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Coming to America for the good of a deaf child: The case of Joy

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ABSTRACT

Families of children with disabilities must make difficult choices about providing health and educational services that their children need and finding an environment where they can be socially accepted. In this study, parents from Kenya whose daughter is deaf weigh their desire to provide the best life for her against their desire to use their professional expertise to help people in Kenya. This article examines the role of cultural beliefs about disability in this family's experience. It highlights issues that deserve further research to learn more about how to meet immigrants' needs in special education, especially immigrant families from African countries with children with disabilities.

Keywords: Africa, deaf, special education, immigration.

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INTRODUCTION

Since the early 1980s, interest in education for people with disabilities has increased around the world. The United Nations commemorated 1981 as the Year of Disabled Persons. This event signaled a growing concern about human development and the rights of marginalized peoples across the globe.

Disability issues became increasingly prominent. The Education for All initiatives and the Millennium Development Goals, begun in 1990 and 2002 respectively, were sponsored by the United Nations in several developing countries. Education is a right guaranteed for all world citizens in the UN Convention on the Rights of a Child. Article 23 specifically discusses children with disabilities and states:

A mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community.... The disabled child [needs] effective access to and receives education, training, health care services, rehabilitation services, preparation for employment and

recreation opportunities in a manner conducive to the child's achieving the fullest possible social integration and individual development, including his or her cultural and spiritual development. (United Nations, 1989)

Nevertheless, opportunities in several East African countries for educating and training children with disabilities remain limited. While the Millennium Development Goals are supposed to provide Education for All, particularly basic primary education, no earmarked money or specific plans in that program are being used to target children with disabilities (Raijmakers, 2005). Even today, people with disabilities in East Africa must deal with discrimination from negative attitudes and beliefs. In addition to poverty and the lack of resources, these beliefs have limited the services and educational opportunities for people with disabilities in African countries. In Kenya, it is unlawful for people with hearing or visual impairments to run for president because the law requires that the president speak and read in Kiswahili and English, not Braille or sign language (Ogechi and Ruto, 2002).

Cultural beliefs about disability in East Africa

Beliefs about disability and the cause of disabilities can be closely linked to the level of acceptance for an individual with a disability. In East Africa, people frequently have beliefs that simultaneously reflect a medical understanding and a spiritual belief about disability and its causes. In some East African societies, disability is determined not through a medical diagnosis, but by one's ability to participate in society and the role that a person plays in that society (Harknett, 1996; Kisanji, 1995; Miles, 2002; Talle, 1995). At times, individuals will provide multiple explanations to help neutralize the negative beliefs about disability, such as suggesting a medical explanation in addition to the traditional belief (Ingstad, 1995). Deaf children are seen as burdens to their families and are often hidden to prevent public shame from coming to the family (Kiyaga and Moores, 2003). Indeed, "The positive indigenous treatment of the disabled is now fast eroding away" (Ogechi and Ruto, 2002). In the Abagusii and Nandi groups of Kenya, people are defined by how well they integrate into social and communal life. People with physical, hearing, and visual impairments are not seen as categorically different, but simply as people with this specific impairment (Ogechi and Ruto, 2002). Among the Maasai of Kenya, people with disabilities, particularly physical disabilities, are viewed as "abnormal" only if they cannot carry out daily activities (Talle, 1995).

Culture, society, and family are three crucial components in this model (Bronfenbrenner, 1992). Bronfenbrenner and Morris state, "throughout the life course, human development takes place through processes of progressively more complex, reciprocal interaction between an active evolving bio-psychological human organism and the persons, objects, and symbols in its immediate external environment" (p. 996) (Bronfenbrenner and Morris, 1998). Viewed from a contextualist approach, people seem to be embedded in the local context, and the context is embedded in the culture; in addition, an ecocultural approach examines the specific impact of context and culture on family, school, and community interactions (Harry, 2002).

Children enter school embodying the characteristics of their families, developed through interactions and experiences with family members. Participating in a nondominant group can mean that different values are being taught and learned at home and school and in the community (Butera, 2005).

Educational opportunities for children with disabilities in Africa

Formal schooling for students with disabilities in African countries is limited. Missionaries have operated schools for the blind or deaf since the 1950s, but these schools tend to be crowded and are likely to be boarding schools,

located far from the students' homes and communities. In Kenya, deaf children are usually educated separately from typically developing students, with few attempts at integration. In schools for deaf students in Kenya, Kenyan Sign Language is used. It has been developed in deaf communities and is not an expression specifically of English or Kiswahili, the two most commonly spoken languages in Kenya. Therefore, it is difficult for people who are deaf to communicate with hearing people except through written language in English or Swahili (Nyang'aya, 1998). Many schools in Africa for children with disabilities, including those who are deaf, have limited resources and teaching staff because of lack of funds and poverty (Hartley et al., 2005; Ihenacho, 1985; Miles, 2002). Finally, most teachers in public schools do not have the specialized training to help students with disabilities (Kiyaga and Moores, 2003). Few Kenyan teachers are currently trained to work with children with special needs (Kenyan Ministry of Education Science and Technology, 2004). In 1998, Nyang'aya claimed that approximately 87,000 deaf people were living in Kenya. Deafness and other disabilities have are more prevalent in Kenya and sub-Saharan Africa than in Northern countries because of higher levels of malnutrition, childhood illness, and lack of access to comprehensive medical care and hearing aids in sub-Saharan Africa (Kiyaga and Moores, 2003; Zeng, 1996).

African Immigrants

Providing for students in the United States who are immigrants, are learning English, and have disabilities can be challenging for local school systems and requires flexibility and understanding of the students' different unique needs (Alidou, 2000; Chu, 2008). In one study, Conger et al. (2007) found that students from sub-Saharan Africa were less likely to be identified for special education services; they had higher levels of attendance, but did poorly on standardized tests.

Proficiency in English and standardized test scores could vary for students from African countries depending on their level of English before coming to the United States and the presence of disabilities. While the migration of people from African countries is rising, they are still less than 10 percent of immigrants arriving in the United States each year. In 2000, students from African countries in the public schools were only 4 percent of the total foreign-born student population (Capps et al., 2005).

Very few studies on African immigrants in this category—immigrants with children with disabilities who came for the child to the US, but stayed for an education, and want to return to their home country—have been done. Most studies on voluntary minorities (immigrants) are on individuals who came to stay in the US or refugees who cannot return home (Ford, 2012; Hurley et al., 2013). There is very limited literature on the experiences of African immigrant families with children

with disabilities in the US, and this manuscript aims to add to that literature.

Harry (2002) suggests why there may be less research in the area of disability and minorities: the disability is seen as the master status, and the other areas are not addressed. Sonntag and Schacht (1994) argue that professionals may unintentionally limit information available to parents from diverse ethnic backgrounds because of misunderstanding in language and culture. Therefore, programs need to be tailored more carefully to the needs of these parents, based on their expressed desires (Sonntag and Schacht, 1994).

Purpose of the study

In this study, a pilot phenomenological study, the author wanted to examine the experiences of a family from an African country with a child with a disability that is currently living in the United States. The author was interested in the family's motivations for coming to the United States, their experiences in the special education system, and how their culture and cultural beliefs about disability influenced their experience of having a child with a disability. The author was particularly interested in a family that chose to immigrate to the United States to get help for their child who is deaf, but still have strong ties to their culture, family, and work in Kenya. Finally, the author wanted to examine the pull they felt from the two different worlds and how that affected their decision-making in the special education system. The author had two initial research questions:

(1) how does the family feel about the educational services offered to them for their child with disabilities? and (2) how do cultural beliefs and values influence their experiences? During the course of the study, a third question emerged: (3) how does the child's disability continue to affect the family's life decisions? Each of these questions sought to provide a rich description of one family's experience, which could help inform future research on immigrants' experiences with special education when the family has a child with a disability.

METHODOLOGY

This is a single, intrinsic case study of one family and its experiences as African immigrants with a child with a disability. Combining the data gathered from the family and the service providers offers a more complete and dynamic look at the coordination of family services than would otherwise be possible. Subjects were recruited using a flyer distributed to local groups of Africans, electronic mailing lists for African studies programs at universities in a Midwestern state, administrators who worked with parents' groups for families with disabilities in the state, and a few local school systems. A key limitation of this study is that only one family that met the

recruitment criteria agreed to participate. For that reason, this study was conducted as a pilot study about the topic, but critical data about the experiences and perceptions of the family that have not been documented widely within this population of families nevertheless emerged.

Theoretical framework

The author chose to follow Charmaz's constructivist grounded-theory approach (2006) to answer the research questions while working from a sociological phenomenology (Bogdan and Taylor, 1975). First, no theory is currently available to explain the experience of Africans living in the United States with children with disabilities. Little, if any, literature discusses Africans specifically as a group when dealing with disability as immigrants: often they are categorized with African Americans, but they have different perspectives and histories, particularly in how and when they came to the United States (Rong and Brown, 2001). Harry states that to study people with multiple dominant statuses, a contextualist approach is necessary, one that "emphasizes the embeddedness of all contexts, so that the individual is seen as embedded in a context, which is in turn embedded in a culture" (Harry, 2002: 132). Because of Kenya's long history of missionaries and white settlement, immigrant families from Kenya could have a culture that was influenced by local and global ideas, including local indigenous knowledge, Western missionary traditions, British colonial policy, and international media. Second, one cannot accurately apply a Western ethnocentric theory of family functioning or service delivery to an African family for whom the theory was not developed and does not take into account their unique cultural beliefs. Additionally, families experience disability in many different ways and will use services in many different ways, depending on culture and the parents' age, economic background, and education (Seligman and Darling, 2007).

Grounded theory lets researchers explain the experiences of a case under investigation and then make general statements that may be useful in other cases in similar situations. A grounded-theory approach allows a researcher capture the uniqueness of the situation, gather a rich understanding of the total context, and make suggestions that may be applicable to future work with other African families with children with disabilities (Charmaz, 2005).

Methods

This case study used emergent design methods and three sources of data collection: observations, interviews, and artifact examination (McMillan and Schumacher, 2001). During two full day observations, I observed Joy¹

¹ The names of the participants and the places have been changed to protect their confidentiality, based on the Institutional Review Board approval for this study.

in her general education homeroom, her inclusive math and English classes, and her resource classroom, where she worked in a group with the teacher for deaf students. I conducted observations at home with her mother and sister to see her in her home environment on four occasions for one hour each. Field notes were taken during the observations and then expanded shortly afterward. Interviews were conducted with each of her parents, four school staff members who work with her daily, and a specialist in speech and hearing science from the local university with expertise on cochlear implants. The parents were interviewed together in the first interview and then were interviewed separately for follow-up interviews, for a total of four hours. The parents responded to additional questions and comments via email. All but two of the interviews were digitally recorded and transcribed within one week of the interview, and additional notes were taken during the interviews. Finally, newspaper articles written at the time of Joy's operation were collected from the parents, along with her class schedule, and work samples were examined at school. The data were reviewed during the collection process to help guide the follow-up interviews and observations.

Data analysis

Field and interview notes were reviewed by the first author and discussed with two peer debriefers to verify the categories and conclusions during data analysis. The author has worked in special education for at least fifteen years and has experience in special education in the United States and Africa. For this phenomenological study, I wanted to understand the experience of the family and develop themes from the data gathered. All the field notes and interview transcripts were read and reviewed multiple times and coded for keywords and categories. The categories were analyzed and combined to develop the themes. Each theme was developed through triangulation of the data using all three data sources. Member checks were completed with the interviewees to verify their responses and the accuracies of my understanding of the data. Table 1 summarizes the themes and initial codes presented in this paper. There are themes and codes from the data not addressed here due to space limitations.

Table 2 gives examples of the questions asked of the family and educators.

Table 1. Themes and categories.

Final Themes	Initial coding categories	Data sources
Cultural beliefs about disability	Laying of hands vs medicalized	Interviews documents
	Family experiences	
	Limited education for deaf people	
	Hearing critical vs sign	
The best life for their daughter	"what will be, will be" attitude with hearing loss	Interviews observations documents
	Health concerns	
	Longevity issues -cochlear implant	
	Educational stigma in Kenya	
The parent's struggle between work in Africa versus Joy's well-being	Joy thriving in US	Interviews observations
	Brain drain	
	Skilled jobs and education	
	Limited medical care in Kenya	
	Limiting Joy and Emma's opportunities	

FINDINGS

Joy and her family's story

Joy was born in Kenya. Her parents, Laura and Robert both held professional jobs. Joy was the firstborn child and had a normal and healthy birth. Joy attended school and was a good student. When Joy was four she experienced gradual hearing loss in her right ear, and then after her seventh birthday suddenly became deaf in both ears. Joy has a typically developing sister, Emma, five years younger.

After visiting several doctors, her parents did not have much hope that her hearing would return, but they continued to pray about it and for her. The consulted doctors seemed to think that Joy was going to have to learn to live with this condition; however, Laura wanted a remedy, not mere acceptance.

Because of Laura's work connections with hospitals, the family was able to secure a pro bono cochlear implant surgery for her in the United States about five months after her hearing loss. Initially, the family planned to return to Kenya shortly after the surgery, but decided to stay for a longer rehabilitation period and during that time

Table 2. Sample interview questions.

Family interview questions	Educator interview questions
1. Where are you from originally?	1. What is your job?
2. Are you part of a particular culture group? What languages do you and the members of your family speak at home?	2. How do you know the student?
3. How long have you lived in the United States?	3. Please describe your relationship with the family?
4. Why did you come to the United States?	4. What do you know about the family's culture and language?
5. Please describe your family.	5. Have they shared anything specifically about their culture or about their beliefs?
6. Please describe your child's disability?	6. Has culture or language been significant in how you provide teach the student? Changing anything that you do?
7. When and how did you learn the child had a disability?	7. Is the student part of the class or school community?
8. Does your cultural group have particular beliefs about people with disabilities or the origin of the disability? If so, please describe them.	8. Do you see that the family has been integrated into the community?
9. Did you have any interactions with people with disabilities in your native country? Please describe them.	9. Do you think the family is happy with the school services they have received?
10. How do believe your cultural group looks at people with disabilities and their participation in daily life?	10. Have they ever asked you to do anything differently?
11. Please describe the services your child and/or your family receive related to the disability?	
12. How did your beliefs influence you to seek or not seek services?	
13. How did you find out about the services?	
14. Have you been satisfied with the services provided? Why or why not?	
15. Is there anything the service providers could have done to help you more?	
16. How have your beliefs about disability influenced you asking for services in the United States?	
17. How has your culture been addressed by your child's teacher/service providers?	
18. How have these services helped you care for your child or family?	

both parents were admitted to doctoral programs. The parents took advantage of their opportunity to help their children have a better life in the United States through education and healthcare for Joy's deafness, as well as to improve their lives with advanced degrees.

The first time I met Laura and Robert, they both talked about going back to Kenya after their degrees to help their country and to support the people with their new knowledge and expertise. From the beginning, they expressed hesitancy over taking Joy back to Kenya, given the limited facilities for handling her implant.

When they first arrived in Hartsville, Joy and Emma attended Sligo Elementary School. After the first year, Laura and Robert decided to move the girls to Rover Elementary because at Sligo "she was the only child with a cochlear implant and the only black child in her class." Her parents preferred Rover because of the racial, ethnic, and socioeconomic diversity, as well as the opportunity for Joy to be with both deaf and typically developing students in an inclusive classroom with support in a resource room from a teacher, Ms. Tucker, for deaf and hard of hearing students. At the time of the study, Joy

was eleven years old.

In the special education classroom, Ms. Tucker teaches American Sign Language, how to read lips, and she uses lots of visual cues, implementing a total communication approach. Additionally, Joy works with Mrs. Gardner, a sign language interpreter, and with Ms. Arden, the speech language pathologist. Joy has worked with all three teachers since she started at Rover Elementary. Mr. Bernard is her homeroom teacher and one of four subject area teachers. Joy and her deaf peers use sign language and speech together to communicate among themselves and with their teachers. Joy's family narrative described above was developed through the interviews, observations, and documents provided by the family and the school and provide a foundation for the explanation of the themes that emerged from this case study.

Themes

Three major themes were interconnected and illuminated in the love this family had for Joy, the gravity of the

decisions they have made to give her a good life, and the importance of the decisions they will make to help both Joy and her sister. The themes are cultural beliefs about disability, the best life for their daughter, and the parent's struggle between work in Africa versus Joy's well-being.

Cultural beliefs about disability

Interviewing the family and school staff showed that cultural beliefs about disability, particularly those that put disability in a negative light, were not part of this family's daily life. When Joy was first diagnosed, Robert and Laura had to face many different beliefs from different people. Laura recalled,

I remember someone making a comment when Joy went deaf and they said maybe there is something we didn't do right or a relative, it is something coming—coming upon on the family, or somebody failed to live up to obligations. So it is almost like a belief in a punishment from the gods or God for failure to live up to a ritual or to something, some deviance of some sort, you know.

These explanations are common in the literature as detailed above, but they are changing.

Published papers (Mallory, 1993; Ogechi and Ruto, 2002; Talle, 1995) explain that some people in Africa believe that disability is caused by God or is a punishment for a mistake made by a family member; however, Laura discusses a new concept, one that does not appear in the literature. Joy's family was attending a local Pentecostal church, and Laura remembered:

Then there were religious people, who brought—very Pentecostal people, who came to pray for her, lay hands on her. These ones, their line of argument was it is a curse, and if they pray and lay hands on the child and on the family, we can take away the curse and the child is going to hear.

The laying on of hands for healing and other purposes has occurred in recorded history for thousands of years and it has become a common practice in African countries to remove spirit possession. People believe that energy or healing power from God can be passed directly to a child with a disability through a pastor (Master, 1995). After coming to the United States, Laura and Robert found the treatment and discussion of disability to be more medicalized. Laura emphasized that in Kenya the people who can live in the community with whatever condition they have, they are actually left to live with family members or left to live on the streets. I mean it is something we all know; it is not an issue. "So and so is

on that corner, and give him some bread when you pass." It is not as medicalized as it is [in the United States].

In Kenya, the doctors had thought that whatever was causing Joy's deafness would run its course, or she would learn to live as a deaf person; they did not discuss treatment other than sending Joy to a school for deaf students if she remained completely deaf. Deafness is seen as an invisible disability, and disabilities are often ignored as long as someone can find a job and be integrated into the community, regardless of the disability. Robert added,

They are really ignored in a way. You know that so-and-so's child is not normal. I don't know how they would explain it in the past. Some people would probably look at it as a curse or something was not done, but it depends on which culture it is and the reason people would use to explain why that child is the way that it is. But I can't think of specifically, culturally, what we would do, because I am thinking of my home area, and there were not very many people who had like disabilities; they were there, and a few who lost it mentally, you know, but they were few and far between.

People with disabilities exist, but it seems that the definition of what makes a person truly disabled and unable to participate in society is what makes that person noticeable to the community as deviant from the norm. For Joy, if she could live as a deaf person and participate in the community, she would be accepted, but with her cochlear implant she would be different from everyone else.

The best life for their daughter

The parents have wanted what is best for Joy and have tried to make the right decisions to make her as successful as possible. In Laura and Robert's minds, Joy's success depended upon her being able to hear, successful in school, and accepted and happy. They believed they were really lucky to have the right connections to find the opportunity to give her the cochlear implant and the educational and medical services she has received. They thought this was what they had to do. Robert stated, "We thought she would miss out a lot in the course of life if she didn't have her hearing. We made the decision to do everything we could to help her get her hearing." When they were still living in Kenya, they had different options, but the doctors asked and her mother responded,

[They asked,] "Do you want to have surgery done?" I want to give her a chance. If it means that I have to fly to America to give her an

opportunity to hear, I am going to do it. And I never had second thoughts; I actually thought that I was doing the right thing.

The last sentence of the quote hints that Laura may be having second thoughts now. Talking to her more about her feelings gave the impression that she just does not know what the future holds and how Joy will do. She is worried about the cochlear implant technology. Both parents have much apprehension about the care and maintenance of the implant over the next few years and Joy's lifetime. Cochlear implants are common now, but unanswered questions about long-term use and maintenance remain. Laura and Robert want to be reassured that the cochlear implant was the best long-term decision. The parents keep many files of research on cochlear implants and the impact of a cochlear implant on children as the implant ages.

Laura and Robert have been happy with Joy's school and teachers, and Joy is doing well in school. She enjoys being in the program for students who are deaf or hard of hearing, but she spends most of her time in her inclusion class. Her IEP reflects her ability to participate fully in her inclusion classes, but she still receives support for pragmatic language issues and support for continued sign language development. She can hear with her implant, sign, and read lips fluently to take advantage of all of her modes of communication. Observing her shows that she shifts between talking and signing easily, depending on who she is talking to and their mode of communication. In class, Joy was seen to sign with a deaf friend, even after being told to stop talking; they knew they could get away with signing because they were not making any noise, until the interpreter noticed their discussion. In the neighborhood, Joy plays with a deaf child who goes to a different school; they play and sign, and Joy serves as an interpreter between this friend and her parents.

The teachers at Rover Elementary have been impressed with the parents' involvement in Joy's education. The parents attend conferences and are active in the school. Mr. Bernard commented,

They are really big on making sure she's doing the right thing at school. If her grades aren't in the right place, they make sure that they get there, so I know those things are really strong in their family life: school, and doing well, and doing the right thing, and things like that.

Laura discussed Joy's current school and class: "She doesn't feel that she's alone and the only one with that disability; it's good to be in an environment with kids with similar issues." Joy's parents are worried that if they return to Kenya, Joy will not fit in and will not have as many friends because of her disability. Joy is unique in both the United States and Kenya: in the United States,

she is an African immigrant who has found ways to succeed in school and fit in socially, despite her disability; in Kenya, she would be a native with a strange device in her head who communicates differently from both the deaf community and her typically developing peers. She is a cultural bridge between Kenya and the United States and between the deaf and hearing worlds. This quality allows her to find her niche in her local community.

For Joy, fitting in involves more than just being with people with a hearing disability or with people from similar socioeconomic backgrounds. Over the past four years, she has assimilated into her school and community, and her parents have made sure that she has been with other children like herself. Laura talks about when Joy was at Sligo Elementary,

Because she was the only kid who had an implant, so she was the odd kid that everyone wanted to ask about. Why is she wearing that? Why is this? Why is she not hearing? Why is she shouting? When she had [*sic*] to do that? And when we took her to [*Rover*], and she saw that there were kids who were even more disadvantaged than her, and they were still struggling to pronounce words, and she could help them out, she started feeling like "Oh, I'm not so bad after all," and she stopped feeling like an outcast—not really an outcast, but different.

At the time of the interviews, Joy did not want to share much about her Kenyan culture in the classroom. Her sign language interpreter stated,

She is very reluctant to share very much about her culture. She really wants to be Americanized; she is very shy, and she does not want to talk about Africa very much, and I don't push it because it makes her uncomfortable.

Joy was so well adjusted and her cochlear implant worked so well for her in the classroom that she and the teachers did not work on cultural-understanding issues except as they related to language. For example, during one observation, Ms. Tucker discussed the terms related to the state assessment test and what it examined. They discussed vocabulary that was used in the results letter and what it meant for students to go to summer school if they did not pass the test. Another teacher stated, "It's mainly, if there's academic or new things that she needs support in, but besides that it is just the language and cultural things, with idioms and figurative language, and that's what the speech-language pathologist will work on too." Based on observations and interviews, it was clear Joy had found her place in the American school and had several close friends in her neighborhood and in her class. She frequently spent time with other deaf students and had two good friends in her class with cochlear

implants who used a combination of sign and speech. Her special-education teachers talked about reducing her services to consultation because she was doing so well with her implant and signing. She was reaching her potential academically, as she was preparing for middle school and adapting socially to the United States. Nevertheless, her parents believed that their place was in Kenya helping the people of Kenya.

In Joy's first year at the Rover Elementary, her parents came in and shared Kenyan music and culture with the school during a cultural event, but Joy does not speak Swahili or demonstrate any specific cultural characteristics at home. Her parents speak their indigenous languages, plus Swahili and English, fluently. Joy remembers a few words of Swahili, but Emma speaks only English and does not remember much about Kenya. Laura does not know if Joy wants to go back to Kenya. Both Joy and Emma went back to Kenya for one semester after Joy's surgery before returning to the United States. During that time, they attended school and loved to be with the other children. Laura said,

When I talk about Africa, she has a negative image, especially when she sees a World Vision advertisement of something seeking funds.... There was a time I was watching CNN about HIV, and it looked so bad. She said, "I don't want to go back there." ... She can't remember the good side as much and worries about losing her friends.

Laura hopes that Joy could readjust and make friends if she returns to Kenya after a short time.

Work in Africa versus Joy's well-being

Robert and Laura have many worries about whether to return to Kenya or stay in the United States. Both are working on their advanced degrees. Laura works with issues related to HIV/AIDS, and Robert works in higher education and public health. Both are involved with nonprofit organizations that serve children in Kenya. From the outset, they stated, "Initially, we planned to go back to Kenya, but because of Joy we may need to stay in the US for her services." They are dedicated to both their work and their daughters. They want to go back and serve their country, but they also want what is best for their daughter. They worry about the services available in Kenya. During recent short trips related to their research, they did not find good educational options, and now they worry that doctors in Kenya would not be able to treat Joy if she had a head injury that affected the cochlear implant. Laura said,

There are a few deaf schools, but they don't have sufficient resources, so they are

overcrowded, 'cause there are very few. So all the deaf kids, everybody tries to get them there, and then, those who have impairments and can use hearing aids—we have a few of those, but I rarely see them.

Based on documents provided from their research on deaf education in Kenya and personal experiences, her parents did not believe that she could not reach her potential and receive adequate services for her hearing loss at home.

Robert was also concerned:

We have schools for the deaf, but they are not very good environments, not good facilities. In regular schools, there are not kids with hearing aids. The deaf schools are few and scattered around the country and are for kids who are totally deaf.

Both parents feel they have commitments in the United States because of the funding they received for their degrees. Robert said their plans were not concrete, but he wanted to work at a university, probably in the United States. Laura's dilemma is obvious in her words,

I don't want to put my career before her or look back and say that's what I did, 'cause I definitely want to go and work in Africa, irrespective of whether I go and work there for the rest of my life or not. Right now, I know I want to go and work there, but Joy can't benefit from the medical system: nobody will know what to do with her condition.

It is natural for parents to be concerned about the health, education, and well-being of their daughter. Additionally, Laura and Robert worry about the stigma Joy may face from being deaf and having a device visibly implanted in her head. Laura talked a little bit about that stigma:

Impaired kids won't go to a regular school; they go to special school. Even kids who have other disabilities, like limbs, they go to a special school. I think that probably society feels like it is a way to protect the kids from sticking out like a sore finger and to [have] special facilities and special teachers.

It is natural to want to help people using one's skills, particularly people seen to be in need. Since both parents will soon have advanced degrees, they feel an obligation to stay in the United States to give back for their funding opportunities and help in their local communities. Laura contemplated,

It is interesting that you came and we talk about

something that I have been thinking about: my career and going back. You asked the same question. It is difficult. I definitely want to work in Africa, because I am working on HIV/AIDS and women and children, and I need to be there more than on this side.... I will definitely work there first; I feel a social obligation to work there for at least 24 months. After that, I am hoping I can get a job that keeps me on the continent of Africa longer than in a Western country, but any country where I can get an applied job to work on HIV/AIDS issues would really be of interest to me. That way, she gets that care. I can go to Kenya with her and she is fine; all I really need is a big bag of batteries. [For] the mapping, she will at least have to come [to the United States] annually.

During the study, Laura wavered as to what she should do and what would be best for Joy and Emma. She is going to wait to see what opportunities arise as she finishes her degree.

CONCLUSIONS

The findings in this study illuminate the need to reexamine current cultural beliefs about disabilities and how those beliefs affect family decisions regarding children with disabilities. Different belief systems and modes of acculturation can shape their experiences with the special-education system (Harry, 2008). Joy's family built social and navigational capital to maneuver the educational system to best support Joy—something that can be difficult for immigrant families—and now they want to stay in the United States to help Joy take advantage of the family's social and navigational capital (Vesely et al., 2013). In addition, Joy's family is a unique case because her parents are educated and they came to the United States with a strong knowledge of English. Research has shown that Asian and African immigrant families are more likely to be successful in the United States than other immigrant groups because African immigrants are more educated when they arrive, like Joy's family (Crosnoe and Turley, 2011). Nevertheless, this family still represents the strong commitment to education seen in immigrants from Africa and the desire to improve the lives of future generations typical in all immigrants (Conger et al., 2007).

This exploratory case study lays a foundation for future research on the experiences of African immigrants with children with disabilities. As mentioned in the section on methodology, this is a pilot study with limitations for generalizability, but the messages from this family are important. More research needs to be conducted with other families in different locations and across disability categories. In this case, specific cultural beliefs about

disability were expressed, but did not affect the family's participation in special-education services. The parents were satisfied with the services provided to them and their child. In fact, they were so satisfied that the quality of services may now be influencing their decisions, namely deciding whether to return to Kenya (as originally planned) after their studies or to stay in the United States to provide their daughter with continued educational support for her hearing impairment and medical services for her cochlear implant.

For this family, having Joy in a community with children from similar racial and socioeconomic backgrounds, as well as children with her disability, is highly important, as it gives Joy a sense of belonging and the parents feel they are providing her the best life possible, along with necessary treatment, healthcare, and education. Though Laura and Robert were well educated, they were still a low-income family, and they wanted Joy to be around children and families who shared their values (Vesely et al., 2013). Her well-being was their motivation for coming to the United States, staying in the United States, and making decisions about her care. It is important to understand why they came, how that affects their decisions to find educational and medical services, and how they feel about them. Laura and Robert are pleased that Joy is a well-adjusted student who is learning and using her hearing and sign language in school and in her social circles. Joy, in turn, wants and needs to be accepted in a community that understands her cochlear implant, her status as an African, and her status as a child living at a low to moderate socioeconomic level. She enjoys her status as a student with a cochlear implant and who uses sign language because she has found a peer group. To succeed, immigrant children in special education need to receive services to support their special needs, but also to find social support in the classroom and the community. For this family, it was critical that Joy had a peer group similar to herself and the school recognized the parents' commitment to her education and success, regardless of her disability. To learn this information and other important perspectives of parents of children with disabilities from other countries, educators and early interventionists can use eco-mapping and routine-based interviews for younger children (McWilliam, 2010) and person-centered planning for elementary and secondary students (Holburn and Vietze, 2002).

All immigrant parents should have the opportunity to find the best life possible for their children and have such positive experiences in the educational system. In this case, the family developed relationships in the special-education system and the school and collaborated with educators to support their child. Immigrant families do not always succeed at this, and additional information on the special-education system is needed to build these collaborative relationships (Fujiura et al., 2005; Lo, 2009; Park et al., 2001; Tellier-Robinson, 2000). Joy's story

illustrates the difficult choices that parents make to provide the best life they can for their children. Immigrant parents with children with disabilities have difficult decisions to make every day about their children's health and education, in addition to worrying about sending remittances and fulfilling responsibilities in their native countries. Joy's family knew that the education and medical services available to her in her home country and other African countries were insufficient compared with those in the United States (Muderedzi and Ingstad, 2011). By choosing to stay in the United States, they are choosing to take advantage of the services available to help Joy reach her potential as promised in the UN Convention on the Rights of the Child, but had to defer or forgo their work in their home country and are part of the brain drain. In this case, Joy will not just receive an adequate education under the Individuals with Education Improvement Act, but will have the opportunity to succeed because she has learned to use total communication to be a successful student because of the special education and medical services she has received.

Limitations and future research

The main limitation of this study is that it is one family and their experiences. This family's unique characteristics give us the phenomenological understanding of their lived experience and how that impacts their decision making. Nevertheless, the findings of this study lead to additional research questions for the future. For example, students can receive educational services not possible in their country because of their disability, but how do they fit into the schools socially, socioeconomically, and academically? Will all students be as successful as Joy, and what key factors made her so successful? The public schools and the special education system will be challenged to think outside the box to meet the needs of an increasingly diverse population. More research needs to be conducted on the perceptions for African immigrants about their children's education and disability and how to meet the needs of immigrants in the US public schools, the special education system, and the early intervention system.

REFERENCES

- Alidou, H. (2000).** Preparing teachers for the education of new immigrant students from Africa. *Action in Teacher Education*, 22: 101-108.
- Bogdan, R., and Taylor, S. J. (1975).** Introduction to qualitative research methods. New York: Wiley.
- Bronfenbrenner, U. (1992).** Ecological systems theory. In R. Vasta (Ed.), *Six theories of child development: Revised formulations and current issues* (pp. 187-249). London: Jessica Kingsley.
- Bronfenbrenner, U., and Morris, P. A. (1998).** The ecology of developmental processes. In R. M. Lerner (Ed.), *Handbook of child psychology* (5th ed., Vol. Volume 1, pp. 993-1028). New York: Wiley.
- Butera, G. (2005).** Collaboration in the context of Appalachia: The case of Cassie. *The Journal of Special Education*, 39: 106-116.
- Capps, R., Fix, M., Passel, J. S., Ost, J., Herwanto, S., and Murray, J. (2005).** The new demography of America's schools: Immigration and the No Child Left Behind Act. Washington, DC: The Urban Institute.
- Charmaz, K. (2005).** Grounded theory in the 21st century: Applications for advancing social justice studies. In N. K. Denzin & Y. S. Lincoln (Eds.), *The Sage handbook of qualitative research* (3rd ed., pp. xix, 1210). Thousand Oaks, CA: Sage Publications.
- Charmaz, K. (2006).** Constructing grounded theory: a practical guide through qualitative analysis. Thousand Oaks, CA: Sage Publications.
- Chu, S.-Y. (2008).** Implementation of supportive school programs for immigrant students in the United States. *Preventing School Failure*, 53: 67-72.
- Conger, D., Schwartz, A. E., and Stiefel, L. (2007).** Immigrant and native-born differences in school stability and special education: Evidence from New York City. *International Migration Review*, 41: 403-432.
- Ford, D. Y. (2012).** Culturally different students in special education: Looking backward to move forward. *Exceptional Children*, 78(4): 391-405.
- Fujitara, G. T., Park, H. J., and Rutkowski-Kmitta, V. (2005).** Disability statistics in the developing world: A reflection on the meanings in our numbers. *Journal of Applied Research in Intellectual Disabilities*, 18, 295-304.
- Harknett, S. G. (1996).** Cultural factors in the definition of disability: A community study in Nyankunde, Zaire. *African Journal of Special Needs Education*, 1: 18-24.
- Harry, B. (2002).** Trends and issues in serving culturally diverse families of children with disabilities. *Journal of Special Education*, 36(3): 131-138,147.
- Harry, B. (2008).** Collaboration With culturally and linguistically diverse families: Ideal versus real. *Exceptional Children*, 74: 372-388.
- Hartley, S., Ojwang, P., Baguwemu, A., Ddamulira, M., and Chavuta, A. (2005).** How do carers of disabled children cope?: The Ugandan perspective. *Child: Care, Health and Development*, 31: 167-180.
- Holburn, S., and Vietze, P. (2002).** Person-centered planning: Research, practice, and future directions. Baltimore, MD: Brookes Publishing.
- Hurley, J. J., Warren, R. A., Habalow, R. D., Weber, L. E., and Tousignant, S. R. (2013).** Early childhood special education in a refugee resettlement community: challenges and innovative practices. *Early Child Development and Care*, 184(1): 50-62.
- Ihenacho, I. J. (1985).** Introduction to special education in Nigeria: historical and sociological perspectives. Plateau State, Nigeria: 3 Division Printing Press Limited.
- Ingstad, B. (1995).** Mpho ya modimo-A gift from God: Perspectives on "Attitudes" toward disabled persons. In B. Ingstad & S. R. Whyte (Eds.), *Disability and culture*. Berkley, CA: University of California Press.
- Kenyan Ministry of Education Science and Technology (2004).** Development of education in Kenya. Nairobi.
- Kisanji, J. (1995).** Attitudes and beliefs about disability in Tanzania. In B. O' Toole & R. McConkey (Eds.), *Innovations in developing countries for people with disabilities* (pp. 51-70). Chorley, England: Lisieux Hall Publications.
- Kiyaga, N. B., and Moores, D. F. (2003).** Deafness in Sub-Saharan Africa. *American Annals of the Deaf*, 148: 18-24.
- Lo, L. (2009).** Collaborating with Chinese families of children with hearing impairments. *Communication Disorders Quarterly*, 30: 97-102.
- Mallory, B. L. (1993).** Changing beliefs about disability in developing countries: Historical factors and sociocultural variables. In D. E. Woods (Ed.), *Traditional and changing views of disability in developing societies: Causes, consequences, cautions*. Monograph #53. New York: World Rehabilitation Fund, Inc.
- Master, R. S. (1995).** The saga of the developmental disabled through the eons. *Indiana Journal of Psychiatry*, 37: 59-69.
- McMillan, J. H., and Schumacher, S. (2001).** Research in education: A conceptual introduction (5th ed.). New York: Longman.
- McWilliam, R. A. (2010).** Routines-based early intervention: Supporting young children and their families. Baltimore, MD: Brookes Publishing.
- Miles, M. (2002).** Children with hydrocephalus and spina bifida in East Africa: Can family and community resources improve the odds?

- Disability & Society, 17(6): 643-658.
- Muderedzi, J., and Ingstad, B. (2011).** Disability and social suffering in Zimbabwe. In A. H. Eide & B. Ingstad (Eds.), *Disability and Poverty: A Global Challenge*. Bristol, UK: Policy Press.
- Nyang'aya, D. (1998).** Addressing special populations. *Africa Link*, 20-23.
- Ogechi, N. O., and Ruto, S. J. (2002).** Portrayal of disability through personal names and proverbs in Kenya: Evidence from Ekegusii and Nandi. *Vienna Journal of African Studies*, 3: 63-82.
- Park, J., Turnbull, A. P., & Park, H. S. (2001).** Quality of partnerships in service provision for Korean American parents of children with disabilities: A qualitative inquiry. *Journal of the Association for Persons with Severe Handicaps*, 26: 158-170.
- Raijmakers, M. (2005).** Impaired millennium development goals? Retrieved from <http://www.dcd.nl/?2810>.
- Rong, X. L., and Brown, F. (2001).** The effects of immigrant generation and ethnicity on educational attainment among young African and Caribbean blacks in the United States. *Harvard Educational Review*, 71(3): 536-565.
- Seligman, M., and Darling, R. B. (2007).** *Ordinary families, special children: A systems approach to childhood disability* (3rd ed.). New York, NY: The Guilford Press.
- Sonntag, J. C., and Schacht, R. (1994).** An ethnic comparison of parent participation and information needs in early intervention. *Exceptional Children*, 60(5): 422-433.
- Talle, A. (1995).** A Child is a child: Disability and equality among the Kenya Maasai. In B. Ingstad & S. R. Whyte (Eds.), *Disability and culture*. Berkley, CA: University of California Press.
- Tellier-Robinson, D. (2000).** Involvement of Portuguese-speaking parents in the education of their special-needs children. *Bilingual Research Journal*, 24: 225-239.
- Vesely, C. K., Ewaida, M., and Kearney, K. B. (2013).** Capitalizing on early childhood education: Low- income immigrant mothers' use of early childhood education to build human, social, and navigational capital. *Early Education and Development*, 24: 744-765.
- Zeng, F. G. (1996).** Cochlear implants in developing countries. *Contact*, 10(4): 5-9.

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