Title

Understanding stigma from a socio-cultural context: mothers' experience of stigma directed towards children with Special Educational Needs

# **Authors**

1. Chijioke Dike UBA

Northampton Business School, The University of Northampton, Northampton, UK

Chijioke. Uba@northampton.ac.uk

2. Kechinyerem Amaka NWOGA

Logert Ltd, Manchester, UK

Ka nwoga@yahoo.com

### **Abstract**

Although the need for a better understanding and deconstruction of the barriers that underpin and impede the realisation of inclusive education in many developing countries is acknowledged, few studies focus specifically on exploring how stigma affects the choices that parents in developing countries make on behalf of their children. This paper contributes to the understanding of the stigma experience of mothers of children with special educational needs (SEN) in a Nigerian context. The aim of the study was to explore how parents' interpretation of stigma directed towards their children with SEN affects the educational decision they make on behalf of these children. The study consisted of 8 interviews with mothers of children with SEN in Lagos, Nigeria. Specifically, stigmatization of children with SEN was found to be underpinned by a "non-materialistic" culture and worldviews that construct disability as "nonnormal". Findings also uncover a range of coping mechanisms adopted by mothers to deal with courtesy stigma and stigma stress. Theoretical and practical contributions to the literature on stigma and inclusive education are subsequently discussed. Theoretically, we introduce and discuss the import of "stigma transference" (the different modes that stigma can be transferred from one individual to the other) and practically, we discuss implications of findings for antistigma intervention.

Key words – Stigma, stigma transference, Special Education Needs, material and non-material culture, inclusive education

#### INTRODUCTION

Inclusive education welcomes and supports diversity among all learners (Ainscow and Cesar 2006). It promotes social inclusion and participation at wider levels (Slee 2001; Cesar and Oliveira 2005). The underpinning argument is that education, a basic human right and the foundation of a more just society, needs to be accessible to all if social inclusion and social justice are to be achieved (Zajda, Majhanovich, and Rust 2006; Lalvani 2013). Accordingly, national policy approaches as well as academic discourses have focused on identifying and eliminating barriers that impede the attainment of inclusive education for all learners (Rustemier 2002; Lloyd 2008). However, while significant effort and research have gone into developing effective strategies to help achieve inclusion in schools in developed countries such as the UK (see Ainscow 2002; Florian and Black-Hawkins 2011; and Armstrong, Armstrong, and Spandagou 2011), significantly lower success rates are recorded in many developing countries (Eleweke and Rhoda 2002). Although the low success rates are attributable to complexities of factors, the stigmatisation of learners requiring Special Educational Needs (SEN) is identified as a major barrier impeding the achievement of inclusive education in many developing countries (Garuba 2003; Abang 1992; Obiakor and Offor 2011). The need for a better understanding of the effect of stigma on the attainment of inclusive education in developing countries becomes apparent. This is because such an understanding could enhance the design and implementation of effective intervention that enables education for all in these countries (Obiakor and Offor 2011; Fakolade, Adeniyi, and Adeyinka 2009).

The current study explores how mothers' interpretation of stigma directed towards their children with SEN affects the choices they make on behalf of these children. Specifically, it explores mothers' experience of stigma directed at their children with SEN and the coping strategies they adopt to negotiate the pressures and stress arising from their stigma experience.

It also explores their interpretations of this stigma experience may underpin the educational choices and decision made on behalf of their children. Key findings are discussed in terms of practical and theoretical relevance for the enhancement of efficient anti-stigma intervention.

### LITERATURE REVIEW

## **Stigma and Inclusive Education**

Numerous studies on Inclusive Education highlight that social cognitions and constructions underpin the stigmatisation of learners with SEN (see Crocker, Major, and Steele 1998; Humphrey 2008; Salmon 2013). Humphrey (2008) uncovers the different negative and false constructions around autism. Consistent with Humphrey (2008), Salmon's (2013) study highlights how children with special needs stick together as a means of coping with the social exclusion that follows necessarily from being stigmatised. The awareness of being stigmatised and the stress of perceiving oneself as stigmatised may lead to low self-esteem and, ultimately, results in self-exclusion (O'Brien 2000). Furthermore, studies highlight that the perceptions of those who stigmatise often translate to discriminatory behaviours which hinders the inclusion of the stigmatised learner (Hornby 1999; Zajda, Majhanovich, and Rust 2006; Salmon 2013).

sense of self, they are not likely to participate actively in communal learning (Corbett 2001; Salmon 2013). The implication is that learners with SEN are likely to be less productive if they perceive themselves or are perceived as being able to make little contribution to the wider society. Unfortunately, this has often been the case when it comes to how learners with SEN are perceived by others and by themselves in societies of both developing and developed countries (McKeever and Miller 2004; Obiakor and Offor 2011).

People with disabilities are one of the most disadvantaged in most societies. They are subject to social discrimination and their educational experiences are impoverished (Hegarty and Alur 2002). In relation to achieving education that incorporates this category of learners, the situation today is that most countries have adopted the imperatives of the inclusive education framework (Uchem and Ngwa 2004) While there is consensus on the need to implement wholesale inclusive education due the potential social and educational benefits for learners with special needs, both advanced and developing countries face challenges in implementing inclusive education (Uchem and Ngwa 2014).

Developed countries are said to face challenges when it comes to effective inclusion of children with special needs and those from ethnic and language minorities into mainstream schools (Motala 2000). Furthermore, the formulation and implementation of special education policies may pose challenges for these countries. For instance, there are indications that policies for inclusive education in the UK are partly determined by political party ideologies rather than the actual needs of SEN learners (Runswick-Cole 2011). On the other hand, developing countries also face context-specific challenges that hinder the actualisation of wholesale inclusive education (Charema 2007). Such challenges include economic and developmental difficulties that make unrealistic the achievement of Western-type notions of inclusive education (Charema 2007), inadequate personnel training programs, especially, for non-teaching professionals (Elewek and Rhoda 2000) and negative cultural perceptions about disability (Mba 1995; Obiakor and Offor 2011). It is also argued that despite the attainment of reductions in illiteracy rates across different educational year groups by developing countries (Barro and Lee, 2013), stigmatisation of people with special educational needs remains an area of concern for many developing African countries (Mba 1995; Obiakor and Offor 2011)

Stigma of people with SEN; the Nigerian experience

Obiakor and Offor's (2011) study highlight that the Nigerian government has always been in league with foreign volunteer agencies since the earlier inceptions of special education programs in the country. Such collaboration facilitated the approval of policies and schemes for special education over the years (Ozoji 2005). For instance, the Nigerian National Policy on Education (NPE) (2004) in section 10 clearly outlines inclusive rules guiding the education of special needs persons in Nigeria (Eskay, Onu, and Igbo 2012). Specifically, the government recommends the education of children with SEN in mainstream schools. According to Eskay, Onu, and Igbo (2012) the increasing quest for enhancing Inclusive Education in Nigeria has also led to the proliferation of academic studies and discourses on the nature on Inclusive Education in the country. Unfortunately, neither the proliferation of inclusive education literature nor a plethora of policies has translated to wholesale inclusiveness of learners with SEN (Uchem & Ngwa 2014). This view echoes that of Fakolade, Adeniyi and Adeyinka (2009) who argue that although Nigeria has some of the best laws on inclusive education in the African continent, actual implementation continues to be hindered by different factors. To a large extent, cultural perceptions about the value of people with disability largely underpins the stigmatisation and discrimination against people with disability in Nigerian society and schools (Obiakor and Offor 2011).

Evidence suggests that nature of stigma against people with SEN in Nigeria is largely linked to pronounced cultural misconceptions about people with disabilities. According to Obiakor and Offor (2011) such misconceptions have continued to have adverse effects on the achievement of inclusive education in Nigeria. Specifically, study findings highlight that the stereotypes and labels attached to people with special needs (specifically disabilities) in Nigeria are underpinned by societal misconceptions and superstitious beliefs. These misconceptions are far reaching and include those that view people with disability as curse(s) on the family or wider community for offences committed against the gods or as punishment to parents' for

their failings (Obiakor 1998). Disability is also perceived as punishment on the child for offences committed in their previous life prior to reincarnation; anger from ancestral spirits for parents' breach of promises or neglect of duty to these ancestral spirits; wicked acts that originate from wizards or witches and/or punishments for offences that were committed against laws of the land (Obiakor 1998; Ogbue 1995; Obani 2002). Stigma in Nigeria reflects the broad cognitive representations or views that people have of themselves, others, roles, events and the social world, as well as how these become embedded in practices and ways of living (societal schemas). Etuk's (2002) distinction between Western and African cultures is relevant in shedding more light on the cultural underpinning of stigma in Nigeria. S/he describes the African culture as 'non-materialistic' as opposed to the western culture ("materialistic"). The materialistic culture views the human body as material (it grows dies and decays - matter) and links in to the belief that science holds the key to all explanations. However, in the nonmaterialistic worldview a very thin line exists between the physical and the spiritual. Specific types of occurrences in the physical are assumed to be caused by forces in the spiritual realm. Hence, physical disability can be considered a curse or punishment from the "gods" for a parent's action.

In the then traditional African societies, a diviner would normally be consulted to prescribe appropriate sacrifices and rituals to cure the afflicted person or to appease whatever forces had been offended (Etuk 2002). Etuk (2002) further notes that the emergence of Christianity saw a decline in the use of diviners as they were now considered pagans for their belief in more than one God. It did not, however, change the 'non- materialistic' nature of the culture but instead shifted focus from the deities and the diviners to the Christian God, priests or pastors and the church. The continued existence of a non-materialistic culture may account for why a supposed "new wave" of rationality has not led to more inclusion of children with SEN in mainstream schools (Ajuwon 2012). Mba (1995) notes the effects of negative cultural perceptions on

special needs provision in Nigeria. According to Mba (1995) there is a corresponding perception that the needs of the majority who are considered "normal" have to be met first before the needs of people with disability or SEN. This ties in with the view that the expenditure for services for people with disabilities is a waste of scare resources is underpinned by non-materialistic worldviews. Specifically, this view may account for a lack of political to follow up existing policies (Mba 1995).

It is argued that the cultural misconceptions held about people with disabilities suggest that mainstream education may not meet the needs of learners with special educational needs in the Nigerian context (see Fakolade, Adeniyi, and Adeyinka 2009). Along this line, Stainback, Stainback, and Sapon-Shevin (1994) contend that the nature of stigmatisation of people with SEN in developing countries such as Nigeria implies that they would be better off in segregated schools rather than in mainstream schools. Two broad accounts are proffered in support of this argument. On one hand, there is the view that this category of learners are likely to receive targeted education in segregated schools. Such schools, it is argued, would be specialist and better equipped to cater for their needs unlike mainstream ones. On the other hand, the arguments for educating people with SEN in specialist schools are linked to claims that societal misconceptions held about them may make them targets for exclusionary practices in mainstream schools.

Although the Nigerian government recommends the inclusion of children in mainstream schools, the situation is that the public-education (mainstream and specialist) system lacks adequate government funding (Adebayo 2009). This has resulted to a dearth of specialist teachers in mainstreamed public schools in the country (Fareo and Ojo 2013). In their study of mainstreamed public schools in Nigeria, Fareo and Ojo (2013) found that essential materials and facilities such as braille, hearing aids and lower toilets were not available. In instances

where basic facilities such as typewriters and wheel chairs were available, they were often in poor condition. These views resonate with those of Garba (2003, 191) who argues that "while countries within the advanced economies have gone beyond categorical provisions to full inclusion, Nigeria and most countries of Africa, are still grappling with the problem of making provisions for children with special needs especially those with handicaps even on mainstreaming basis".

In a bid to address the shortcomings in public schools, many parents therefore resort to private schools. There is the general belief that private schools possess better facilities in comparison to public schools (Rolleston and Adefeso-Olateju 2014). Findings suggest that they have higher levels of teachers' commitment and willingness to cater for all categories of student, less teacher absenteeism and an overall quality education experience (see Tooley, Dixon and Olaniyan 2005; Rose 2009). This is despite that private schools are generally more expensive than public schools in the country (Rolleston and Adefeso-Olateju 2014). It is important to note that the reported lower levels of commitment of teachers in public mainstream schools do not necessarily imply their rejection of inclusive education values. Studies have shown that teachers in such schools report positive views towards inclusive education in Nigeria. However, they may not be prepared for the actual challenges of inclusion that arise from cultural mind-sets and an overall lack of facilities (see Igbokwe, Mezieobi and Eke 2014).

Private schools take many forms and can be run by different actors with a range of interests and motives for engaging in the sector (Harma and Adefisayo 2013). In most parts of the country, it is the small school owned privately by an individual that is most popular. This broad category of private schools is autonomously managed and they are "unaided" in the sense that they are wholly school fees funded. Thus, they are essentially different from aided-private schools that are often funded wholly or partly by grants. The dominant private-unaided sector

is heterogeneous in the sense that levels of quality differ and schools cater for different demographics (Adelabu and Rose 2004). There are those that cater for the elite and expatriate communities, those that serve the middle class and lower middle and the "low fees schools" that target the poorer segments of the society (Harma and Adefisayo 2013). The autonomy in this sector extends to hiring and choice of pedagogical approach. The latter (pedagogical autonomy) is tied to a key characteristic of International Private (primary and secondary) Schools. Unlike the "low fees" schools that cater majorly for the poorer segments of the society, International private schools at pre-university levels "are providers of primary and secondary schools with international standards" (Obasi, Adesina and Obasi 2015, 11) that cater for the elite and expatriate communities in upper-class areas of big cities in the country (Harma and Adefisayo 2013). The pedagogy (especially curriculum design) of the International Private Primary/Secondary Schools often draws from those of countries such as the USA and Britain. This approach is a selling point for International Private Schools as it aligns the school's strategy with the values of the mostly expatriate clients (Obasi, Adesina, and Obasi 2015).

In sum, it is argued that collaborative efforts between all key stakeholders are needed for inclusive education to be successful in Nigeria. These are important to address the cultural perceptions on disability and other mind-set barriers that hinder the successful implementation of inclusive education in the Nigerian setting (Omotosho, Aina, and Ogungbade 2009; Adeniyi, Owoloabi and Olojede 2015).

Although stigmatisation has been identified as a social barrier hindering the attainment of inclusive education in many developing countries, the emphasis of research for both developing and developed countries has largely been on the direct effect of stigmatisation on learners with SEN or those with disabilities (see Omotosho, Aina, and Ogungbade 2009; Chharbra, Srivastava, and Srivastava 2010; Singal 2006; Kalyanpur 2014; Hale 2014). Specifically,

research on how stigma directed towards learners requiring special needs in the African context affects significant others (specifically parents and/or guardians) remain minimal (Fakolade, Adeniyi, and Adeyinka 2009). Stigma scholars, especially those interested in how the stigma experience is interpreted by relatives of learners with SEN, have not focused extensively in this area (Lizhen et al. 2010). Specifically, the idea of "courtesy stigma", that is, an extended labeling and stereotyping of a significant other on the basis of their relationship with the primarily stigmatised (Goffman 1963; Salter et al. 2010) is hardly explored within the context of inclusive education in developing countries. This is unfortunate given that numerous studies have noted that parents' interpretations of the stigma experience influences the choices made on behalf of their children (Mc Keever and Miller 2004; Cao et al. 2006; Lizhen et al. 2010; Karnieli-Miller et al. 2013; Dempster, Wildman, and Keating 2013; Johnson and Benson, 2014)

Specific to developing countries such as Nigeria, the important aspect of how stigma could affect the educational choice and decision that parents make on behalf of children with SEN is largely unexplored (Abang 1988; Omotosho, Aina, and Ogungbade 2009). Studies along this line have the potential of creating the sort of deep level understanding required for the formulation of effective intervention aimed at enhancing wholesale inclusive education. As we uncover and discuss in later sections of this paper, findings that focus on this relatively unexplored area also have the capacity of shedding more light on the import of stigma within and across different nationality contexts. The current study adopts this approach and seeks to address some of the outlined gaps. Accordingly, the current study's objective is threefold; 1) to explore mothers' experience of stigma directed towards their children with special education needs. 2) To uncover the coping strategies adopted by this category of parents in negotiating the social and individual pressures that arise from the stigma experience and how these may affect the decision made on behalf of their children with SEN within the context of inclusive

education. 3) To discuss the relevance of the study's findings for anti-stigma intervention (policy and practice) aimed at enhancing inclusive education in different contexts.

### THEORETICAL FRAMEWORK

In this part of the paper, we explore stigma theory from three broad perspectives and discuss how the core assumptions of these three theoretical perspectives underpin the current study's methods.

## Stigma as social construction and "relationship"

In his seminal work on stigma, Goffman (1963) opines that stigma is an attribute that is discrediting; one that reduces the individual that is stigmatised from a whole and usual person to one that is tainted and discounted. Three categories of stigmatising attributes are identified as follows; bodily abomination, individual character blemishes and tribal stigma. Although stigma arises commonly from bodily transformations, individual character blemishes or affiliation to membership of a group that is despised (Baral, Karki, and Newell 2007), Crocker et al. (1991) contend that it is the attribution of a devalued social identity to an individual within a particular context that captures the essence of stigma. Central to these definitions is that the stigmatised possess attributes that mark them as different, and that their "devaluation" is underpinned by differential markers (attributes that are perceived by others as differentiating them from the mainstream or conventional). Differential markers could be visible or nonvisible, controllable or uncontrollable by individuals (e.g. race) or group membership (Black British). They are evaluations and stereotypes that are widely shared by members of a society and they become basis for exclusion or avoidance (Croker, Major, and Steele 1998) and keeping the stigmatised out or down (Phelan, Link, and Dovidio 2008; Link and Phelan 2014).

Goffman (1963, 30) also introduces the idea of "courtesy stigma". This pertains to the "tendency for stigma to spread from the stigmatised individual to his [sic] close connections..." The underpinning implication is that society may treat the stigmatised and individuals closely related to them "in some respects as one" (Goffman, 1963, 30). Correspondingly, related others "are obliged to share some of the discredit of the stigmatised person to whom they are related' (Goffman 1963, 30). Thus, "differential markers" directed toward an individual may be transferred to a significant other who does not necessarily who is not "bodily transformed. The overall implication is that Stigma does not necessarily have to reside in the individual. It is "relationship – and context-specific", residing within a social context (Everett 2004; Bjarnason 2013) and occurring as a process (labelling, stereotyping, separation, status loss and discrimination) (see Link & Phelan 2001).

# Stigma as a "stressor"

Stigma scholars have explored the relevance of stigma as a "stressor" or form of stress (Miller and Kaiser 2001) that arises largely from "marks of oppression" (Alport 1954). The lives of the stigmatised can be more stressful than those of their stigmatised counterparts and the stress experienced requires the individual experiencing stigma to cope (Miller and Major 2000). The extent that the individual is able to cope depends on their perceptions of threat as relevant to self and the extent that the individual possess the wherewithal to cope with the stress (Miller and Kaiser 2001). The individual's ability to cope is dependent, at least to some extent, on the nature of the individual's stigma consciousness. Stigma consciousness refers to an individual's awareness of their stigmatised status and a corresponding monitoring of own experiences aimed at determining how and if people treat them according to their status (Pinel 1999; Link and Phelan 2014). People who experience stigma (directly or as "courtesy") are often aware of how they are perceived (stigma consciousness) and when stigma-relevant stressor(s) is present

and appraised by the individual, the individual would find ways of coping with the stress caused by discrimination, expectancy confirmation, activated stereotypes, and threat to individual and social identity (Major and O'Brien 2005).

# Stigma as deriving from "adaptive mechanisms"

Although most stigma scholars agree that stigma is a social construction, evolutionary scholars highlight that there are common attributes that people in different societies tend to focus on when the "other" is stigmatised. Such attributes are underpinned by adaptive cognitions that have been developed overtime. These stigmatising attributes are those that signal the individual as being poor in forms of social exchange (e.g. an ex-convict), carrying a parasitic trait (such as a physical deformity) or membership of "an out-group that can be exploited for in-group gain" (Major and O'Brien 2005, 395). They may also be transferred from an individual to close "others" (Goffman 1963). Understanding stigma, therefore, necessitates recognition that stigma may be underpinned by adapted cognitions that are common and generic to many societies. On the other hand, the socially constructed aspect of stigma also highlights that, in addition, stigma may be underpinned by constructions that are unique to specific social groups.

The theoretical frame that we adopt to guide the collection and analysis of data draws from the discussion in the foregoing sections. We explore mothers' awareness of the social constructions underpinning stigma directed towards their children (stigma consciousness) and their interpretation of the stigma experience. Consistent with stigma as a "stressor" we then explore the range of coping mechanisms that mothers adopts in coping with their stigma experience. More specifically, we also focus on uncovering experiential patterns and underpinnings of courtesy stigma that are distinctive to the Nigerian inclusive education context.

### **METHODS**

Focusing on the individual's narratives is a good way of uncovering the individual's claims about self and identities (Orbuch 1997; Bamberg 2004). Narratives are individuals' self-explicated accounts of connected events and/or the point-of-view individuals adopt in representing selves and negotiating identities (Bamberg 2004). In offering representative accounts of self, the individual speaker usually appeals to master narratives. Master narratives structure how the world is intelligible or how it is dominantly constructed (e.g., girls as non-violent) (see Bamberg 2004). The non-materialistic construction of people with disability (as not "normal") can be seen as a dominant master narrative about stigma in the Nigerian context. However, the individual in representing self may appeal to narratives that counter those of the master narratives, if this counter narrative serves the purposes of aiding justification for the sense of self the individual wishes to communicate. In other words, the individual in countering "master narratives" may appeal to contradictory frames in addition to representing own self along the lines of the counter frame (Bamberg 2004). In the case of a mother of a stigmatised child, a counter narrative could be the claim that the master narrative (e.g., the non-materialistic view of the disabled not "normal") is underpinned by unfounded superstitious beliefs.

Since the study's main objective is to explore the mothers' interpretation of the stigma experienced by their SEN children and how this affects choice made for their children narrative interviews were considered appropriate for our study. Narrative interviews are useful when the researcher, as in our case, seeks to gain insight into how respondents make sense of their everyday lives in relation to the research objectives (Bates 2005). Thus, narrative inquiry is considered relevant in uncovering mothers' accounts and interpretation of their (courtesy) stigma experience, the mechanisms they adopt (e.g., countering master narratives on stigma) in coping with their stigma experience and how these may determine their representation of selves, experiences and decisions.

The study focuses extensively on the experiences and narratives of mother of children with SEN. Our rationale for focusing exclusively on mothers as against any other key stakeholder (e.g., fathers or children) goes beyond any obvious practicality for doing so. Like many other societies in the world the Nigerian society is stratified along gender classifications (Omadjohwoefe 2011). Traditionally, African women were seen as actual or potential housewives and "child-rearers" (Omadjohwoefe 2011). However, the increasing number of African women who work outside their homes suggests that this traditional worldview is no longer as cogent as it was in previous years (Fadayomi 1991). Be that as it may, gender relations, roles and social mobility patterns in Nigeria are still underpinned by traditional patriarchal attitudes and constructions of women as housewives. Makama (2013 p 115) argues that in Nigeria "...there is the commonality of general belief system that the best place for women is in the 'Kitchen'". Routine childcare duties (e.g., "school runs") and other domestic chores are still considered "feminine" roles in the Nigerian setting (Fapohunda 1982). Children may be sent to child care centres or boarding schools where the mother works and is not able to undertake such activities (Fapohunda 1982). Alternatively, she may procure the services of "substitute mothers" if she can afford it. Substitute mothers are often paid household servants or unemployed relatives who assume the child care roles while the mother is at work (Fadayomi 1991). The role of mothers as the prominent child care provider in the family qualifies them as key stakeholder in the overall education of the child. This prominent role makes them an interesting and relevant category of respondents for studies aiming to explore aspects of their children's education.

A total of eight in-depth interviews were conducted with mothers of learners with SEN in three different International Primary Schools and a public primary/secondary school in Lagos. The age range of respondents is 35-54 while the age range of their children is 6-15. Save for one child who was supposedly home-schooled all other children attended either private

primary/secondary or public primary/secondary schools. Respondents were evenly split along the line of their marital status (four married and four single). The majority of respondents (6) were currently residing in estates or duplexes in the Lekki Penisular area of Lagos. This area is the fastest real estate market in the whole of Africa and monthly rents (approximately 500 - 700USD as at 2012) are consistently on the increase (Iroham et al. 2014). The average rental price is significantly higher than the average monthly income (480 -645 USD) of middle-income earners in the metropolis (see Robertson, Ndebele, and Mhango 2011). According to Babawale and Olusola (2012, 7691) "house prices and rents represent some of the highest in the metropolis and are, in some cases, denominated in dollars". In addition "residents of this area share similar locational characteristics and income groups"

# (INSERT TABLE 1)

Initial telephone contact with three private and three public schools was made by the researchers from UK. Subsequently, one of the researchers visited the schools to arrange interviews with their mothers. The researcher was advised by the school head teachers to approach mothers as they dropped off their children to the school in the morning. Initial response rate was poor. None of the mothers were willing to grant interviews in three of the schools (one public and two private) initially visited. However, three respondents agreed to be interviewed in a different International School where one of the researchers had previously worked. We attribute this favorable response rate to the sensitive nature of the topic whereby respondents' familiarity with this researcher played a part in their recruitment. Given the sensitive nature of the topic and the problem of recruiting respondents, a snowballing method was then applied. The first set of mothers that were recruited were requested to recommend other mothers of SEN children from any other schools to participate in the study. The researcher then contacted the snowballed mothers from other schools and arranged interview dates and

time over the phone. Interestingly, one of the mothers who turned down the initial interview request when she was met by the researcher at her child's school later agreed to be interviewed when contacted by one of the initially recruited mothers. Our approach confirms the views from previous research (see Goldstein 2002; Tansey 2007) that the use of snowballing enhances response and participant rates for studies where key informants' responses to sensitive topics (stigma in this case) are required.

The interviews started with a clarification of the stigma concept (in line with the explication of Link and Phelan, 2001) to ensure all respondents understood the concept and that data collected was consistent across board. Consistent with the study's objectives, mothers were asked direct questions that centre on their experiences and interpretation of stigma directed towards their children with SEN. Following from this they were asked questions that required them to account for how the stigma experience affects the education related decisions (for instance to send or not send their children to school) made on behalf of their children. The interviews were conducted at respondents' choice locations and time. Five interviews were conducted at respondents' workplace, one in the market place and two at the respondents' residence. The mothers interviewed at their workplaces were top managers in different organisations and resided in Lekki Peninsular. The rest rest were traders (two) and an unemployed housewife; one trader residents in Lekki and the other two in Mushin, Lagos. The interviews lasted between 45minutes to one hour. This time frame has been used in a significant amount of studies and is assumed sufficient for discussions that will yield in-depth data (Massey 2010). The principle of data saturation (Clisett 2008) was applied to ascertain if there was need for further interviews. Consistent with this principle, data collection was stopped when nothing new was being discovered after the eighth interview. Six out of the eight interviews were recorded and transcribed verbatim by the researchers. Notes were taken during the course of the other two interviews as these respondents did not consent to having their views recorded.

The transcribed interview data and interview notes formed the data set that was analysed.

Bamberg's (2004) idea of "positioning" was combined with thematic analysis at semantic and latent levels (Braun and Clarke 2006) in the analysis of the interview data. First, we draw from Bamberg's (2004) ideas of positioning to analyse data at two levels. The first level corresponds with analysis at the semantic level (Braun and Clarke 2006). Here the focus is on the analysis of narrative content, that is, respondents' accounts and responses to the interview questions and how these are consistent or inconsistent with the dominant societal perspectives (master narratives) about stigma. The second level focuses on establishing how respondents "position themselves in relation to discourses by which they are positioned" (Bamberg 2004, 367). This is aligned to thematic analysis at the latent level. At the latent level, a deeper interpretative approach is employed. This approach goes above the semantic in that it is concerned with uncovering the underlying ideas, assumptions and conceptualisations that are theorised as shaping or informing the semantic content of the data. Specifically, analysis at this level allowed us to uncover how respondents own narratives are employed to negotiate the dominant worldviews or master narratives (sometimes by countering them) about stigma in their bid to (re)position self and (re)present identities in line with their situation as mothers of SEN children. We do not focus extensively on any individual's life story rather we focus on uncovering prominent themes that capture something important in relation to the overall research objectives and the adopted theoretical framework. As such, the prominence of the theme(s) that are presented and discussed are "not necessarily dependent on quantifiable measures – but in terms of whether it captures something important in relation to the overall research question" (Braun and Clarke, 2006: 81) and in line with the analytic frame. Correspondingly, the quotes that are included in the presentation of findings are the ones that are considered representative of the key idea(s) underpinning the themes presented. This analytic approach allowed us to provide an overall rich description of the entire interview data (Braun and Clarke, 2006).

The study findings are presented thematically and discussed at both content and latent levels. Direct quotes from respondents are used to back up our interpretation of the main ideas underpinning specific themes. In line with McLellan, MacQueen, and Neidig (2003) we adopt a naming convention (where P1, is Parent 1, P2 Parent 2...P8 Parent 8) to link specific respondents with own quotes while ensuring complete anonymity.

## PRESENTATION OF FINDINGS

The study findings are presented and discussed under four themes; the social construction of stigma in Nigeria, stigma experiences within the school environment, mothers' interpretation of their child's stigma experience and the coping mechanisms (different ways of dealing with stigmatisation of children with special needs) adopted in dealing with stigma stress. These themes resonate with the research objectives and core assumptions of the adopted theoretical frame.

# The social constructions of stigma in Nigeria

Responses as to whether their SEN children had experienced any form of stigmatisation showed that most mothers had experienced stigmatisation from friends, family, neighbors and even schools. In the words of one of the mothers interviewed;

Sadly my son has experienced stigma from my friends and family. He has been diagnosed with Asperger's syndrome and people don't quite know how to deal with him. They

(neighbors and people at school) find him too intense and so they avoid him (P2).

In addition, the following representative quote is consistent with those of previous studies that the stigmatisation of individuals with disabilities may be underpinned by a superstitious and "spiritual" construction of reality:

Some of my neighbors and friends believe that he (son with SEN) is possessed by demons or a curse from the gods as a result of some doings by our ancestors (P4).

Specifically, the quote above resonates with the findings discussed in the literature reviews of (Obiakor 1998; Ogbue1995; Obani 2002) and highlights that despite claims for new waves of rationality in African countries, superstitious beliefs ("spiritual" constructions of reality) may still constitute dominant ways of seeing the world even in cosmopolitan cities such as Lagos. This finding ties into Etuk's (2002) description of African cultures as "non-materialistic" Consistent with Etuk's (2002) view, the comments of P4 clearly highlights a supposed dominant construction of reality whereby events in the physical or natural world as seen as underpinned by supernatural forces.

Interestingly, there a female single parent (P5) reported experiencing courtesy stigma. This respondent reported that her neighbors avoided her and her son because they claim that his condition was a consequence of her having a child out of wedlock. This form of stigma attribution reflects a wider disdain for people (especially females) who bear children out of wedlock. According to the respondent, females in this situation are often stigmatised and discriminated against on the basis of being labeled "loose" or promiscuous. Attributing her son's impairment to her behavior can therefore be seen as courtesy stigma, that is, an extension

of stigma from the mother to the child with the child stigmatised twice. In this case, the child is stigmatized twice; as a child of a "wayward" mother and, secondly, as an individual with disability. Again, Etuk's (2002) explication of a non-materialistic culture provides basis for contextualising this mode of courtesy stigma or "transference". The non-materialistic worldview that assumes a thin line between the material and the spiritual implies that attributing cause of the child's disability to the behavior of the mother (as punishment for B's behavior) not only provides justification for stigmatising the child on the basis of his disability. It also underpins the stigmatisation of the child on the basis of a superstitious stereotype attached to, and transferred from, the mother (P5).

## Stigma experiences within the school environment

Most of the mothers interviewed reported that their children have experienced stigma in different contexts but mostly within school environments. Consistent with the views of Corbett (2001) and Salmon (2013), respondents' comments confirm that stigma in the school environment puts pressure of the child and lower their self-esteem. According to a respondent, some children were set standards and targets that were beyond their capabilities which meant that they struggled. The majority of respondents reported that it was basically an expectation that the child read at a particular age and, often, no allowances or considerations were made for the children's varying needs. These children were sometimes made fun of by their mates when they did struggle as a result of their special needs not being met. The following quote highlights how teachers may encourage the exclusion of SEN children in their bid to make them reach levels that they consider necessary for the children to attain, albeit, with no considerations for their specific needs.

So she (the teacher) was trying to force him to read in front of the other students. Even when he did this mistake like; she made fun of him in front of other colleagues (P6).

The implication of being ridiculed, according to this female parent, was a lowering of her child's self-esteem and confidence;

it affected him (the stigmatised child) in negative way because he stopped reading for a while, he got this impression that whenever he reads someone will laugh...he used to love his books so much, but he then used to just open them and look at the pictures and could not open even his mouth and talk because he doesn't want to take it anymore. So this delayed his progress in reading (P6)

Some mothers also felt that typically developing children who had no notion of stigma were learning from their teachers when they (teachers) drew undue attention to these children with special needs in their bid to force them to meet school attainment levels imposed on them. Other children became aware of their 'difference' and treated them differently. A mother's worry is reflected in the statement that; "if you most of the time, you are giving them tasks that are beyond their abilities that's what can draw attention to them." (P7).

However, it is important to highlight a possible link between the import of P6's claims with study findings that found high levels of commitment and a willingness to cater for all categories of learners on the part of teachers working in private schools (Rolleston and Adefeso-Olateju 2014; Rose 2009). Consistent with these findings, it maybe that in trying to get students with special needs attain expected levels the teachers might be acting with good intentions without

realising that their actions may have the unintended consequence of leading to exclusion. As such, the manner of discrimination suggested in P6's claims may be tied to teachers' ignorance about SEN as against an intentional quest to stigmatise or discriminate on the part of the teachers

However, some mothers also reported their children being out rightly denied enrolment at particular schools because of their special needs. An expatriate mother of two children with special needs in Nigeria shares her experience in these words;

So we were quite open with the people that I saw but that hurt us, because what happened is even though they passed the entrance exams with flying colors, the schools wouldn't accept the children because of their diagnosis and I know a lot of other people who if they could kick them out they would kick them out because of their disabilities and I understand that has been a problem for other parents as well (P3)

The quote above highlights further how the perceptions of special needs may lead to discrimination and exclusion in an environment that should actually work towards the inclusion of children with special needs. Thus, even though teachers may discriminate unintentionally as in the quote of P6 discussed earlier, P3's views suggests that the perceptions held about children with SEN and how discrimination on this basis is prevalent ("...a problem for other parents as well") persists.

Mothers' awareness and interpretation of their stigma experience

Consistent with the theoretical perspectives on stigma consciousness, mothers' perceptions of stigma are aligned to an awareness of the master narratives underpinning their society's constructions of stigma, how they view themselves (victims) as members of their society (Deacon, Stephney, and Prosalendis 2005) and how the overall interpretation of the stigma experience underpin responses to the experience of stigma. An implication is that since stigma is based on master narratives about disability, the preconceived notions that mothers have about stigma might be over exaggerated in relation to actual experiences of stigma. Our findings suggest that it is possible that in talking about stigma mothers could be reacting to own stigma interpretation of dominant master narrative as opposed to the actual experience of stigma by the learner. Along this line a respondent notes that;

These children really don't feel anything. It is the parents that carry the burden for the children and that makes them worry for what the kids are not worried about. They should concentrate on looking for help for these kids instead of keeping them at home and feeling that they can't do well (P5)

The assumption that the child does not really feel anything appears to contradict the views of P6 that stigma seriously affected her son; leading to low self-esteem and withdrawing from reading out loud. We consider, therefore, that the claim that "children really don't feel anything" is better interpreted as an exaggerated claim that aims to water down the effect of stigma directed towards the child. However, strong and/or over exaggerated parental interpretation of Stigma may reduce the chances of mothers being open about whatever challenges their children face. While this is likely to stem from a quest or desire to protect themselves and their children from the hurt of stigma, the unfortunate implication could be that

some mothers may end up doing what they think they are avoiding- excluding their children and reducing their chances of being included. The following statement sheds more light;

Whenever it's your problem you will think it's more than those of others and when something concerns you, you will be more sensitive. This type of nature is like, let me just hide instead of just facing people, you know? So this is it, the idea of facing people (P8)

The result is that some mothers may refuse to discuss their children's' needs for fear of facing stigmatization. Some may even hide the child from society. In the words of a different respondent:

Awareness is very important especially in Nigeria so that people will stop seeing people with special needs as a curse on society, something to be prayed about or hiding their child so that people will not see and tag you with that stigma (P3)

The last two quotes suggests that it is the perception and interpretation of the overall stigma experience that determines to a large extent the responses and choices (such as "hiding their children") that are made on the children's' behalf.

Coping mechanisms: different ways of dealing with stigmatisation of children with special needs

Because the general view of interviewed mothers is that the societal perception of people with special needs is negative and they (mothers) are sometimes blamed or seen as the cause of their children's condition, mothers may find unique ways of coping with the perceived social and

cognitive pressures that go with parenting a stigmatised child. Coping methods adopted by the respondents include, but are not restricted to, "leaving it to God", seeking assistance in specialist schools including those outside Nigeria, protectionist moves (keeping children at home) and various forms of denials (for instance, denying the magnitude of the problem).

Interestingly, the dominant coping mechanisms employed by mothers appear to be underpinned by predominant societal worldview and corresponding non-materialistic culture. For instance, seeking for cures/remedies in churches or traditional deities was noted as dominant ways of coping. One mother noted that "Mostly, they (parents) won't talk about it (stigma)...parents that have children with disabilities would rather go praying about it and expect miracles" (P1). Such views stem from the cultural or traditional religious notions discussed previously; the non-materialistic perspective of Etuk (2002). Here the traditional views of leaving things to the hands of deities (or the Christian God following the advent of Christianity) can be seen as underpinning this way of coping. Some mothers by shifting the responsibility to something greater and able to take away all problems (God) become rest assured that their problems are in good hands. In addition to the non-material "supernatural", denial constituted a dominant way of coping for most mothers. In denial, respondents counter the dominant master narratives in a bid to represent themselves and their child's situation. We see this in the respondent's comments that; "My son does not have a problem; it is just a jinx that needs twigging" (P7). In this case, the medical view (diagnosis of her child's situation) is the master narrative that is countered with the aim of situating her child's condition in a less "discrediting" position. This specific form of coping by countering dominant medical views has been reported in previous studies (see Bamberg 2004)

It is however interesting to note that one of the mothers interviewed, in describing her child's experience of stigma, used a different form of cognitive appraisal to deny the magnitude of the

"problem". In her words; "some people avoid her because they believe that she is possessed by demons, but she is not; she is just 'mentally retarded'...she is not even an 'imbecile'..." (P8). She compares her child's situation with a condition presented as being of greater magnitude than her child's "actual" condition. Thus, whilst acknowledging that her child has impairment, she waters down the magnitude of this situation by comparing it with a condition (imbecility) presented as being more serious. At the same time, the master narrative implicit in her first claim (the dominant perception of disability in line with a non-materialistic worldview) is countered, even if indirectly. Although the coping mechanisms quoted appear different ("leaving it in the hands of God and denial of the problem) both may serve the essential purpose of helping those that employ them to cope with the stigma stress.

Furthermore, instances where mothers reported sending their children to schools that are more accommodating of children with SEN can also be considered ways of coping and working around stigma. The implication is that some coping mechanisms may not necessarily be different from the choices that are made on behalf of their children. In fact, findings suggest that the educational choices made on behalf of their children could essentially be the same as coping mechanisms. This is evident in the view of some mother who argued that the decision to send children with special needs to school offered temporary relief from having to see and deal with an impaired child. The quest for education may not be the only or sole motive for sending their children to school. Rather, this specific decision stems, at least partly, from a quest for "temporary relief" from caring for a disabled child.

Evidence further suggests that the mothers who reside in Lekki Peninsular may have more awareness of their children's condition and needs. This may be due to their educational and high income levels. Thus, for wealthier parents, the decisions to send or not to send their children to school appear not to be a major concern. With strong financial backing, this

category of parents has access to private schools or specialist provision for their children (Ushie et al. 2012). They are therefore in a better position to meet their children's special educational needs. These views are clearly evident in the following parent's account;

I suspected something was wrong so we flew abroad to have her diagnosed. She was diagnosed with autism and was tutored privately for a while in the UK. I got recommendations to hire an LSA when I got back to Nigeria...coming to the UK helped with the decision that education was paramount for my child (P1)

The United Kingdom was identified as choice country for diagnosis and specialist attention by two different Lekki residents (P1 and P3) for two main reasons. First, there was the shared belief that the UK has a better understanding and is more open to providing quality education for children with SEN. Secondly, that the national curricula of both countries shared similarities made it, according to P1, the ideal country of choice when deciding to seek solutions outside Nigeria.

Higher tuition costs imply that parents in the low income category are likely unable to afford private schools or access to other specialist forms of addressing their children's special educational needs. As a result, they may be restricted to public schools if they are to send their children to school. Given that the state of public schools in Nigeria at the moment is said to be lamentably poor (Igbuzor 2006) chances are that children of this category of parents are not likely to meet their SEN in these public schools. Parents who are limited to these private schools may choose not to send children with SEN to school on the basis that they would be exposed to further stigmatisation instead of learning. The following quote from a parent

suggests that this may be the case; "If he goes there, (public school) he will not be learning anything. Instead, the other children will be laughing at him and abusing him" (P7)

It may be that this mother's quote is used here mainly to justify the choice of homeschooling her child. However, that such parents may also choose to keep their children with SEN at home for economic reasons is evident in the following quote; "There is no money for two of them to go to school so instead, let his other brother go so that he can get a good job and help out the family" (P7). Their reasoning behind this choice is that the limited available fund should be channeled towards feeding the family and educating the "normal" child who is more likely to achieve some form of status within the society without the added pressure of stigma. This view is consistent with those of Mba (1995) discussed in the literature review. This parent also noted that the choice of schools for their children with special needs was restricted due to the area where they live; the majority of private and good schools were said to be located in affluent areas.

Conclusively, the manner in which parents construct their accounts and justifications for the choices they make for their children suggest that the intention of the parent is to provide some form of care. This view is consistent with those of Baral, Karki, and Newell (2007) who argues that underlying most coping mechanisms employed by mothers in addressing concerns relating to their children with special educational needs is the quest to cater for these children. Thus, the coping strategies adopted by these mothers are essentially ego defense mechanisms and their use highlight the different ways that the sampled mothers may represent and/or position selves in relation to their stigma experience.

#### **DISCUSSION**

We explored parents' experience of stigma attributed to their children who require SEN in a Nigerian context. We also uncover the coping strategies adopted by this category of parents to negotiate the social and individual pressures that arise from the stigma experience and how these affect choices made on behalf of their children. Our findings are relevant to the broad literature on stigma from, at least, theoretical and practical points of view.

Theoretically, we draw from the findings to argue that stigma directed at an individual may derive from different forms of "transference". While studies on stigma have highlighted the issue of courtesy or "secondary" stigma as the extended labelling and stereotyping of a significant other on the basis of their relationship with another (see Goffman 1963; Salter et al. 2010; Lizhen et al. 2010; Johnson and Benson 2014; Scatz and Gilbert 2014), the nature of association uncovered in these studies is limited to "secondary relationality". This form of relationality contends that stigma directed at Person A may relate to Person B (say, a mother) by 'contamination' (stigma through one's degree of proximity to the stigmatised) and 'causal implication' (stigma through an assumption that they are to blame for the crimes of the stigmatised) (see Holt and Wilkins 2015). What we infer, therefore, is that current studies stop short of highlighting that person B's experience of stigma as a stressor occurs as a secondary relation (for instance, when Person A experiences stigma because they are a relative of Person B who is stigmatised due to some form of "contamination"). Our findings uncover a unique pattern of stigma "transference". Specifically, it demonstrate that the same Person A can be stigmatised because they are associated with Person B in the sense that stigma attached to Person B is transferred directly, and not secondarily as noted in current literature, to Person A. It is aligned to "contamination" and "causal implication" as means of stigma transfer (secondary stigma) but highlights a more complex, yet specific, mode of transfer. The case of the single female parent discussed noted earlier is relevant in explaining this more complex pattern of stigma transference. Unlike in secondary stigma where the parent is assumed to

experience stigma in relation to a differential marker attributed to the child, the mode of transference uncovered in this study highlights that the stigmatisation of the child may be attributable to the child's disability at the same time as it is to the socially attributed cause of the disability - the female parent's own behavior (bearing a child out of wedlock). This mode of transference, we argue, highlights a specific form of societal construction of difference that is underpinned by a non-materialistic worldview. As such, it may be unique only to societies where non-materialistic cultures and worldviews are dominant.

Although single mothers may be stereotyped as wayward or lazy in developed country contexts (Jarret 1996), the non-materialistic construction of single mothers in the Nigerian inclusive education context highlights a context-specific phenomenon of significant import for both mother and child. This non-materislistic form of transference extends the horizon of the situational and circumstantial contexts that mothers with SEN children may have to negotiate when responding to stigma directed towards their children or to themselves in the Nigerian context. An instance where stigma towards a child with special needs is underpinned primarily by stereotypes attributed socially to their parent (for example, as wayward or cursed) is likely to affect the psychological well-being of the parent more than instances where stigma is experienced only as "secondary relationality". The implication is that mothers experiencing stigma in the former fashion are likely to experience more stigma stress and may require different coping strategies unlike counterparts who experience stigma as in the latter. In turn, the SEN Child may be affected if the mother adopts coping mechanisms and decisions with potentially negative consequences (e.g., experiencing significant pressure to "hide" the child)

Practically, the study's findings are relevant for anti-stigma interventions. Findings from interviews with parents highlight how dominant societal worldviews (especially, superstitious beliefs) may underpin the constructions of "difference" and stigmatisation of learners requiring

SEN in the Nigerian non-materialistic cultural context. Given that stigma perceptions are constructions which are communicated within cultures using language, a good way of intervening to address or deconstruct the worldviews (master narratives) that drive stigma would be to counter their underpinning constructions using linguistic devices similar to those that are used to construct and dissimulate them in the society. For instance, Etuk's (2002) explication of the African world view as being non-materialistic and the recent shift from belief in deities to churches and pastors suggest that these actors (pastors and churches) could therefore become avenues of creating awareness and deconstructing superstitious beliefs in non-material African cultures.

The overall implication is that interventions are likely to be more effective if they become more target specific; recognizing the different experiences of key societal stakeholders (stigmatised learners and their parents/relatives). A specific implication is that intervention focusing primarily or extensively on punishing the perpetrator (that is, the stigmatiser) as a deterrent may not be the most effective. This is because such approaches may fail to factor-in adequately the specific self-interest points of view of different stakeholders in the stigma "relationship". Specifically, stigma transference highlight that some parents may need more targeted support than others. For instance, where non-materialistic worldviews and cultures are dominant, finding ways to educate and help parents recognise the need to 'do something' differently will go a long way in assisting them to accept responsibility for action as against "leaving or putting everything in the hands of God".

In addition, the issue of teachers not considering the specific needs of children with SEN because they want them to attain expected levels is relevant for inclusive education policy and practice. Practice-wise, teachers need to engage with various forms of evidence that can enable them reconsider their assumptions and improve on their delivery. Engagement could come in

different forms (e.g. bespoke trainings) but should emphasise alternative and more effective ways of working that take into account learners' specific needs (Ainscow 2007). This approach can significantly change the ways that individual teachers and the school as a whole define and address pedagogical issues pertaining to inclusive education. Furthermore, it can also equip teachers with knowledge and skills to then engage other students in discussions on disability. Specific to the study's findings, this approach can be used to work around instances of exclusive behaviour where "normal" children laugh at those with SEN because they do not read well in class. Government and schools are also required in terms of formulating policies that support the recommended practice intervention approaches.

Furthermore, our findings are relevant for the enhancement of anti-stigma intervention in some developed countries. In a recent study conducted in the UK, migrants with disability from developing countries (Nigeria, Algeria, Zambia and Bangladesh) reported being more marginalised by people from their own communities (Murphy 2013). Such findings highlight that the societal worldviews underpinning stigma subsists even outside of its original social milieu. Consistent with Murphy's views (2013), our study findings point to the compounded potential challenges and pressure that parents of people with disability and their children may have to negotiate when living in diasporas. This highlights the need to identify and cater for this specific category of people within the context of inclusive education. This is particularly relevant for countries witnessing high migration rates from Nigeria and other countries where similar non-materialistic cultures may exist. Our findings inform policy makers and practitioners in such countries that any assumption that non-materialistic worldviews are obsolete may be synonymous to a denial of the existence of a serious and important challenge for inclusive education.

Despite making numerous contributions, this study has some limitations. The qualitative approach that was adopted and the low number of respondents make it impossible to generalise findings. Although the interviewing of only female parents can be justified on the basis that mothers are often more hands on when it comes to education of children in Nigeria than fathers, the exclusive focus on mothers may limit the findings to mothers' views as against parents as a whole. Furthermore, studies can extend the scope of the dialogue by addressing some of the limitations noted above. For instance, it would be beneficial to consider the views of male parents and/or the stigmatised child(ren) alongside those of female parents using methodologies such as focus groups to capture how male and female parent perspectives are constructed and/or negotiated in social interaction. Studies that employ use of quantitative techniques are also recommended in that they can lead to findings that can be generalised to specific target groups and/or societies at large. In addition, the import of non-materialist cultures and transference can be extended to other non-educational contexts.

Finally, the current study's findings even if not conclusive or generalisable, introduce new dimensions to understanding stigma in different contexts. It provides fertile grounds for further discussions on the consequences in cultural life of placing terms such as courtesy stigma, "transference" and non-materialist worldviews in the debate on stigma theorising on one hand, and inclusive education within and across nationality contexts on the other.

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