

Exploring caregiver experiences of stigma in Ghana: *They insult me because of my child*

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## **Abstract**

Families of children with disabilities experience stigma by association with their child. This article examines social and internalised stigma experienced in the family by caregivers who participated in a caregiver programme in Ghana. Stigma is pervasive, and gendered, with most mothers blamed for bringing disability into the home. Emotional distress, isolation and lack of support are common experiences. We argue that the mothers can experience forms of disablism. Stigma is multi-layered, and a range of factors intersect with disability-related stigma, including poverty. A support group model can have a positive impact on caregiver internalised stigma and begin to address isolation. This should be part of a wider package of support to address wider structural issues. Families can play an important role in mediating

change, but first we need to better understand the social disruption caused by disability-related stigma at the familial level.

## **Introduction**

Stigma experienced by persons with disabilities is well-documented (Mostert 2016; World Health Organization and World Bank 2011). Less is known about the dynamics of stigma within the family of a child with a disability. This is despite the fact that families play a crucial care and support role, and arguably more so in low- and-middle income settings where services are scarce or non-existent (World Health Organization and World Bank 2011). In this article we explore the experiences of stigma among caregivers of children with cerebral palsy in Ghana who engaged with a caregiver training programme for children with cerebral palsy. First, we review the concept of stigma and the literature on stigma for caregivers of children with disabilities.

## **Concepts of stigma**

Stigma is a complex social construct, and there have been various theories, categories and concepts. Goffman pioneered work on stigma in the 1960s, and defined stigma as an 'attribute that is deeply discrediting' (p.3 1963) and reduces the bearer from 'from a whole and usual person to a tainted, discounted one' (Goffman 1963, 3). If the stigma is visible, then problems of interaction result, and the person is '*discredited*'. If hidden, then problems of information management result, and the person is '*discreditable*'. Although the work of Goffman can be helpful, the main criticism is that it focussed on the micro-level of the individual. Conflicting perspectives in the disability field put problems of interaction into the context of social barriers and social exclusion (Oliver 1990). Goffman's theory has now

been further developed and reframed over the next fifty years to explain health-related stigma.

In extending the theory of stigma, Scrambler (1989; 2009), in his 'hidden distress model of epilepsy', distinguishes between '*Felt*' stigma as distinct from '*Enacted*' stigma. Enacted stigma refers to overt examples of discrimination experienced. Felt stigma is the individual's internal feelings, such as a sense of shame, or anticipation about stigma, such as a fear of encountering possible discrimination. Increasingly, there has also been a greater focus on understanding the macro-level dimensions of stigma. Link and Phelan's model (2001; 2014) explores the effects of stigma and how they operate in relation to disability. Here the focus shifts from the effects of stigma on individual labelling, towards examining how an individual experiences oppression arising from wider society and environmental factors. Their model thus includes the broader operation of stigma in terms of institutional or structural discrimination *i.e.* having a 'disabling environment'. The notion of structural stigma resonates with Parker and Aggleton's (2003) conceptual framework on AIDS-related stigma and the work of Corrigan et al (2005) on the stigma of mental illness where they argue for the need to examine structural discrimination which exists against certain groups at an institutional level, even in the absence of individual discrimination.

A further revised concept of health-related stigma outlined by Weiss et al. (2006) similarly portrays stigma as shaped by socio-cultural, historical, economic and political context, best understood through the social structures which moderate social interactions, emphasising the need to understand how stigma varies across different cultural contexts. This model

usefully extends earlier concepts by distinguishing between those who stigmatise and those who are stigmatised, and defines health-related stigma as *'a social process- experienced or anticipated - characterized by exclusion, rejection, blame or devaluation that results from experience, perception or reasonable anticipation of an adverse social judgement about a person or group identified with a particular problem'* (Weiss, Ramakrishna, and Somma 2006, p.280)

Many of the later stigma concepts and models also emphasise the role of power, and that it takes power to stigmatise, but also that stigmatization plays a role in producing and reproducing relations of power and control, intricately linked with social inequality (Link and Phelan 2014; Parker and Aggleton 2003). These models also emphasise the intersectionality of stigma with the health condition or impairment compounded by other factors such as poverty, gender and ethnicity (Link and Phelan 2001; Pescosolido and Martin 2015; Weiss, Ramakrishna, and Somma 2006).

A different but useful way of articulating the different levels of stigma is the notion of social, structural, and internalised stigma. Social stigma is enacted stigma or public stigma, operating at a meso level and is interpersonal in nature. Structural stigma or institutional stigma operates at the macro or systems level. Internalised stigma refers to the individual, and to self or felt stigma at the micro level, embedded within a sociocultural context. It is characterised by negative feelings about self, maladaptive behaviour, stereotype endorsement resulting from an individual's experience or anticipation of negative social

reaction (Corrigan, Kerr, and Knudsen 2005; Livingston and Boyd 2010). It is this conceptualisation of stigma which we use in our study.

### **Stigma, the family, and caregivers**

Attending to the interpersonal nature of social stigma, there is a growing recognition that the families of people with health problems or impairments warrant attention in understanding the diverse manifestation in which a stigmatised condition is experienced.

Whilst the initial focus of the literature search was on families, this was extended into understanding how individual caregivers experience stigma. The term 'caregiver' is used to describe the main family caregiver, who is in an informal or unpaid care role (Shewchuk and Elliott 2000). This is predominantly a female relative, most notably mothers or grandmothers (McKenzie and McConkey 2016; World Health Organization and World Bank 2011).

Goffman first described stigma applied to people who associate with those who are stigmatised, such as family members, as 'courtesy stigma' (Goffman 1963). Later conceptual models also reflect the fact that people who do not have an impairment or illness, may themselves also experience 'felt' and 'enacted' stigma (Scambler 2009). Mak and Cheung (2008) coined the term 'affiliate stigma' to describe the internalisation of feelings which arise from being associated with a person with a stigmatising condition, leading to heightened emotions such as despair, anger or being behaviourally withdrawn.

Much of the literature on caregivers has focused on the broader experience of caregiving, with stigma as one component of the overall narrative. Literature which focuses on the role

stigma plays in the family, particularly in countries in Africa, is more limited. Within this, the focus is often on caregiving for those with intellectual disability and mental health.

### **Internalised stigma**

It has been argued by Yang, in a study of Chinese caregivers of people with intellectual disability, that internalised self-stigma is one of the most damaging forms of stigma for families (Yang 2015). In this study, internalised stigma is categorised into (1) feelings, such as shame, embarrassment and guilt, (2) cognition, with feelings of self-worthlessness and (3) behaviour, such as social withdrawal. Caregivers with concern about their social image, described as 'face stigma', were more likely to internalise feelings of shame, as did those in a lower socio-economic status group. Self-blame seemed to be particularly felt by those whose relatives were born with intellectual disability where the cause tended to be attributed to the family, such as the 'bad habits' of parents, or 'bad' genes. In the absence of clear diagnosis and aetiology, the resultant ambiguity around the cause also sometimes increased distress, although other studies offer mixed evidence about the links between attribution and stigma (Mak and Kwok 2010).

High levels of caregiver internalised stigma have been shown in studies across various country settings, with self-blame in part attributable to internalising others' accusations (Mak and Cheung 2008; Zhang et al. 2018; Huang, Kellett, and St John 2012; Johnson, O'Reilly, and Vostanis 2006). In one study, conducted in the US with families of children with autism, mothers who felt that their child was discriminated against by others in the community were more likely themselves to feel embarrassed, guilty, ashamed, resentful, and/or emotionally upset. One consequence of this was to self-exclude from social events

(Gray 2002). Similar patterns were found in a UK study where it was noted that, as their child was aging, mothers felt burdened with the fear that their child would be rejected, discriminated and isolated in the future (Green 2003).

In terms of studies conducted in Africa, there are few studies which have specifically looked at caregiver internalised stigma. However, within the limited empirical literature, similar patterns emerge. One recent study of children with developmental disabilities who attended a clinic setting in Ethiopia, showed that 45.1 % of caregivers reported feeling ashamed about their child's condition and 43.1% worried about being treated differently (Tilahun et al. 2016). The findings of this study did not show significant differences in levels of stigma across disability types, or age or gender of child.

There is some evidence from studies in high income countries that the experience of internalised stigma may vary depending on the types of disability. For example, a higher level of affiliate stigma has been shown among parents of children with autism in comparison to parenting a child with physical or intellectual disability (CHECK REF) , but other research has been equivocal on this (Werner and Shulman 2015).

### Social stigma

Social or enacted stigma is more commonly captured in research on caregiving of children with disabilities. Those who stigmatise can be from the community, service providers, and within the family. This stigma is both directed towards the child, but also commonly towards

family members and can reinforce caregiver feelings of self-blame and worthlessness (Huang, Kellett, and St John 2012; Johnson, O'Reilly, and Vostanis 2006).

Stigma within the family can manifest itself in terms of both physical and emotional conduct, and despite very different cultural contexts, similar issues emerge. These include family members not wanting to use the same furniture in the house as the child with the disability, not wanting to look at the child, and/or both caregivers and children experiencing negatives looks, negative language, being shouted at or insulted by both family and community members. Exclusion of caregivers with their child from family and community events is also commonly reported (Aldersey et al. 2018; van der Mark and Verrest 2014; Qayyum, Lasi, and Rafique 2013; Heng-hao 2009; Zuurmond et al. 2015; 2016; Patel et al. 2017).

Whilst studies reflect on social stigma within the family, fewer studies explore the gender dimensions, and how this may affect caregivers' experiences differently. A study conducted in Taiwan illustrated that mothers felt shamed and devalued by their husbands and parents-in-law because they had given birth to a child with cerebral palsy. Consequently, this discouraged them from feeling able to ask for help within the family (Huang, Kellett, and St John 2012). Bearing a disproportionate burden of caregiving while simultaneously being blamed by others within the family is a common experience of mothers and is noted within the literature across different settings. A study of Latina mothers of children with



behavioural disorders demonstrates that they felt stigmatised because, within their culture, the primary responsibility for children's behaviour is assigned to the mother (Fernández and Arcia 2004). In one study in the United Arab Emirates, mothers reported being left by their husband, unable to remarry, and 'blacklisted' by family and medical authorities for having a child with a disability (Crabtree 2007). Similar discriminatory and abusive behaviour of paternal relatives towards mothers, resulting in marital discord, abandonment of the mothers, and experience of domestic violence as a result of the blame placed on them has also been highlighted in a small number of other studies in Pakistan, Zimbabwe, the UK, and Tanzania (Qayyum, Lasi, and Rafique 2013; van der Mark and Verrest 2014; Fazil et al. 2002; Aldersey 2012).

The resultant lack of support for caregivers is a recurring issue across both high and low income countries (Yang 2015; Ali et al. 2012; Johnson, O'Reilly, and Vostanis 2006). It can also be exacerbated by a common response whereby parents hide the child from the community and other family members, sometimes in fear of their child's safety, thus reinforcing social isolation. This isolation can also be further exacerbated by lack of availability of services (Roy McConkey, Kahonde, and McKenzie 2016; Heng-hao 2009; van der Mark et al. 2019). As well as parents being fearful of violence, another consequence of social stigma is violence perpetrated by the parents themselves and by teachers, peers and community members (Njelesani et al. 2018).

In the context of Ghana, where our study is based, two ethnographic studies in the Upper East region have documented the phenomena of the '*Spirit child*' to refer to children with

an 'abnormality' as '*bush spirits*' born into the family in human form (Denham et al. 2010; Awedoba and Denham 2014). These children are perceived to cause misfortune to the family, unless killed. Within this patrilineal system the mother is considered to be an 'outsider' within the family, and combined with her procreative power, it is interpreted that her 'behaviour' has put the family at risk (Awedoba and Denham 2014). Other studies in different regions of Ghana also document the abuse of children with disabilities as a consequence of stigmatising beliefs (Kassah, Kassah, and Agbota 2012), and how mothers of children with cerebral palsy experience substantial felt and enacted stigma which contributes to significant emotional maternal distress (Nyante 2016).

In this paper we explore the experience of stigma among caregivers with a child with cerebral palsy in Ghana, focussing on both the personal level and meso-level of the family.

## **Methodology**

This paper draws on qualitative data from a larger study conducted in Ghana to evaluate the impact of a community-based caregiver training programme for children with cerebral palsy. Further details of this training programme, methodology, and impact on the quality of life of the child and caregiver have been published previously (Zuurmond, O'Banion, et al. 2018; Zuurmond, Nyante, et al. 2018). Here we provide a brief summary.

## **Participant selection**

Caregivers were identified through the community-based screening programme and hospital records of children diagnosed with cerebral palsy. Children were aged 18 months to 12 years, and caregivers had not attended any parent support group nor any regular

physiotherapy with their child. Four (out of eight) sites were then purposively selected for a more in-depth qualitative study, ensuring a geographical spread, families of different, socioeconomic status, and a mix of children according to gender, age, and severity of cerebral palsy. A total of 18 families were visited up to three times over the course of the programme; two months before the start of the training support group programme; approximately six months into the training; and within 1 month of completion of the programme.

### **Description of programme**

Community level support groups were established for 8-10 caregivers of children with cerebral palsy across each of the eight sites. The caregivers received a participatory training session of approximately half a day on a monthly basis, and one monthly home visit from a group facilitator over a 12-month period. The modular programme called 'Getting to know cerebral palsy' (LSHTM and Hambisela 2013) is further detailed in Additional document 1- **Insert**

Diagram of training modules

### **Data Collection and ethics**

A total of 37 in-depth interviews were conducted. Seventeen of the 18 participants were women: 14 mothers, 3 grandmothers and 1 male cousin. The overall level of caregiver education was low, with eight never having attended school and only three having attended high school or tertiary education. A socioeconomic index illustrated that most families were extremely poor, and fathers were completely absent (n=11) or lived separately/worked away from home commonly with infrequent visits (n=6), detailed in the paper on understanding impact on wellbeing (Zuurmond, Nyante, et al. 2018) .

Supplementary short interviews were conducted with selected secondary caregivers at the time of the household interviews, in order to capture additional perspectives on the caregiving experience within the household. Detailed field notes were also kept and incorporated into the analysis.

All interviews were conducted either by a local Ghanaian or an international researcher (female Ghanaian GN and White-British female MZ). Interviews were conducted in four local languages with translation into English as required. Interviews were audio recorded, translated into English and transcribed.

Ethics approval was obtained from the Noguchi Memorial Institute for Medical Research, University of Ghana and from the London School of Hygiene and Tropical Medicine.

Informed written consent was obtained from all participating caregivers, with a signature or thumbprint. All children identified with malnutrition were referred for follow-up, and the CBM child protection policy was adhered to.

### **Analysis**

Two key stages of the analysis were conducted: a thematic analysis across all the interviews, and a biographical case study analysis. The data included transcripts, as well as fieldnotes, to provide a more holistic overview of caregiver lives in the local context, in line with guidance for qualitative analysis (Creswell, 2013; J. Green & Thorogood, 2009).

### **Findings**

#### **Social stigma at the familial level**

Social stigma within the family was a strong recurring theme across almost every interview.

This continued through the training programme, with some level of change. It included

stigmatisers from extended family or community members, but there was also a high level of stigmatisation within the household. This presented in a variety of forms, towards the child, but also towards the primary caregiver. A common recurrent experience was rejection and attribution of blame to the mother by the husband and/or husband's family members for bringing a child with a disability into their family. As one mother reflected, *'they believe the sickness in the child is in my family'*. This manifested itself in different ways: family members not engaging with the child or helping with caregiving, as one caregiver described in tears *'they don't help me, I don't have anybody'*; the caregiver *'not on talking terms'* with other family members or with the community; and *'not taking care'* of the mother and child, even from family members living nearby.

In the two sites in the Upper East region, the patrilineal culture means that a wife typically lives with her husband's family and/or in the husband's village. In one case-study, the mother lived with her husband's family whilst her husband worked away from home and visited once only over the study period of 14 months. The mother wanted to leave, and return to her own parents, because of a tense relationship with her mother-in-law who played a pivotal role in the family, at least around child-rearing practices:

*My own mother in-law sometimes shouts at the child and I tell her that children like this should be treated with care and not to be shouted at. She leaves the child and begins to insult me. She doesn't help me. It's the children in the house here who help a lot in looking after her. (Code 9990)*

Exclusion enacted within the household appeared to be a particularly painful experience.

This was illustrated by the case of another mother who described how her husband's family

members avoided her, even when she played with her son in the communal courtyard. By the time of the final interview the father moved out of their shared room, and the family wanted her husband to divorce her, or look for a second wife.

One indicator of the high level of family-level stigma was the almost complete absence of fathers from the household, because of separation or divorce, working away from home for extended periods, or polygamy. Whilst in Ghana it is not uncommon for men to work away from home, the level was still high when compared to national data (Ghana Statistical Service March 2015) and the fact that the child had a disability was often given as a reason for a husband leaving, living separately, or taking a second wife. There were, importantly, examples of where individual family members were supportive, and this was frequently from the maternal side of the family, such as sisters and maternal grandmothers, who offered a welcome safety net for the mothers and children.

### **Internalised stigma**

In terms of internalised stigma, we found that caregivers' negative feelings about self and anticipated stigma were often inter-woven in their narratives and it was not always possible to disentangle these different experiences. The internalised feelings about their child's condition were more evident in later interviews, accompanying the realisation that they were not to blame for the child's condition:

*People used to say I have given birth to a Kinkiriku (spirit child). They said I have used him for money rituals. And that used to disturb me a lot..... I used to be very*

*sad each time they say this, but after I was told what was wrong with him, I worry no more (code 9921)*

The caregivers commonly reflected on the social stigma experienced in the community and family, which were then internalised into a variety of caregiver feelings, including anger, sadness, emotional distress, and *'feeling hurt'*.

*Anytime I remember, I grow angry and even weep. He [my husband] came to tell me that in his family, no one has ever given birth to a child like this, so what I've given him is a curse. (Nav 02b)*

*At first, when they insult me because of my child, I cry a lot (Code 3344)*

Caregivers described difficult relationships with the family, and it was sometimes difficult to disentangle what was exclusion and what was self-exclusion. Feelings of blame over an extended period compounded by sadness, worry and stress, appeared to add to caregiver feelings of *'being on their own'*.

The case studies also illustrated the intersectionality of factors which shaped the caregiver's experience and served to magnify or mitigate the stigma experienced. This included levels of education, caregiver status in the community, and poverty. One mother (case 3339), classified as extremely poor, worked as a day labourer, and had never attended school. She lived alone with her daughter who had severe cerebral palsy, together with an older son. She was a widower and explained that her husband's family were against the marriage, even before the birth of her daughter. She and her daughter were totally excluded within the community and *'no one will touch her [daughter]'*, which meant that she carried her daughter even whilst working. In contrast, a nurse described how supportive her husband

and his family were towards her and her son with cerebral palsy. Although her husband worked away from home, she lived in a hospital compound where her neighbours were from a medical background, *'were educated'*, and frequently visited to give support. She also paid for a nanny to care for her son . She reflected on her experience of working in the local hospital, where children with disabilities were hidden and neglected as a result of her culture where *'many of our relatives and people in our community see these as children from a different place'* and consequently, *' if you are a mother then you are afraid to even bring this child out [of the house]'*.

## Drivers of stigma

### Traditional beliefs

Stigma was both driven and reinforced by pervasive traditional beliefs. In the Upper East region, across every interview, mothers referred to the term *'Kinkiriko'* (spirit child) which was commonly used to describe their child. This spirit could *'deceive'* the family. The researchers were shown a *'spirit hill'* where historically there was infanticide and whilst there is considerable work being done in the region to change this practice, it was evident that these beliefs still remained. Across other regions, traditional belief systems about disability and *'abnormality'* similarly existed. For example, in Greater Accra, it was common to talk about their children having *'Asram'*, a traditional illness of a new born which cannot be treated in hospital. One mother explained how in the past they would *'take the child to the river, shoot a gun, and the child would turn into a snake and return to the river'*. Despite different cultural explanations for the impairment across the different ethnic groups the reasons given still commonly reflected on the mother. For example, the mother may have been unfaithful , or some action that happened to the mother when she was pregnant, or the mother using her child *'for money rituals'*.



One consequence of these beliefs was the use of different types of traditional healers, including taking a child to a church to *'cast out the spirit'*. *'Concoctions'* of local roots and herbs from the traditional doctors sometimes caused convulsions in the child; if the child died and returned to the *'bush'* this then confirmed her as a spirit child. These beliefs were exacerbated by low levels of knowledge about the condition and reinforced by the fact that there was often no diagnosis or cure for cerebral palsy at the hospitals, and rehabilitation services were scarce.

For example, M was five years old, had severe cerebral palsy and was severely malnourished when we first met her. Her mother had left her at the age of three years to be cared for by her grandparents in Upper East Ghana. It was a very poor household, and it was not uncommon for her to be left for hours lying on the ground whilst the grandmother went to the market. The grandmother explained that *'In our Frafra culture, once she [the child] cannot sit, they say it's a tree god that is responsible for that'*. She expressed fear about the power the child had over the family. The grandfather had recently organised a calabash of flour and two fowls for libation to treat the child when she was ill. Sadly, three months into the training, N died. Another mother from the same support group reflected on how the child was neglected because of the beliefs, and when attending the child's funeral the grandmother had continued to use negative words to describe the child, and *'acted like someone whose burden had now been lifted'*.

## Social responses to the condition

The level of severity of cerebral palsy did not appear to play a role in the level of stigma experienced. However, there were some elements of the condition which appeared to further exacerbate the stigma, including, for example if the child experienced epileptic seizures and/or drooling. It is not uncommon for some children with cerebral palsy to excessively drool, and this may trigger feelings of disgust, or possibly fear around 'contagion'. One mother described having to separate from her husband and move out of their rented accommodation because the landlady would not go near the child even when *'the boy had moved to the edge of the veranda about to fall'*, and was *'all the time complaining'*; the continual drooling was identified as a key reason for the landlady's attitude. Another mother described what was most useful from the training was understanding about the drooling, as *'the child used to sit with her mouth full of saliva and they [community] used not to like associating with her'*. (Case 1194)

## Contribution of the training programme

The data illuminated how the programme offered some support in addressing both social and internalised stigma. In particular the support group appeared to help in reducing feelings of self-blame and shame. These reductions in internalised stigma seemed a crucial element in building caregiver resilience, that is, their ability to cope and adapt even in the face of continued adversity within the family and community.

*The change in my life is that sometimes I put my child on my back and went to my colleagues, and they made fun of me. I became angry and held a grudge against them.*

*But now when I go to them and they mock me, I also laugh at them. So, this has brought about happiness and improved life for me. (Code 3344)*

The group support sessions offered a safe space to discuss their experiences and peer support, and this sometimes extended outside of the of the training. For example, one group of mothers visited another home where a child was regularly locked up: they wanted to give moral support to the mother because the husband wanted the child to be '*removed or even thrown away*'.

Yet, despite these changes, the caregiver narratives indicated that the environment of the family and community often remained unfavourable.

## **Discussion**

This study showed the pervasiveness and often detrimental consequences of both social and internalised stigma experienced by caregivers in a family with a child with a disability in Ghana.

Our study demonstrates the intersectionality of gender and caregiving in framing the experiences of stigma, with blame largely attributable to the mother when there is a child born with cerebral palsy. These findings concur with Link and Phelan's (2014) model of stigma that emphasises the centrality of power and illustrates the importance of attending to the gendered dimension of caregiving stigma. Our findings also concur with the argument made that mothers of children with disability can experience a form of disablism, and their role needs to be repositioned in the discussions on childhood disability (Ryan and Runswick-Cole 2008). In this way we argue they are likely to be in a better position to effect positive change for their children, alongside other family members.

In considering the intersectionality of caregiving our study highlights that we must attend to the role of relationships within the family, including the role of fathers. This is one of the few studies that has documented the absence of fathers in the household where there is a child with a disability (Zuurmond, O'Banion, et al. 2018). Our findings illustrate the need for programmes which can effectively engage with fathers and address the challenges posed by absent fathers. Whilst fathers may not traditionally take on child-rearing roles in many societies, their absence both reflects and reproduces stigma, which exacerbates the challenges faced by the female caregiver. She not only loses the support from him as an individual, but it also depletes her capacity to ask for help from others within the family. There are lessons that we can learn, for example, from more proactively engaging with fathers as part of an early intervention, and offering them some practical skills (Smythe et al. 2019). It is also important that any parenting programme is assessed through a gender lens and does not further add to the burden of caregiving.

Our findings are also in line with the few studies in Ghana that show how traditional beliefs related to disability are powerful and pervasive. This includes the view that children are not of human form, that the mother is blamed for bringing misfortune into the family as an outsider, and children with disabilities can be subject to various types of abuse (Denham et al. 2010; Awedoba and Denham 2014; Kassah, Kassah, and Agbota 2012; Nyante 2016). This role of cultural beliefs fuelling stigma is well documented (World Health Organization and World Bank 2011; Riddell and Watson 2014), and where shame can be reinforced by

traditional healers who attribute the disability to evil spirits or misdeeds (Roy McConkey, Kahonde, and McKenzie 2016).

In addition to gender, other factors which can layer on the disability-related stigma were also illustrated. Our findings draw attention to how household composition affects income and resources, so caregiving stigma intersects with the stigma that may come from extensive poverty or the consequence of being a divorced or separated mother. This ties in with the conceptual models of stigma which emphasise the intersectionality of various factors in the experience of disability-related stigma, such as caregiver education, standing in the community and poverty (Weiss, Ramakrishna, and Somma 2006; Link and Phelan 2006). Despite this, many programmes targeting the economic empowerment of persons with disabilities, are often not inclusive of caregivers and families (Stienstra and Lee 2019). We would argue that this is a missed opportunity to improve the lives of children with disabilities. Any parenting programme in LMIC settings which aims to address stigma should consider economic empowerment of caregivers, combined with a package of caregiver supportive policies, can be enhanced. This should be part of a multi-faceted approach.

Our research also illustrates that the complexity and heterogeneity of the condition 'cerebral palsy' is worthy of greater attention when understanding how this relates to social stigma. In our study, for example, drooling, which can be common with children with cerebral palsy, was particularly stigmatised, alongside epileptic seizures. Such negative responses to these physical symptoms, and the effect it has on social interactions, has been noted elsewhere (Fiest et al. 2014; Baskind and Birbeck 2005; Scior et al. 2013; Scior 2016).

If we consider the ICF bio-social model of disability (World Health Organisation 2007) , then understanding the social responses to body functions associated with the condition are important if stigma mitigation strategies are to be further strengthened. There is much we might also learn from research in areas such as epilepsy, where there is a large body of research on approaches to address stigma (Baskind and Birbeck 2005; Fiest et al. 2014).

In terms of the consequences of internalised or felt stigma, it has been argued that this type of stigma can be more disruptive than social or enacted stigma (Scambler 2009; Yang 2015). This study does not necessarily illustrate that one category of stigma is more disruptive than another, instead each category appears to mutually reinforce each other, exacerbating the caregivers' experiences.

One of the main consequences of stigma is the negative impact on mental health and quality of life, with wide-reaching consequence for the caregiver, their child and their household (Elafros et al. 2013; Zhang et al. 2018; Ali et al. 2012; Brouwers, van Brakel, and Cornielje 2011). The isolation experienced is likely to only exacerbate that, and arguably even more so when you feel the stigma of members of your own family. A quality mother-child dyad relationship, and responsive caregiving, are known to be critical in the early years for the child's development, (World Health Organization, UNICEF, and World Bank Group 2018), and arguably more so for children with a developmental disability who are likely to have additional needs (Kohli-Lynch, Tann, and Ellis 2019; Aboud and Yousafzai 2015) . It is well evidenced that maternal depression, and specifically postnatal depression, can result in adverse infant outcomes (Dadi, Miller, and Mwanri 2020; Herba et al. 2016). We argue,

therefore, that far greater consideration needs to be given to the consequences of stigma on caregiving, specifically on maternal mental health, and in turn, on the implications for childhood development for children with disabilities.

Of course stigma is not the only factor contributing to caregiver stress and worry; other factors may include high level of multiple needs, challenges of feeding (Donkor et al. 2019; Polack et al. 2018) and inability to provide even basic needs because of poverty (van der Mark et al. 2019). However, our findings indicate that stigma is likely to further compound these challenges and efforts to address them need to simultaneously engage with ameliorating stigma to achieve sustained success.

Whilst this study illustrates the pervasive impact of stigma on the caregivers, our findings also indicate that the consequences can be reduced through engagement with a support group for caregivers. This model appeared to be particularly influential in reducing internalised stigma. At the meso level, the support group also augmented their social network of support and contributed to reduced feelings of isolation. This has the potential to be an essential intervention in addressing the paradox that ordinarily caregivers are likely to have elevated care demands at the same time as they have diminished resources to draw on for support. Support groups provide an opportunity for caregivers to redevelop supportive structures and safety nets. We would argue that this is extremely important, given the paradox that the children are likely to have greater care needs, whilst stigma fuels a weakening of support structures and safety nets.

The ability of caregivers to challenge stigmatising attitudes within the family, as a result of training received, was less evident within our study. This highlights the potential limitations of an individual caregiver agency to influence the power dynamics of the household, and is explored in more detail in a separate publication on caregiver empowerment (Zuurmond et al. 2020). It also emphasises the need for a multi-faceted approach to stigma mitigation which engages with different levels and gatekeepers, as focusing on the individual caregiver alone will likely be inadequate.

Finally, whilst our findings highlight that family members can be perpetrators of stigma, it is vital to remember that family members can, and do, play a proactive role in tackling stigma, and promoting the rights of their children. The experience of stigma, although derived from a dense constellation of intersecting factors, is not fixed. It is malleable and families can be the powerful advocates for change. Our research and those of others indicate that families can play a crucial mediating role between the affected person and wider society (Roy McConkey, Kahonde, and McKenzie 2016; Elphick, De SasKropiwnicki, and Elphick 2015).

In terms of limitations, our study focus was on the lives of the primary caregivers, which was predominantly a female voice. Much of the available literature is similarly conducted with mothers and female caregivers as they were present in the household. The voices of fathers



are largely absent, and we would need to try to include absent fathers in any future study. Furthermore, we did not directly interview children because of their young age, with an average age of 3.8 years. Future research is needed to explore both perspectives of fathers and of children and how they themselves experience stigma.

### **Conclusion**

The narratives of caregivers emphasise the pervasiveness of traditional beliefs as a key driver of disability-related stigma in the Ghana context, for families with a child with cerebral palsy. Within the family, stigma is gendered. Female caregivers often carry most of the blame, seen as 'at fault' for bringing a child with a disability into the family, and experience both social and internalised stigma. Fathers, as well as other family members, need to be better engaged in the caregiving role.

Emotional distress, isolation and lack of support are common caregiver experiences, and we argue that the mothers can experience forms of disabling barriers. There is a consequential weakening of social support networks, thus compounding the strain of caregiving, with a negative impact on maternal mental health. The caregiver support group programme was found to help address internalised stigma and the isolation experienced, offering social support where it has been absent.

Understanding the social disruption caused by disability-related stigma at the family level requires greater attention if we are to improve the outcomes for children with disabilities, as well as their caregivers. Specifically, we need to better understand how mothers and the social fabric of the family experience the disability of their child in different cultural settings.

All of these experiences are not fixed or indelible, and the caregiving experience can be different and easier. Any programme targeting caregivers should address family level stigma, with a multi-faceted approach which can address the intersectionality of various factors, including poverty. This requires social protection measures and economic empowerment initiatives that are both disability inclusive and caregiver supportive. A support group can be one valuable component to such a programme.

#### **POINTS of interest**

- Stigma amongst family members with a child with cerebral palsy, is very common in the Ghana context, and fuelled by traditional beliefs.
- Caregiving and disability-related stigma is gendered. The stigma of childhood disability is often associated with women's role in child bearing and rearing.
- Better engagement with fathers, and other key members of the family, is needed.
- Emotional distress, isolation and lack of support are common caregiver experiences in Ghana.
- A support group model for caregivers has an impact on how they feel about themselves, reducing levels of self-blame and feelings of isolation.
- We know that the quality of caregiving is really important in the early years of a child's development, so it is important to address any stigma.

- Factors, such as poverty, play a role in fuelling stigma. These other factors also need to be addressed if we want to reduce levels of stigma experienced by families.
  
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- Data availability statement. At the time of conducting this research, the ethics permission allowed for the data to be shared within the research team only.

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Supplementary file 1 : Modules of the Caregiver Training Programme

Figure 1



## 1 References

- Aboud, Frances E, and Aisha K Yousafzai. 2015. "Global health and development in early childhood." *Annual review of psychology* 66:433-57.
- Aldersey, Heather M. 2012. "Family perceptions of intellectual disability: Understanding and support in Dar es Salaam." *African Journal of Disability* 1 (1).
- Aldersey, Heather M, Salome Kavira, Jeef Kiasimbua, Willy Lokako, Pelagie Miaka, and Lucie Monte. 2018. "Stigma experienced by families with members with intellectual disabilities in Kinshasa, Democratic Republic of the Congo." *Intervention* 16 (2):119.
- Ali, Afia, Angela Hassiotis, Andre Strydom, and Michael King. 2012. "Self stigma in people with intellectual disabilities and courtesy stigma in family carers: A systematic review." *Research in developmental disabilities* 33 (6):2122-40.
- Awedoba, Albert K, and Aaron R Denham. 2014. "The Perception of abnormality in Kasena and Nankani infants: clarifying infanticide in northern Ghana." *Ghana Studies*:41.
- Baskind, Roy, and Gretchen L Birbeck. 2005. "Epilepsy-associated stigma in sub-Saharan Africa: the social landscape of a disease." *Epilepsy & Behavior* 7 (1):68-73.
- Brouwers, Corline, Wim van Brakel, and Huib Cornielje. 2011. "Quality of life, perceived stigma, activity and participation of people with leprosy-related disabilities in south-east Nepal." *Disability, CBR & Inclusive Development* 22 (1):16-34.
- Corrigan, Patrick W, Amy Kerr, and Lissa Knudsen. 2005. "The stigma of mental illness: Explanatory models and methods for change." *Applied and Preventive Psychology* 11 (3):179-90.
- Crabtree, Sara Ashencaen. 2007. "Family responses to the social inclusion of children with developmental disabilities in the United Arab Emirates." *Disability & Society* 22 (1):49-62.
- Dadi, Abel Fekadu, Emma R Miller, and Lillian Mwanri. 2020. "Postnatal depression and its association with adverse infant health outcomes in low-and middle-income countries: a systematic review and meta-analysis." *BMC pregnancy and childbirth* 20 (1):1-15.

- Denham, Aaron R, Philip B Adongo, Nicole Freyberg, and Abraham Hodgson. 2010. "Chasing spirits: Clarifying the spirit child phenomenon and infanticide in Northern Ghana." *Social Science & Medicine* 71 (3):608-15.
- Donkor, Claudia Mary, Jackie Lee, Natasha Lelijveld, Melanie Adams, Marjolein Meande Baltussen, Gifty Gyamah Nyante, Marko Kerac, Sarah Polack, and Maria Zuurmond. 2019. "Improving nutritional status of children with Cerebral palsy: a qualitative study of caregiver experiences and community-based training in Ghana." *Food science & nutrition* 7 (1):35-43.
- Elafros, Melissa A, Claire Sakubita-Simasiku, Masharip Atadzhanov, Alan Haworth, Elwyn Chomba, and Gretchen L Birbeck. 2013. "Stigma and psychiatric morbidity among mothers of children with epilepsy in Zambia." *International health* 5 (4):288-94.
- Elphick, Jean, Zosa De SasKropiwnicki, and Rosalind Elphick. 2015. "'Our children have the right to an education too': Strategies Employed by Orange Farm Caregivers of Children with Disabilities in Pursuit of the Right to a Basic Education." *Disability, CBR & Inclusive Development* 26 (4):101-16.
- Fazil, Qulsom, Paul Bywaters, Zoebia Ali, Louise Wallace, and Gurnam Singh. 2002. "Disadvantage and discrimination compounded: the experience of Pakistani and Bangladeshi parents of disabled children in the UK." *Disability & Society* 17 (3):237-53.
- Fernández, María C, and Emily Arcia. 2004. "Disruptive behaviors and maternal responsibility: A complex portrait of stigma, self-blame, and other reactions." *Hispanic Journal of Behavioral Sciences* 26 (3):356-72.
- Fiest, Kirsten M, Gretchen L Birbeck, Ann Jacoby, and Nathalie Jette. 2014. "Stigma in epilepsy." *Current neurology and neuroscience reports* 14 (5):444.
- Ghana Statistical Service. March 2015. "Ghana Demographic and Health Survey 2014." In. Accra: Ghana Statistical Service.
- Goffman, Erving. 1963. *Stigma: Notes on the management of spoiled identity*. New York: Simon and Schuster.
- Gray, David E. 2002. "'Everybody just freezes. Everybody is just embarrassed': felt and enacted stigma among parents of children with high functioning autism." *Sociology of health & illness* 24 (6):734-49. doi: 10.1111/1467-9566.00316.
- Heng-hao, Chang. 2009. "From housewives to activists: Lived experiences of mothers for disability rights in Taiwan." *Asian Journal of Women's studies* 15 (3):34-59.
- Herba, Catherine M, Vivette Glover, Paul G Ramchandani, and Marta B Rondon. 2016. "Maternal depression and mental health in early childhood: an examination of underlying mechanisms in low-income and middle-income countries." *The Lancet Psychiatry* 3 (10):983-92.
- Huang, Yu-Ping, Ursula Kellett, and Winsome St John. 2012. "Being concerned: caregiving for Taiwanese mothers of a child with cerebral palsy." *Journal of clinical nursing* 21 (1-2):189-97.
- Johnson, Robert F, Michelle O'Reilly, and Panos Vostanis. 2006. "Caring for children with learning disabilities who present problem behaviours: A maternal perspective." *Journal of Child Health Care* 10 (3):188-98.
- Kassah, Alexander Kwesi, Bente Lilljan Lind Kassah, and Tete Kobla Agbota. 2012. "Abuse of disabled children in Ghana." *Disability & Society* 27 (5):689-701.
- Kohli-Lynch, Maya, Cally J Tann, and Matthew E Ellis. 2019. "Early Intervention for Children at High Risk of Developmental Disability in Low-and Middle-Income Countries: A Narrative Review." *International journal of environmental research and public health* 16 (22):4449.
- Link, Bruce G, and Jo C Phelan. 2001. "Conceptualizing stigma." *Annual review of Sociology* 27 (1):363-85.
- . 2006. "Stigma and its public health implications." *The Lancet* 367 (9509):528-9.
- Link, Bruce G., and Jo Phelan. 2014. "Stigma power." *Social Science & Medicine* 103:24-32. doi: <https://doi.org/10.1016/j.socscimed.2013.07.035>.

- Livingston, James D, and Jennifer E Boyd. 2010. "Correlates and consequences of internalized stigma for people living with mental illness: A systematic review and meta-analysis." *Social Science & Medicine* 71 (12):2150-61.
- LSHTM, and Hambisela. 2016. "Getting to know Cerebral Palsy: working with parent groups- a training resource for facilitators, parents, caregivers and persons with cerebral palsy ", Accessed 23/09/2016. <https://www.ubuntu-hub.org/resources/gtkcp/>.
- Mak, Winnie WS, and Rebecca YM Cheung. 2008. "Affiliate stigma among caregivers of people with intellectual disability or mental illness." *Journal of Applied Research in Intellectual Disabilities* 21 (6):532-45.
- Mak, Winnie WS, and Yvonne TY Kwok. 2010. "Internalization of stigma for parents of children with autism spectrum disorder in Hong Kong." *Social Science & Medicine* 70 (12):2045-51.
- McKenzie, Judith, and Roy McConkey. 2016. "Caring for adults with intellectual disability: The perspectives of family carers in South Africa." *Journal of Applied Research in Intellectual Disabilities* 29 (6):531-41.
- Mostert, Mark P. 2016. "Stigma as Barrier to the Implementation of the Convention on the Rights of Persons with Disabilities in Africa at [http://www.adry.up.ac.za/images/adry/volume4\\_2016/adry\\_2016\\_4\\_chapter1.pdf](http://www.adry.up.ac.za/images/adry/volume4_2016/adry_2016_4_chapter1.pdf)." *Afr. Disability Rts. YB* 4:3.
- Njelesani, Janet, Goli Hashemi, Cathy Cameron, Deb Cameron, Danielle Richard, and Penny Parnes. 2018. "From the day they are born: a qualitative study exploring violence against children with disabilities in West Africa." *BMC public health* 18 (1):153.
- Nyante, Gifty Gyamah. 2016. "An exploration of the experiences and perceptions of primary caregivers of children with cerebral palsy living in rural communities in Ghana at at <https://curve.coventry.ac.uk/open/file/8315e76f-aa7a-4532-9cec-c51033cc12a1/1/Gifty%20Gyamah%20Nyante%20PhD%20Thesis%20.pdf>." Coventry University
- Oliver, M. 1990. *The politics of disablement* Basingstoke: Macmillan.
- Parker, Richard, and Peter Aggleton. 2003. "HIV/AIDS-related stigma and discrimination: a conceptual framework and implications for action." *Social Science and Medicine* (57):13-24.
- Patel, P, J Baier, E Baranov, E Khurana, C Gambrah-Sampany, A Johnson, B Monokwane, and DR Bearden. 2017. "Health beliefs regarding pediatric cerebral palsy among caregivers in Botswana: A qualitative study." *Child: care, health and development* 43 (6):861-8.
- Pescosolido, Bernice A, and Jack K Martin. 2015. "The stigma complex." *Annual review of Sociology* 41:87-116.
- Polack, Sarah, Mel Adams, David O'banion, Marjolein Baltussen, Sandra Asante, Marko Kerac, Melissa Gladstone, and Maria Zuurmond. 2018. "Children with cerebral palsy in Ghana: malnutrition, feeding challenges, and caregiver quality of life." *Developmental medicine & child neurology* 60 (9):914-21.
- Qayyum, Arisha, Seema Zainulabdin Lasi, and Ghazala Rafique. 2013. "Perceptions of primary caregivers of children with disabilities in two communities from Sindh and Balochistan, Pakistan." *Disability, CBR & Inclusive Development* 24 (1):130-42.
- Riddell, Sheila, and Nick Watson. 2014. "Chapter 1: Disability, Culture and Identity: Introduction." In *Disability, culture and identity*, edited by Sheila Riddell and Nick Watson. London and New York,: Routledge.
- Roy McConkey, Callista Kahonde, and Judy McKenzie. 2016. "Tackling Stigma in Developing Countries: The Key Role of Families." In *Intellectual Disability & Stigma: Stepping out from the Margins*. London: Palgrave-Macmillan.
- Ryan, Sara, and Katherine Runswick-Cole. 2008. "Repositioning mothers: Mothers, disabled children and disability studies." *Disability & Society* 23 (3):199-210.
- Scambler, G. 1989. "Epilepsy. Tavistock." In.: London.
- Scambler, Graham. 2009. "Health-related stigma." *Sociology of health & illness* 31 (3):441-55.

- Scior, Katrina. 2016. "Towards Understanding Intellectual Disability Stigma: Introduction. ." In *Intellectual Disability and Stigma: Stepping Out from the Margins*. . Palgrave Macmillan.
- Scior, Katrina, J Addai-Davis, M Kenyon, and JC Sheridan. 2013. "Stigma, public awareness about intellectual disability and attitudes to inclusion among different ethnic groups." *Journal of Intellectual Disability Research* 57 (11):1014-26.
- Shewchuk, Richard, and Timothy R Elliott. 2000. "Family caregiving in chronic disease and disability." p.555.
- Smythe, Tracey, Antony Duttine, Ana Carolina Dias Vieira, Barbara da Silveira Madeira de Castro, and Hannah Kuper. 2019. "Engagement of Fathers in Parent Group Interventions for Children with Congenital Zika Syndrome: A Qualitative Study." *International journal of environmental research and public health* 16 (20):3862.
- Stienstra, Deborah, and Theresa Man Ling Lee. 2019. "Disabilities and Livelihoods: Rethinking a Conceptual Framework." *Societies* 9 (4):67.
- Tilahun, Dejene, Charlotte Hanlon, Abebaw Fekadu, Bethlehem Tekola, Yonas Baheretibeb, and Rosa A Hoekstra. 2016. "Stigma, explanatory models and unmet needs of caregivers of children with developmental disorders in a low-income African country: a cross-sectional facility-based survey." *BMC health services research* 16 (1):152.
- van der Mark, Elise J, Ina Conradie, Christine WM Dedding, and Jacqueline EW Broerse. 2019. "'We create our own small world': daily realities of mothers of disabled children in a South African urban settlement." *Disability & Society* 34 (1):95-120.
- van der Mark, Elise Jantine, and Hebe Verrest. 2014. "Fighting the odds: Strategies of female caregivers of disabled children in Zimbabwe." *Disability & Society* 29 (9):1412-27.
- Weiss, Mitchell G, Jayashree Ramakrishna, and Daryl Somma. 2006. "Health-related stigma: rethinking concepts and interventions, P280." *Psychol Health Med* 11 (3):p.280.
- Werner, S, and C Shulman. 2015. "Does type of disability make a difference in affiliate stigma among family caregivers of individuals with autism, intellectual disability or physical disability?" *Journal of Intellectual Disability Research* 59 (3):272-83.
- World Health Organisation. "International classification of functioning, disability and health: children and youth version: ICF-CY available at <https://apps.who.int/iris/handle/10665/43737>." <https://apps.who.int/iris/handle/10665/43737>.
- World Health Organization, UNICEF, and World Bank Group. "Nurturing care for early childhood development: a framework for helping children survive and thrive to transform health and human potential available at <https://apps.who.int/iris/bitstream/handle/10665/272603/9789241514064-eng.pdf>."
- World Health Organization, and World Bank. 2011. "World Report on Disability " In. Geneva: WHO.
- Yang, Xue. 2015. "No matter how I think, it already hurts: Self-stigmatized feelings and face concern of Chinese caregivers of people with intellectual disabilities." *Journal of Intellectual Disabilities*. doi: 10.1177/1744629515577909.
- Zhang, Yunjue, Mythily Subramaniam, Siau Pheng Lee, Edimansyah Abdin, Vathsala Sagayadevan, Anitha Jeyagurunathan, Sherilyn Chang, Saleha Binte Shafie, Restria Fauziana Abdul Rahman, and Janhavi Ajit Vaingankar. 2018. "Affiliate stigma and its association with quality of life among caregivers of relatives with mental illness in Singapore." *Psychiatry research* 265:55-61.
- Zuurmond, Maria, Ilias Mahmud, Sarah Polack, and Jenny Evans. 2015. "Understanding the Lives of Caregivers of Children with Cerebral Palsy in rural Bangladesh: Use of Mixed Methods." *Disability, CBR & Inclusive Development* 26 (2):5-21.
- Zuurmond, Maria, Gifty Nyante, Marjolein Baltussen, Janet Seeley, Jedidia Abanga, Tom Shakespeare, Martine Collumbien, and Sarah Bernays. 2018. "A support programme for caregivers of children with disabilities in Ghana: Understanding the impact on the wellbeing of caregivers." *Child: care, health and development*:1-9.

- Zuurmond, Maria, Velma Nyapera, Victoria Mwenda, James Kisia, Hilary Rono, and Jennifer Palmer. 2016. "Understanding how carers cope in a complex childhood disability in Turkana, Kenya: humanitarian setting: original research." *African Journal of Disability* 5 (1):1-8.
- Zuurmond, Maria, David O'Banion, Melissa Gladstone, Sandra Carsamar, Marko Kerac, Marjolein Baltussen, Cally J Tann, Gifty Gyamah Nyante, and Sarah Polack. 2018. "Evaluating the impact of a community-based parent training programme for children with cerebral palsy in Ghana." *PloS one* 13 (9).
- Zuurmond, Maria, Janet Seeley, Tom Shakespeare, Gifty Nyante, and Sarah Bernays. 2020. "Illuminating the empowerment journey of caregivers of children with disabilities: understanding lessons learnt from Ghana." *Africa Journal of Disability (accepted for publication-forthcoming)*.