anymore or bring her out in front of people who visit us at home. This is just to avoid having everyone look at her disdainfully! The way she is, is truly a hardship for me! (Participant 7, Mother).*

In addition to disdainful looks, participants noted distress from hearing their family members referred to using stigmatising language or names. Most families noted that their family member with ID was called a sorcerer, a child of water ('mwana mayi') [Reference to a 'child of water' in a Central African context links the child to witchcraft, particularly as it relates to amassing power and access to

wealth (Janzen, 1992; Biaya, 2004).], crazy, worthless, or an idiot (kisimbi or kizengi in Lingala). One family also noted their child was called a 'gourmand' (someone who eats a lot or eats well – in reference to 'eating' or consuming the family's time/money/energy). Families noted both experiencing derogatory names addressed directly to them (the speaker intended them to hear their words), and they also shared that they would overhear people talking about their family member in a derogatory way (the speaker did not intend for them to hear what they were saying).

Families identified a range of affective reactions when people speak of their children in derogatory ways, from sadness and frustration, to embarrassment, and often, anger.

*Upon hearing those defamatory words, I felt an incredible anger, because she was speaking about my child. [ . . . ] She was talking about my child, the one who eats a lot, is constantly sick, and unable to sit down. [ . . . ] I was really sick and tired of it all. (Participant 5, Mother).*

### Refusing to touch

In addition to derogatory looks and names, participants stated that they have encountered people, who refuse to touch their family member with ID, or to come in contact with items that individual touched (such as water, or cooking/eating utensils). In addition to avoiding items that the individual touched, families said that people will avoid touching their family member directly. For example, one participant recounted encountering medical personnel, who refused to touch her child because they did not want to come in contact with his saliva that would run down his face. She also shared that she was not immune from these experiences, even in church:

*It happened that she [my child] touched another child at church, and suddenly, the mother of this child odiously and hatefully removed the hand of my girl. That really affected me. What did this mother think? Certainly she thought that by touching her child, my child was passing along her intellectual disability! That really breaks my heart. (Participant 5, Mother).*

In addition to community unwillingness to have the person with ID come in contact with other children, families recounted particular experiences with pregnant women avoiding physical contact with people with ID for fear of 'contamination'.

*Women who are pregnant, or those who are continuing to procreate, have horror to touch a [child with ID]. They say amongst themselves "if I touch a child like this, I will surely give birth to a child that will be like him!" . . . people are fearful to touch my child. Even if he falls while I am away when I leave him alone, mothers will come, they will see he has fallen, and they will just pass him by. They are afraid to touch him to pick him back up again! (Participant 7, Mother).*

Although the majority of participants, who discussed experiences related to 'fear of touching' indicated that the feared touch was that of the individual with ID, one

participant noted that her husband's family refused to touch anything that she, the mother, come in contact with:

*If I take forks, or even a pot to prepare food for the children. [My sister in law] will throw those things out. . . . I can't touch them because my children have disabilities, my children are sorcerers, and they don't want that. (Participant 16, Mother).*

To summarise, participants shared that many members of the community directed stigmatising actions towards their family member with ID, and this had negative affective consequences on them as family members. We will now describe when the negative actions are directed at the affiliated family members (rather than the individual with ID).

## Stigma directed at families

In addition to feeling shame, embarrassment, or anger when stigmatising actions are directed at their family member with ID, participants, particularly parents, also identified similar sentiments, when stigma was directed at them. This form of stigma was experienced because it was related to the birth order of the child with ID and to being blamed for the child's disability. Stigma directed at the affiliated family member appeared to be influenced by gender, with females most often experiencing the greatest levels of stigma in this category.

One participant lamented that in giving birth to a child with ID, a mother needs to accept that 'you will be a subject of mockery' or that people will make you feel less than adequate as a parent. Another participant noted:

*Certain people would reproach me for having a child like this, thinking that I had not gotten myself proper prenatal care. They are wrong to think this way, because I regularly had prenatal check-ups. [ . . . ] Yet they say nothing about the women who do not have regular check-ups when they are pregnant but who give birth to children without problems. (Participant 7, Mother).*

Additionally, it seemed that those parents for whom the child with ID was a first born described more stigma. For example, families explained that having a first born child with ID put a mark on the family as being unable to create 'normal' progeny. Some participants believed that the way to remove this mark was to have more children to prove that they could give birth to children without disabilities and that their bloodline was not tainted.

Although many mothers of people with ID noted that their spouse stayed with them and both genders identified co-parents as sources of support in spite of the stigma from extended family and the surrounding community, two mothers shared that their marriages ended because of the disability.

*[My husband believed that my child and I], were both sorcerers who destroy things. He said, "I give you this child as a gift", and then he abandoned me. (Participant 2, Mother).*

A major theme underlying the stigma and blaming directed at families, as apparent in the quote above, was the linking

of disability to sorcery and the occult. Participants argued that families in the DRC are often accused of sacrificing their child's intellect for other worldly gains (e.g. a large house, a job promotion).

*There was a problem that really shocked us. In our neighbourhood, there are people who said that we had constructed a big house and that in order to be able to do this, we have a child with a disability . . . who is linked to the dark world, to the occult. They say that we are occultists and that the proof is the child who is not normal in our family. (Participant 19, Father).*

Accusations of sorcery could affect the whole family unit, not just the parents. For example, one sister of a person with ID stated:

*They said, no, we are sorcerers and that is why our little brother has become the way he is. We were then chased from [visiting the neighbours'] home. (Participant 18, Sister).*

In addition to seeing the family as sacrificing the child for material gain, accusations of sorcery were also levelled at families, when it was believed that the parents were infertile and used sorcery or occultism to become pregnant (and the child's ID was a result of how he was conceived). Being accused of sorcery resulted in various consequences for the family members including being excluded from neighbourhood gatherings or being unwelcome in people's homes. Such accusations could also bring about distress and feelings of frustration.

In spite of the distress caused by stigma directed at both the individual with ID and his or her family, participants outlined a range of strategies that they use to mitigate, avoid, or otherwise manage the experiences of stigma.

## Managing stigma

The range of strategies for stigma mitigation can be organised in terms of (a) accepting the family member with ID at home and including him or her in activities in the community; (b) understanding disability in terms of religion and God; (c) educating the stigmatisers; and (d) finding solace and support in self-help associations.

### *Accepting the family member with ID at home and including him or her in the community*

Many participants believed that reduction of stigma must first start at home. Participants said that they knew other families, who were ashamed and embarrassed of their member with ID. They said that these families hid their member with ID in the home, did not take proper care of his or her cleanliness, health, or hygiene, or themselves called the individuals stigmatising names.

*There are certain families that hide their children. That do not want people to know that they have children like this. But we must not be embarrassed of these children. We need to put it in our head that first and foremost, a child is a creature of God and that we must love him like any other child. (Participant 19, Father).*

When discussing strategies for mitigating the stigma they felt, participants noted that if a family treats their member with ID in a stigmatising or derogatory way, the community is sure to follow. Indeed, as one father noted, *'the greatest force to minimise stigmatisation is us, the parents. The family of the child, that's us and the first form of defence, it's us' (Participant 4, Father).* Thus, participants noted that to reduce the stigma that is directed at the individual with ID, the family must be the first ones to demonstrate great love, affection and absence of discriminatory actions towards him or her. In other words, families need to model the type of treatment that they expect of their family member with ID from the wider community.

In addition to loving and supporting the child at home, some participants shared that they make a particular effort to bring their family member with ID out into the community, in the hope that greater community interactions will reduce stigma. Participants, such as one father, stated the importance of *'finding ways to make them go out so that they are in contact with other people'*, such as going out for walks in the community, going to church, or going to the market. This participant further noted the importance of *'inserting [people with ID] in society: finding them a job to do, or otherwise helping them to be integrated with others outside the home' (Participant 15, Father).*

### *Referencing religion and God*

A majority of the participants discussed key strategies in terms of religion – specifically Christian faith. Participants used religion to discuss how they personally cope with the stigma, how they council other stigmatised families, and how they respond, when people in the community treat them in stigmatising ways. First, a participant shared that she *'accepts that people will mock me and my child, but God is the only thing that matters'*. She further stated that she tries not to pay much mind to the stigma that she experiences, rather she has begun to *'put everything in God's hands, because the child also knows God, and our Lord will take care of us' (Participant 1, Mother).* Another reflected that she has no problem giving her child value and paying no mind to others' negativity because *'it is God who gave me this child' (Participant 10, Mother).* Finally, another noted that he does not pay any mind to those, who tell pregnant women not to touch people with ID, because these beliefs are not in line with his Christian religion. In addition to personal coping strategies, participants used discussions of religion and references to God, when counselling other families with people with ID. For example, one father told us that he tells other families *'you must put it in your head that the child is a creature of God and because of this, we must treat him like all other children' (Participant 19, Father).* Another participant noted that he advises families to stop neglecting or treating their family member with ID poorly because *'perhaps you are neglecting the purpose that God has set out for you . . . this child could be your source of benediction' (Participant 6, Grandmother).*

Finally, some participants evoke God and religion to respond directly to people who stigmatise them or their

family member with ID. *'I tell them, this is a normal human being that God created, and that can also be useful to society'* (Participant 15, Father). Another participant said that when people act as if her child's disability is contagious, *'I respond that they need to stop having these prejudices and that my child will not contaminate them. His disability is the decision of God'* (Participant 5, Mother).

## Education

Another key method to mitigate or reduce stigma used by families is to educate or reason with the people perpetuating the stigma. Participants would share information about the individual and/or about the individual's disability. For example, some participants would explain to their neighbours the history of the family member and his or her disability (e.g. that it was a result of an illness), to reduce allegations of sorcery or occultism. One participant admitted that she carried pictures taken of her child before she acquired an ID to be able to prove to outsiders that her child was once 'normal'. Others take the time to try to provide reasons to those making accusations why the individual or the family are not sorcerers, such as arguing that their child is clean and well-dressed and, thus, not a sorcerer, or responding that the family is poor, so *'what did we gain if we were occultists?'* (Participant 19, Father). Still others would simply try to explain that an ID is not contagious, and that there is not a possibility that others will 'catch' the disability.

## Self-help associations

The last major strategy used by many participants was to find solace and share experiences with others in similar situations, such as other parents in a self-help association. Participants believed that through self-help associations, they can *'forget'* the stigma (Participant 6, Grandmother), *'find peace'* (Participant 1, Mother), or *'get used to the challenges posed by the disability'* (Participant 15, Father). Others spoke of the benefits of solidarity in the face of stigma.

*Being part of an association, this has brought me so many benefits. First, in a moral sense, I can tell myself that I am not alone. Because, like they always say, l'union fait la force [there is power in numbers]. As soon as you understand that you aren't alone with a problem, you get the impression that the problem has dissipated, and you feel some relief.* (Participant 19, Father).

The phrase used in the above quote 'l'union fait la force', was used by three different participants, when talking about how coming together with other family members helps them to mitigate or cope with the stigma. In addition to having emotional support with which they could cope or deal with stigma on a personal level, participants also found that coming together with others helped in taking action against stigma in society.

## DISCUSSION

This study examined stigma experiences of 17 parents, one sibling and two grandparents of people with ID in

Kinshasa, DRC. All participants in this study discussed experiencing stigma at some point in their lives. The stigma described by participants in this study could be classified as public stigma (stigma directed towards the family member with ID), stigma by association (stigma was directed towards the parent or family member because of their affiliation with a person with ID) and affiliate stigma (psychological responses to the stigma by association). The feelings expressed by families in this study are similar to those expressed in other cultures around the world, specifically, feelings of shame, embarrassment and distress arising from being a parent or family member of a person with disabilities (Baxter & Cummins, 1992 ; Chang, 2009; Green, 2004, 2007; Ntswane & van Rhyn, 2007; Perkins, Holburn, Deaux, Flory, & Vietze, 2002; Shin et al., 2006). It is possible that stigma was more acutely felt by female family members (and particularly mothers) because ID is often attributed to pre- or perinatal exposures, and, thus, women are blamed as having caused the ID in some way. Stigma may also be more acutely felt by women due to persisting gender imbalances in the DRC, wherein women continue to experience vulnerability and inferiority (Mbambi & Faray-Kele, 2010) and, therefore, may be more common targets of stigma or public scorn than men.

Family members identified a range of coping strategies that they used to minimise the stigma. These included accepting the family member with ID at home and including him or her in activities in the community; understanding and discussing disability in terms of religion and God; educating the stigmatisers; and finding solace and support in self-help associations. Many of the coping mechanisms expressed by families in this study are also in alignment with coping mechanisms of families identified in a recent global systematic review, such as educating others, turning to religion/God and having supportive friendships (such as those one would find in self-help associations) (Ali et al., 2012).

The specific reactions of the community towards the person with ID that were uncovered in this study, such as staring, name-calling and fears of contagion have been observed by others in numerous contexts as well (e.g. Baxter, 1989). Name-calling, in particular was an issue that was frequently raised by this study's participants. In recent years, there has been an increasing focus on the power of language because it relates to disability, and in particular, the consequences of labelling, categorisation and related stigma. English and French language terminology as it relates to ID has changed over history, with mental retardation, along with a suite of more offensive terms all being used to describe this population in the last 200 years (Schalock, Luckasson, & Shogren, 2007). 'Intellectual disability', or 'déficience intellectuelle' in French, is now a less-offensive, less negative and less stigma-evoking term than those used in the past (Schalock et al., 2007; Government of Ontario, 2004). At present, there does not exist a widely utilised, non-stigmatising term for people with ID in Lingala, the language spoken most widely in Kinshasa. The findings of this study provide corroboration that public stigma is still often triggered by a label

(Bos, Pryor, Reeder, & Stutterheim, 2013). Presently if families want to identify or classify their child with ID in non-stigmatising terms, they often simply utilise 'déficience intellectuelle' in French. Therefore, we suggest that there is a need for targeted efforts and public sensitisation campaigns in the DRC to reduce or eliminate negative and stigmatising names (e.g. kizengi) for people with ID and develop an appropriate terminology in Lingala and the other national languages of the DRC.

The findings of this study provide further confirmation and illustration of how, as some researchers argue, stigma can be culturally-linked (Chiu, Yang, Wong, Li, & Li, 2013; Yang et al., 2007, 2010), with culture 'associated with stigma-linked attributions, affects, and behaviour' (Mak & Cheung, 2008, p. 542). Specifically, understanding 'deviance from the norm' as being intrinsically linked to sorcery and the occult, while perhaps unusual in a contemporary North American or European context, is well-established in Congolese and broader African understandings of difference and misfortune (e.g. Corin, 1979; Devlieger, 1995; Livingston, 2005; White, 2004). For example, Whyte (1998) identified that mental disability in eastern Uganda is often dealt with in an explanatory idiom that posits spirit and human causes for misfortune, where spirit refers to the ancestors and the use of sorcery. In the DRC, sources outside the tangible world, such as God, ancestors, spirits or sorcerers, are just as important as more tangible factors, such as nature and biomedicine, to the onset, maintenance or remediation of difference or (mis)fortune (Devlieger, 1995). This was clearly evident even in the derogatory name frequently identified by families in this study, mwana mayi, which translates to 'child of water', which in a Central African context links the child to witchcraft, particularly as it relates to amassing power and access to wealth (Biaya, 2004; Janzen, 1992). Specific to a Kinshasa context, researchers have argued that sorcery is used as an explanatory model to describe things that are beyond comprehension or that violate established norms (Aldersey et al., 2014; Corin, 1979; White, 2004). This study provides further confirmation to this body of literature, demonstrating that people with ID and their families in Kinshasa continue to be connected to sorcery and the occult in the mind of the public when they are seen to be different from established norms of appearance, behaviour, or societal contributions.

These findings related to increased stigma, when ID is linked to sorcery seem to be more widely applicable beyond the DRC. For example, in a global review of stigma and ID, Scior (2011) identified that throughout Asia and Africa and in other locations worldwide, stigma can arise due to 'deep rooted prejudice and stigmatising beliefs about the causes of intellectual disability' (p. e294). Understanding narratives of sorcery may help one to understand the importance of stigma mitigation and coping strategies of educating the community about the cause of the disability. This, in a way 'normalises the disability as a result of an illness and addresses the culturally-determined factor of the degree to which family members are held responsible for life outcomes (Crandall & Martinez, 1996).

If family members are able to use education to demonstrate that they were not directly responsible for the disability because of use of the occult, they may experience less stigma in the community. This particular strategy of educating others about disability to prevent or reduce disability-related stigma has also been found useful outside of discussions of sorcery (Ali et al., 2012; Baxter & Cummins, 1992; Todd & Shearn, 1997). For example, Farrugia (2009) found that parents of children with autism spectrum disorder resisted feeling stigmatised by providing medical knowledge in an attempt to reconstruct normality.

Findings from this study indicated that family-targeted interventions will need to address the importance of honouring people with ID as valued and respected members of the family, to avoid contributing to public stigma of these individuals. Next, family interventions should advocate for the importance of community outings and targeted, local, credible and continuous contact with stigmatised persons as a means of reducing public stigma (Corrigan & Kosyluk, 2013). It would also be beneficial for a family-targeted intervention to provide discussions around strategies or techniques for addressing negative looks, vocabulary and actions towards the individual with ID and his or her family. Next, participant responses indicated that gender may be an important factor in stigma experiences in Kinshasa. Researchers in other contexts have also indicated that gender differences may exist in the experience of stigma (Chang, 2009; Edwardraj, Mumtaj, Kuruvilla, & Jacob, 2010; Fazil, Bywaters, Ali, Wallace, & Singh, 2002; Mak & Cheung, 2008). Therefore, it is advisable to integrate discussions and strategies that take gender into consideration in the structuring of any targeted family intervention. Additionally, the content of a family intervention in Kinshasa might also discuss how having faith in God can be another major coping strategy for families of people with ID (Crabtree, 2007a,b; Edwardraj et al., 2010), or could be used as a strategy for engaging the public with discussions around shared humanity and common human experience, which may reduce stigma tied to understandings of difference or deviance from a cultural norm.

Finally, it is important to underline the key role that family self-help associations can play in reducing or mitigating stigma experienced by families affected by ID. Our findings about family associations in the DRC align with a recent global study of stigma and ID, wherein Scior et al. (2016) identified the crucial role of parents as advocates in reducing stigma related to ID. Research has shown that many family members prefer to frequent places that are more accepting of people with ID, such as support and self-help groups (Power, 2008; Shearn & Todd, 1996; Todd & Shearn, 1997). In a systematic review of stigma of people with ID and their families, Ali et al. (2012) identified that receiving support from friends was negatively related to stigma, and concluded, therefore, that 'having supportive friends may be one approach to reducing the impact of affiliate stigma' (p. 2135). Self-help and advocacy groups may function as such a support mechanism, reducing stigma through the sharing of experience and the provision of assistance to one another (Chang, 2009; Shu & Lung,

2005). Going further and engaging in activism or action to mitigate stigma, as discussed by participants in this study, can also help family members to experience less shame and even pride in parenthood, or could give mothers respect and heightened status in the eyes of other members of the family (Chang, 2009).

## Limitations

This study is not without limitations. First, the recruiting method that we used (e.g. drawing on the network of one parent self-help association) is likely to have limited the representativeness of participants we recruited and the nature of the answers we received. Nevertheless, we believe that the insight provided by people within this association's network also has the potential to resonate with and benefit people outside of this network. Additionally, although we welcomed anyone who self-identified as a family member of a person with ID in our study, our final sample represented parents more than other types of family members, due to limited time and resources for more wide-reaching recruitment methods. This is a limitation in that historically, representations of 'family' experience tend to reflect primarily on the experiences of parents, and more specifically, mothers. As such, our results should be read as experiences of a select group of family members, the majority of whom were parents.

## Conclusion

We do not believe that there exists a location, in which people with ID and their families are completely unaffected by stigma. Although experiences of stigma can vary from person to person or from culture to culture, this study provides further indication that many experiences of stigma may indeed be quite common. In spite of common experiences, we believe that based on our results, a case can be made that stigma related to ID in the DRC is particularly widespread and severe and has far reaching consequences for people with ID and their families. Interventions that place people with ID and their families at the frontline of combating such stigma are essential, and this PAR study was one attempt to do just that. In the years to come, we envision building on this research to take family-driven action grounded in evidence to improve the lives of people with ID and their families in the DRC.

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## Conflicts of interest

There are no conflicts of interest.

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