

# To raise a child with autism spectrum disorder: A qualitative, comparative study of parental experiences in the United States and Senegal

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Adair Cardon<sup>1,2</sup> and Tara Marshall<sup>3,4</sup>

## Abstract

Raising a child with Autism Spectrum Disorder (ASD) can often be a difficult and stressful process for families and caregivers. Though research on ASDs in Africa is burgeoning, very little is known about autism in francophone West Africa. Furthermore, no known ASD studies have explored parental experiences in particular from a cross-cultural perspective. This research used Interpretative Phenomenological Analysis to analyze in-depth, semi-structured interviews with seven Senegalese and seven American families to investigate parental experiences within the Senegalese community with further illustration by cross-cultural comparison. Comparative analysis of data across the two countries was undertaken to identify cultural variables previously unreported, especially those that may affect Senegalese family experience. Analysis of interviews revealed thematic differences in social and community support. Although access to effective treatment services was low among Senegalese families compared to the American families, traditional Senegalese household structures and community relations were hypothesized to serve as protective factors against the high social isolation and resulting logistical struggles reported in the U.S. sample. Further targeted research within the Senegalese environment is recommended, particularly to explore social stigma and its possible effects on families with autism, causal beliefs and treatment practices, and parental mental health and wellbeing.

## Keywords

autism spectrum disorder, culture, lived experiences, parental experiences, qualitative methods, West Africa

## Introduction

The prevalence of autism spectrum disorder (ASD) has been rising in many countries according to the World Health Organization (WHO, 2017) and it has been recognized as a significant concern for global mental health (WHO, 2013). Most research on ASD, however, has been conducted in high-income regions such as North America, with a dearth of research within low- and middle-income regions, notably Sub-Saharan Africa (Elsabbagh et al., 2012; Hahler & Elsabbagh, 2015; Khan et al., 2012). Additionally, comparatively little research on ASD has been conducted that examines the influences of culture and societal context. Within Africa, in particular, little is known about autism, as many countries are not yet represented in the literature and there is an urgent need for education, awareness, and services (Abubakar, Ssewanyana, de Vries, & Newton, 2016; Franz, Chambers, von Isenburg, & de Vries, 2017).

Cultural background and other contextual factors heavily influence the help-seeking behaviors and treatment decisions of families of children with autism, as well as the nature of help they receive (Ennis-Cole, Durodoye, & Larris, 2013; Mandell & Novak, 2005). Within clinical and research practice, cultural research on ASD can describe family structures and sources of

<sup>1</sup>Division of Psychology, Brunel University London, Uxbridge, UK

<sup>2</sup>University of California, Santa Barbara, USA

<sup>3</sup>Department of Health, Aging & Society, McMaster University, Hamilton, ON, Canada

<sup>4</sup>Centre for Culture and Evolution, Brunel University London, Uxbridge, UK

### Corresponding author:

Adair Cardon, Brunel University, College of Life Sciences, Division of Psychology, Uxbridge, UB8 3PH, UK.

Email: adair.cardon@gmail.com

support, as well as the probability of specific etiological views, religious beliefs, and other perspectives that may affect elements such as stigma, interpretation of abnormal behaviors, and referral decisions (Bernier & Gerdts, 2010). Cultural knowledge can shed light on a family's adaptation to their child's diagnosis and their appraisal of treatment recommendations, yielding culturally sensitive clinical practice (Bernier, Mao, & Yen, 2010; Ennis-Cole et al., 2013). Additionally, cultural and local context can illuminate regional variations in prevalence rates, demographic data, and differences in the reported clinical presentation of ASD. Cultural and contextual factors include, for instance, differences in mental health training, medical record-keeping, household factors affecting referral, and cultural definitions of concerning behavior (Bakare, 2011; Bernier et al., 2010; Fombonne, 2005; Kopetz & Lee, 2012).

The cultures of Sub-Saharan Africa differ greatly from Western cultures. These differences, along with other contextual factors such as economic and health infrastructure variables, may contribute to reported variations in parental experiences of raising a child with autism. This study aimed to compare themes related to parental caregiving for children with autism between a Sub-Saharan African culture (Senegal) and a Western culture (the United States) using qualitative group comparison alongside interpretative phenomenological analysis to (1) develop hypotheses towards the role of environmental and/or cultural variables affecting the experiences of parents of children with ASD and (2) illuminate the specificities of the Senegalese environment.

### *The caregiver experience*

The caregiver experience within families raising children with autism has been well documented in high-income areas around the world (Corcoran, Berry, & Hill, 2015; DePape & Lindsay, 2014; Ooi, Ong, Jacob, & Khan, 2016), but has been less studied in low- and middle-income countries. Caregiver studies in these regions can be particularly beneficial in areas lacking other types of ASD research, as their insights can reveal (1) a variety of elements within the family and community environment that may affect ASD detection and care (DuBay, Watson, & Zhang, 2017; Liao, Dillenburger, & Buchanan, 2017), (2) unmet family needs (Gomes, Lima, Bueno, Araújo, & Souza, 2015; Sitimin, Fikry, Ismail, & Hussein, 2017; Tilahun et al., 2016), (3) underlying elements such as cultural, lingual, and religious factors (Hampton, Rabagliati, Sorace, & Fletcher-Watson, 2017; Jegatheesan, Miller, & Fowler, 2010; Kheir et al., 2012), (4) local knowledge and awareness of ASD

(Heys et al., 2016; Wetherston et al., 2017), and (5) accessibility of resources and services (Daniels et al., 2017; Minhas et al., 2015; Zeleke, Hughes, & Chitiyo, 2018). Adjustment information, such as emotional states and socio-relational changes, may speak to local needs for mental health education as well as emotional and social support for families (Hobart, 2008; Koydemir & Tosun, 2010; Rayan & Ahmad, 2018). Research on caregivers of children with ASD report increased financial and emotional strain, increased stress levels, and an increased likelihood of mental health problems compared to caregivers of typically-developing children, as well as a lower sense of parental competency (Abbeduto et al., 2004; Bromley, Hare, Davidson, & Emerson, 2004; Estes et al., 2009; Khanna et al., 2011; Kuhlthau, Hill, Yucel, & Perrin, 2005; Olsson & Hwang, 2001).

Among the literature on the experiences of caregivers in Sub-Saharan Africa, 10 of the 17 total peer-reviewed studies have been conducted in the nation of South Africa, to date representing the second-highest GDP on the continent (The World Bank, 2016). Of the remaining articles, Kenya, Tanzania, Ethiopia, Nigeria, Ghana, and Zimbabwe are represented. Table 1 lists all known peer-reviewed studies of the parental experience in raising a child with autism in Sub-Saharan Africa. All studies, except four, used qualitative methods. Recurring themes among these studies include (1) parent emotional distress, (2) a lack of satisfactory family and treatment services, (3) difficulties in care and behavior management, (4) struggling with stigma and shame, (5) social and

**Table 1.** List of all caregiver experience studies within Sub-Saharan Africa

Country	Authors (Year)
Ethiopia	Tilahun et al. (2016)
Ethiopia	Zeleke, Hughes, & Chitiyo (2017)
Ghana	Thomas, Badoe, & Owusu (2015)
Kenya	Gona, Mung'ala, Newton, & Hartley (2011)
Nigeria	Olagunju et al. (2017)
Tanzania	Ambikile & Outwater (2012)
Zimbabwe	Majoko (2017)
South Africa	Alli, Abdoola, & Mupawose (2015)
South Africa	Du Toit & Kok (1999)
South Africa	Fewster & Gurayah (2015)
South Africa	Greeff & van der Walt (2010)
South Africa	Guler, de Vries, Seris, Shabalala, & Franz (2017)
South Africa	Kapp & Brown (2011)
South Africa	Meiring, Seabi, & Amod (2016)
South Africa	Mitchell & Holdt (2014)
South Africa	Olivier & Ah Hing (2009)
South Africa	Schlebusch, Samuels, & Dada (2016)

relational issues with family and community members, and (6) a lack of awareness of autism in professionals (see Table 1).

Among international caregiver perspective studies, which includes American samples, a meta-analysis of qualitative research by DePape and Lindsay (2014) found recurring themes to include (1) specific expectations surrounding developmental milestones, (2) emotional distress, (3) finding solutions, (4) personal growth, (5) family activities and participation, (6) occupying and pacifying the child, and (7) frustrations that life revolves around the child and at being “robbed” of normal family life. A meta-analysis of studies on lived experiences of parents of children with autism in the United States identified six recurring themes: (1) emotional stress and strain, (2) adaptation, (3) impact on the family, (4) talk of services, (5) stigmatization, and (6) “appreciating the little things” (Corcoran et al., 2015).

## Methods

This study employed the interview-based Interpretative Phenomenological Analysis (IPA) method (J. A. Smith, Flowers, & Larkin, 2009) to gain an increased understanding of parents’ experiences raising children with ASD in the United States and Senegal. Within IPA, eidetic reduction (i.e., distilling the essential components of a given phenomenon) is achieved via extensive review and thematic analysis of interview content. Unlike other qualitative analysis methods, such as thematic or content analysis that seek to identify patterns across individuals, IPA focuses on understanding the unique perspective of each participant, in particular their own personal perception and interpretation of the experience in question. Thematic comparison across subjects and culture groups within this study only began once an in-depth understanding of the individual’s lived experience was reached.

## Setting

**Senegal.** This research was carried out in the Senegalese capital of Dakar. The West African nation of Senegal is a predominantly Muslim country, historically colonized by France. Since its independence in 1960, Senegal remains one of the most stable democracies in Africa. Though Senegal has preserved the French healthcare structures, general mental health services are limited. According to a report from Monteiro, Ndiaye, Blanas, and Ba (2014), mental health concerns include a severe lack of (1) mental health training and resources, (2) funding, and (3) planning for integration and access. According to past research, mental illness beliefs in Senegal often centered around the

preternatural such as spiritual or genie possession. A report by Zempleni and Rabain (1965) described the autistic-like culture-bound syndromes of *nit ku bon* among the Wolof and *tji pa xeer* among the Serer. Patients and their families consulted local marabouts, religious leaders, and traditional healers in the community, visiting Western medical facilities as a “last resort” (Ames, 1959; Collomb, 1975; Collomb, Beiser, Burr, & Ravel, 1973; Martino & N’Diaye, 1969; Zempleni, 1968). Similar consultation priorities continue today (Monteiro et al., 2014). Marabout diagnostics and treatment often comprise of a blend of Islamic and traditional African practices (Monteiro et al., 2014). Today, psychiatric services are still heavily separated from the traditional care model, despite best efforts from the World Health Organization and local governmental entities to “ally” the two systems (Diagne, 2016; Fassin & Fassin, 1988). Although some families choose to pursue treatment from both systems simultaneously, traditional treatments are usually seen as more socially acceptable, in line with local religious beliefs, and economically viable (Diagne, 2016). Notwithstanding that a number of special education schools exist in Senegal, specialized therapies and services are very rare. A single paper on pervasive developmental disabilities has been published from Senegal, authored by Fall, Sylla, Ndongo, and Thiam (2014), detailing cultural variables as they pertain to the care of persons with autism. In Senegal, evidence-based diagnostic tools are not known to be used in the three currently existing diagnostic centers, though Diagne (2016) reports that this is gradually changing.

**The United States.** The majority of global ASD research has been conducted in the United States. According to the U.S. Centers for Disease Control and Prevention (CDC), the prevalence rate for ASD in the United States is 1 in 68 and increasing. ASD is 4.5 times more frequent among boys than girls and has been reported to occur in all racial, ethnic, and socioeconomic groups within the country (CDC, 2016). The US currently has the world’s highest density of experienced, specially trained diagnostic professionals, intervention professionals, and specialized organizations for autism. Among the many centers in the country, 11 are recognized as Autism Centers of Excellence (National Institutes of Health, 2016). However, most likely due to the rise in diagnoses, current demand for services in the US remains higher than what is available.

## Participants

Participants included 14 caregivers of children with autism (7 in Senegal and 7 in the US) who took part in interviews (Table 2). As is recommended for IPA

**Table 2.** Participant demographics.

Participants	Caregiver role	Caregiver employment status	Household structure	Number of children with ASD in household	Gender of child(ren) with ASD	Ages of child(ren) with ASD <sup>a</sup>
USA						
B.	mother	unemployed	non-nuclear	1	Male	6
E.	mother	unemployed	nuclear	1	Male	4
H.	mother	unemployed	nuclear	3	male, female	21, 10, 8
K.	mother	unemployed	nuclear <sup>b</sup>	1	Male	3
L.	mother	employed (part-time)	nuclear <sup>b</sup>	2	male, male	21, 17
M.	mother	employed (full-time)	nuclear	2	Male	7
R.	mother	employed (part-time)	nuclear <sup>b</sup>	1	Male	17
Senegal						
A.	sister	unemployed	non-nuclear	1	Male	9
F.N.	mother	unemployed	non-nuclear	1	Male	9
F.S.	mother	unemployed	non-nuclear	1	Female	4
M.Y.	grandmother	unemployed	non-nuclear	2	male, female	7, 12
M.D.	father	employed (part-time)	non-nuclear	1	Female	23
O.	mother	employed (full-time)	Nuclear	1	Male	12
S.	father	employed	non-nuclear	1	Female	15

<sup>a</sup>Ages are approximated within the Senegalese group. <sup>b</sup>Denoting a nuclear household plus at least one grandparent.

studies, recruitment was continuous, with data analysis conducted immediately after data was collected for each participant. Sample size was determined by data saturation with a goal of at least six participants per group (Mertens, 2015). Per inclusion criteria, all participants were primary caregivers of children or young adults with autism within their families and were native-born residents of their home country. Thirteen primary caregivers were parents or stepparents, and one was a maternal grandparent of the child.

Among the Senegalese group, all participants lived in the Dakar region and represented a broad range of socioeconomic categories. All children except one were diagnosed at Fann Hospital in Dakar. Specific diagnosis information, such as dates, were not available, as reports were never given, and families were often uncertain of exact dates and occasionally the child's own age. Six of the seven children were currently receiving no care. The primary symptom of concern for the Senegalese group was crying, seconded by language delay, which mirrors past findings from Nigeria (Bakare, 2011) and Ghana (Thomas, Badoe, & Owusu, 2015). Six of the seven families lived in large, extended family homes where childcare from the family was common. The seventh lived in a nuclear household and hired a full-time nanny. All participants were purposively sampled via support groups for parents of children with autism. Natural snowballing within the Senegalese group resulted in recruitment from the Network for the Protection of Vulnerable Children in the area of Pikine in Dakar.

Among the U.S. group, participants were recruited from all major regions of the US and represented a broad range of socioeconomic categories. All participants were mothers of the affected child. Diagnoses were obtained from a variety of professionals and settings. All children were enrolled in special education or educational supports as well as specialized or other therapies. The Americans cited sensory sensitivity and restrictive/repetitive behaviors as their primary behavioral concerns. American mothers also reported higher language levels than the Senegalese (subjective reporting only). Four of the seven mothers lived in nuclear family households consisting of a mother, a father, and their children.

### Data collection

Interviews with American participants were conducted over the phone with an average length of 60 minutes. Senegalese interviews were face-to-face, conducted in French with the support of a Wolof–French interpreter (except one which was conducted in English) and at the participants' place of residence or work. Due to some challenges in securing a private place to conduct interviews, Senegalese interviews were shorter and averaged 30 minutes in length.

All interviews were conducted between July and September 2017. Interview techniques followed guidelines for narrative interviews set by Kvale and Brinkman (2009). Interviews were based on a 27-question guide that was followed flexibly. All interviews



started with the open-ended question, “When did you first notice that your child was different from other children?” Participants were asked about their experiences before, during, and after diagnoses, as well as what kinds of support they received and from what sources. Participants were also asked about their child’s characteristics, treatment, and routines. For cultural sensitivity reasons within the Senegalese group, topics such as employment, money matters, internal emotional states, and some social relations were not initiated by the interviewer. Interviews were recorded and were transcribed verbatim and analyzed within 48 hours. Live translation of Wolof into French was done on-site by native speakers. Translation from French into English for ease of data analysis was done by fluent speakers after transcription.

### Data analysis

Interpretive Phenomenological Analysis (IPA) was used to analyze the interview data (Pietkiewicz & Smith, 2012). An idiographic approach was taken within this analysis, beginning with the analysis of individual transcripts, then comparing transcripts with all others in the group, and finally comparing analysis across groups (J. A. Smith & Osborn, 2008). This process involved the following steps: (1) the original transcript was read with no analysis. Demographic data was checked and entered at this stage; (2) the transcript was read a second time, and statements relevant to the research questions were marked and annotated. Annotations paraphrased the data, noted inconsistencies or points of interest, and began a preliminary attempt at summarization; (3) the transcript was then uploaded into NVivo 10 qualitative analysis software (QSR International, 2012) and read a third time, referencing the annotated version, to begin identifying emerging patterns in the discourse. Tentative labels were created and relationships between labels identified to develop theme and subtheme hierarchies (J. A. Smith & Osborn, 2008). After the first interview for each group was analyzed, a decontextualized master codebook was created. Through an iterative process, themes and subthemes for all following interviews were created, revised, and finalized with the input of this codebook, while still allowing for new themes be added. Refinement of the master list by reclustering, renaming, and adding new themes and subthemes occurred as analysis of each transcript progressed, checking back to the original transcripts to gauge for accurate representation of the data. Each participant’s theme report was then read separately, including all relevant quotes from the text. A list of common themes was produced separately for each country

group. Themes that were not reported by the majority of the participants within their country group (4 out of 7 participants) were not included, except for noting some trends (defined as 3 out of 7 participants). Simple thematic comparison between country groups was then conducted to generate cultural and contextual hypotheses surrounding the phenomenon of raising a child with autism.

### Findings

Our analysis identified 10 themes in four interview categories: (1) diagnostics and care: *the diagnostic journey* and *securing services*; (2) daily life: *daily experiences* and *emotional needs*; (3) social relationships: *social isolation*, *spousal tension*, *social tension*, and *sources of social support*; and (4) introspection: *role as a caregiver*, and *visions of the future*. Each theme contained at least two subthemes. Not all themes were present for both country groups. Table 3 illustrates each theme and corresponding subthemes and their presence or absence in the two country groups.

#### Diagnostics and care: The diagnostic journey

Before securing a diagnosis, several American parents received at least one instance of professional reassurance that their child was developing normally (coded as *failure to “catch” the autism*). One American mother of a teenager described the lack of awareness of autism at the time of his diagnosis:

This was back in 1996 or so. The doctors said “Oh, he’s just a late bloomer.” They really hadn’t heard too much at that time.

Three Senegalese parents consulted *traditional or spiritual treatment* before taking a medical route to seek help. Local spiritual leaders claimed spiritual possession as the cause of the disorder, and treatments included both spiritual and non-spiritual methods. All three reported eventually leaving spiritual council. One mother recounted:

They said it was from bad spirits . . . I was everywhere, I went everywhere in Senegal to see the marabouts. But with time, I decided to return to the hospital, because if you speak to the marabouts, they’re going to say that the child will never heal. . . . Finally, I understood that it was not a spirit.

The majority of American parents (4 out of 7) reported *positive emotional reactions* to the diagnosis of autism for their child, including relief at having an answer,

**Table 3.** Presence or absence of themes and their corresponding subthemes by country.

Themes	Subthemes	USA	Senegal
Diagnostics and care			
Diagnostic journey <sup>a</sup>	failure to “catch the autism”	X	absent
	traditional/spiritual treatment	absent	X
	caregiver emotional reaction	X	absent
Securing services <sup>a</sup>	navigating the system	X	absent
	asserting control	X	absent
	insensitivity of professionals	X	absent
Daily life			
Daily experiences <sup>a</sup>	routines and activities <sup>a</sup>	X	X
	parents’ emotional needs	X	absent
Social relationships			
Social isolation	absence of “comparison children”	X	absent
	lack of a “social life”	X	absent
Spousal tension	spouse’s negative reaction to the diagnosis	X	X <sup>b</sup>
	spouse’s resistance to child treatment	absent	X <sup>b</sup>
Social tension <sup>b</sup>	negative social interactions	X	absent
	encountering ignorance	X	absent
Sources of social support <sup>b</sup>	family	X	X
	friends	X	X
	Community	X	X
Introspection			
Role as a caregiver	as provider of services	X	absent
	as advocate (for services/in public)	X	absent
	as caretaker	X	X <sup>b</sup>
	as teacher	X <sup>b</sup>	X <sup>b</sup>
Visions of the future <sup>a</sup>	visions of success	X	absent
	where will the child live?	X	absent

Note. Presence of a theme is defined as occurring in 4 out of 7 group participants or more.

<sup>a</sup>Topic prompted by interviewer. <sup>b</sup>Trend (defined as 3 out of 7 participants within a group).

curiosity, and motivation at the thought of moving forward. As one mother stated:

... And now we had a reason why he had a total tantrum and smashed his head on the floor when we went out in public... It was easier to be like, “Okay, now we know. We have a direction now.”

Negative emotions, such as sadness, distress, and denial, were also reported. Mentions of emotional reactions were generally not initiated by the Senegalese excepting two who mentioned negative emotions (“It hurts... It hurts.”).

### *Diagnostics and care: Securing services*

The overall theme describing the process of securing services was absent among the Senegalese, possibly due to limited local service availability. Among the Americans, the subtheme of *navigating the system* of care was present, which included finding and securing services, navigating insurance coverage and waitlists, and finding childcare. Five American mothers were

without childcare aside from the other parent. One mother described:

Getting daycare is impossible... The one common factor I’ve noticed with a lot of these autism parents is just the lack of being able to financially support your family. It’s difficult when you have to have someone at home all the time. Like, I don’t have \$30–\$40 an hour for someone to babysit my kids because they’re autistic.

The theme of *asserting control* over the quality and quantity of care their child received was present in 6 out of 7 American mothers. This came in the form of overriding professional recommendations in their child’s best interests, combating resistance from other household members, advising care professionals on curricula, or dismissing services deemed unsatisfactory. As one mother advised:

Listen to your gut. Listen to your kids. You are their mother... I live with my kids every day. They don’t.

Four American mothers shared narratives describing *insensitivity among care professionals*. Parents reported

neglectful care, parent blame, “feeling brushed off,” or that they were not being listened to.

### *Daily life: The parents’ daily experience*

Daily routines for American mothers often centered around the child(ren) and their services, including frequent one-on-one interaction and densely scheduled activities. Questions regarding routines were often answered in tandem for both mother and child. This mother describes a “day off” with her child:

His bedtime is 7 o’clock, he falls asleep between 8:30 and 9:00, and then wake up usually between 7:00 and 7:30. . . . Sometimes [we have] a play date at a friend’s house, sometimes it’s at a library. We’ve had some classes through the school system. . . . [My son] loves to bake, so we usually do something like that.

For the Senegalese, routines often centered around caring for the home and preparing meals for the larger family. Childcare was done collectively by all family members, so the parent was often free to leave the home when needed. The following exchange illustrates this looser style:

Interviewer: Okay. And her day, what does she usually do during the day?

Translator: She says that she [her daughter] is very active. She doesn’t even know all of her activities during the day.

Among working parents of both countries, their days tended to be busy managing their multiple obligations. Some mothers of both groups reported guilt at their “absence” in their children’s lives.

Among the Americans, 4 out of 7 mothers spontaneously made mention of their own emotional needs, including social support and stress-free alone time:

I can’t watch anything that’s gonna stress me out at all. Nothing. . . . I have enough stress in my life.

### *Social relationships: Social isolation*

This overall theme did not occur within the Senegalese group where households comprised extended family groups, as is the custom within collectivistic Senegalese society. *Lack of a social life* was reported in 5 out of 7 of the U.S. group, who attributed this experience to not being able to leave home without the child, where they often lived alone with their spouses, citing (1) frequently needing to be home to

do childcare and (2) the aversive, negative reaction of others outside the home when they left with their child. One mother describes:

You know, you spend a lot of your life trapped. . . . We didn’t go out or associate with a lot people. . . . Just ‘cause I have to have my eye on them at all times, so it’s hard to go do stuff, you know?

Four American mothers mentioned difficulties in observing and tracking their child’s development and well-being, citing a *lack of “comparison children”* in their lives to give real-life examples of typical development. An example from one mother:

And I didn’t particularly notice anything, because he was, like, my first child. But my family members would say, “Oh, he’s really different. Is everything okay with him?”

This theme did not occur among the Senegalese, who were all exposed to typically developing children of the family and community on a daily basis.

### *Social relationships: Spousal tension*

In both country groups, *negative reactions of the spouse* to a child’s diagnosis of autism manifested in two forms: (1) rejection/denial of the diagnosis of the child and (2) extreme negative emotional reaction. Most American mothers responded to the father’s negative reaction with various strategies to promote acceptance and to contribute to the care of their child (strategies unmentioned by the Senegalese). From an American mother:

And I didn’t push him. ‘Cause at the end of the day, you can’t force someone to gain information or come to terms with something. . . . So I just kind of let him come to terms with it on his own time. In his own way.

It is unclear why these husbands’ reactions to a diagnosis in their child differed from the reactions of their spouses.

Four Senegalese caregivers, all of them mothers, reported their own decision to *restrict the services the child was receiving* by pulling the child out of school or dismissing home tutors. Even though this decision was spoken of as unwanted by other family members during interviews, none of the children were re-enrolled into services. An illustrative example:

Social worker: She stopped school.

Father: Because her mother did not want to bring her. That's why she stopped school. Because she had to be there at 7 in the morning. At 6 in the morning her mother had to bring her to school and come back. She stopped doing that.

Interviewer: Why did she stop?

Father: She had time, it was just... [shrugs].

Interviewer: Did [the daughter] like that school, when she was there?

Neighbor: Yes. She insisted on going to school.

Father: On going to school. But it was her mother... It was the mother who didn't want to bring her.

Among the Americans, two mothers (2 out of 7) indicated that they regularly encountered resistance from their husbands when they attempted to enroll their children in services and activities.

### ***Social relationships: Social tension outside the home***

Interestingly, this theme was only reported within the U.S. sample and affected all seven parents, albeit posing questions regarding tension outside the home were posed to each group. *Negative social interactions* included parent blame, ostracization, discrimination, vocal prejudice, and finding other people staring at the child. Each American parent had their own unique stories to contribute in this vein. One mother reported discrimination from her neighbors:

And when [the neighbors] figured out what was going on, somehow they treated me differently. Like, I'm ostracized because my kids have special needs. Like it somehow rubbed onto me.

Some American parents reported *encountering ignorance* regarding what one can expect from a child affected by autism, sometimes from strangers, but occasionally from extended family members, a common cause of familial tension:

Yeah, that's one of the many reasons we don't do a lot of family things anymore. Because people don't understand... If the kids ignore them completely, they [the family] get upset by that. They think it's like, my fault... People just don't understand, and you can't make them understand.

The absence of this overall theme occurring among the Senegalese sample was striking. When asked how those outside the home reacted to the affected child, reassurances were made by statements such as "everyone understands," "everybody is with her," and "they are all on his side." However, during informal discussions outside of study interviews, mentions of stigma and

parent blame were present, particularly on the part of spiritual leaders.

### ***Social relationships: Sources of social support***

*The family* was found to be a source of support for the majority of both groups. Support from family members came mostly in the form of emotional support, and practical support through child rearing and care.

For the U.S. group, support from *friends* served the same functions as support from the family. For the Senegalese sample, mentions of specific friendships were rare (1 out of 7). In all other instances, the role of "friend" effectively blended with the role of "community member" or "neighbor."

Support from *the community* differed greatly between the U.S. group and the Senegalese group. Within the Senegalese group, community support was communicated as the general acceptance of the child by everyone in the neighborhood. Interviews included multiple mentions of the child entering neighbors' homes to visit, sometimes in the absence of the parents, and playing in the streets with other neighborhood children, often informally supervised by other adults who happened to be on the street at the time:

Interviewer: So she goes out into the neighborhood alone?

Translator: Yes.

Interviewer: That's not dangerous for her?

Neighbor: No.

Translator: She goes to the neighbors' and things like that. Because [?] to go out into the neighborhood, everyone knows her.

Neighbor: And she knows everybody... [And] everybody knows her... She eats in their homes.

Father: In the night, when I come to the bedroom, I don't find her. I look, I don't see her. Then 10 o'clock, 11 o'clock at night, [gestures towards the bed].

Interviewer: She's there in the bed.

Father: Mm-hmm.

A Senegalese grandmother mentioned that neighbors would discreetly drop off nonperishables at the house, as they knew that the family was struggling financially. This communal practice of regularly giving food to neighbors, especially those in need (often dropped off in the middle of the night) is routine in Senegal.

Among the American sample, most support included pre-organized parent support groups in the area, announced via internet postings, whose reception among interviewees was lukewarm. Many mothers (4 out of 7) did not have the time or liberty to leave their children to attend, citing a lack of childcare within



their nuclear families. One mother cited redundancy in meeting proceedings (“It’s always the same thing”), but others found fulfillment in participating online:

You know, if somebody’s going through the same thing as you, you’re not feeling as lonely . . . That’s why the internet’s so great! To be able to talk to other moms who are the same. Yet you relax in your own house, you don’t gotta worry about [being] in 20 different directions.

### *Introspection: Role as caregiver*

While most parents in the total sample worked very hard to provide services for their children, the concept of assuming the *role of provider* (of services) was described almost exclusively by Americans (5 out of 7), except for the only Senegalese mother who had access to multiple services. One American mother described her outlook:

No one chooses this. But it’s what you have. So once you get everything in place for your child, feel free to have a nervous breakdown. You’re not entitled to have one until everything is in place for your child.

Similarly, the *role of advocate* for the child was present only in the American sample during the search for services (see the theme “asserting control”) and in the face of negative reactions to their child from those outside the home; both these elements were absent among the Senegalese. As one American advised: “Be stubborn. Fight for your child. ‘Cause no one else will.”

The *role of caregiver* was reported in both country groups and was often an all-consuming role. An American mother mentioned this issue after discussing her husband’s initial rejection of the child’s diagnosis: “I still feel like I’m doing all the work, which sort of has to be fine. I’m a stay-at-home parent, so.” Here, we can see her attempt to conciliate her frustration with her own accepted parental role. Among the Senegalese, the all-consuming role was also a common theme. As one mother shared:

Since all that, since I came to know he was autistic, I don’t do anything [outside of caring for him]. In him, there is only work. I take him to school, I bring him back. Every day.

Within their parenting practices, 3 out of 7 of both country groups (a non-majority trend) mentioned taking on the *role of a teacher*. Among the Senegalese, a father describes the advice given by a hospital staff member:

When her mother starts to prepare a meal she says, “[Child name], bring me that plate.” She takes it, she brings it over. . . . It was the doctor who said she should do a little work in the house, little by little. After time, she will learn. It comes [slowly].

### *Introspection: Visions of the future*

Examples of “success” differed widely among the American parents, yet 6 out of 7 of the sample spoke of some form of *career or educational success* for their children, such as college plans or work placements. Possible career paths were mentioned for multiple children, all of which stemmed from the child’s own expressed interests. One mother used a model of success from another child to dissuade her husband’s upset by the autism diagnosis:

But that same nephew . . . His robotics [team] won the national first place title, and their organization – He’s 16. . . . My husband would adopt him in a heartbeat. So I keep trying to say, [our son] has this too and probably to a similar degree. . . . So I’ve tried to point out the positives.

Another mother stated her firmness regarding her son’s education:

And I don’t think I ever wanted to make him be something he wasn’t. I said, “He’s going to college. He’s a smart kid, and he’s going to college.” That’s the only thing I’ve ever held fast.

The theme of “success” was not found in the interviews with Senegalese parents. All Senegalese parents cited high language delay (compared to 2 out of 7 of the Americans), a factor which most likely played an important role in parents’ outlook on their child’s prospects.

Among Americans, parental concern for the child’s *future living situation* emerged. In 4 out of 7 parents, visions of the child living independently from their parents and families came to light, which is in accordance with cultural expectations for typically developing children. The fact that living independently would be challenging, if not impossible, was upsetting for most Americans around the time of diagnosis. American parents of older children, however, seemed to have accepted that a living situation for the child would need to be arranged in order to prepare for the parents’ eventual passing away. An example from a mother of a teenager:

But now, the good thing is, there is an autism housing project that's new. They just built it. There's support staff there, and they kind of help you, but you have to be – there's an income requirement, you know. And I'm sure there's a waiting list. But the fact that it exists is great.

Among the Senegalese, expectations of living situations did not arise. Instead, several reported a deep concern for the living conditions of other children with disabilities in their low-income community. It is not unknown for disabled children to become abandoned in the streets, as some families do not have the means to care for them or control their behaviors, which can include running away. As one mother described:

There are many autistic children here. There are many. Some of them, their parents don't have the means. The children are in the street. It hurts [to see that]. . . . The parents, they love their children, and their hope has fallen, because an autistic child can do nothing [for themselves]. We very much need to help them.

## Discussion

This study comparing the lived experiences of American and Senegalese parents of children with autism with a focus on events surrounding diagnosis, social support, daily life, and introspection identified important social and cultural differences. Differences began at the outset of the parents' diagnostic journey. While seeking support, the U.S. group reported frequent individual research using books and online searches. These resources were unfortunately limited among the Senegalese. Most Americans reported a drawn-out diagnostic journey through multiple professionals before being referred to a specialist trained in diagnosing ASD. The Senegalese participants experienced a similarly winding journey, which often passed through the consults of local marabouts, receiving spiritual diagnoses and advice first, before eventually rejecting these interpretations and self-referring to the local hospital. Some families initially expressed fear of brain tumors and requested a "scan" before being referred to the psychiatric ward. Any community and religious repercussions for the rejection of the local belief system were not mentioned.

The prioritization of traditional care when treating mental health problems has been found to be prevalent in much of Sub-Saharan Africa, including West Africa (e.g., Ali & Agyapong, 2016; Jack-Ide & Uys, 2013). In line with past research in Senegal (Ames, 1959; Collomb et al., 1973; Zemleni & Rabain, 1965), all spiritual interpretations of ASD-like symptoms within

this study consisted of involuntary spiritual possession. This is contradictory to past field research within Sub-Saharan Africa, where witchcraft is often perceived as causal, and where blame can be dangerous for those accused (e.g. Aidoo & Harpham, 2001; Ikwuka, Galbraith, & Nyatanga, 2014; Ventevogel, Jordans, Reis, & de Jong, 2013). Senegal's historic blame-free pattern is in line with a noticeable lack of any mention of stigma within this study's interviews. Though mental health stigma exists all over the globe, Senegal being no exception (Drame & Kamphoff, 2014), a comparative reduction within Senegalese culture can be hypothesized, perhaps due to significant community support, culturally-bound norms of tolerance and solidarity, and spiritual interpretations.

All the U.S. children were enrolled in multiple services, whereas none of the Senegalese children were enrolled in services or school; however, many parents reported past participation in special education schools. Withdrawing their children from school was explained by several factors, including lack of funds. The discrepancy in available services between the two groups is hypothesized to have had a great effect on the emerging themes of this study, affecting parents' daily experiences, outlook, and reflections on their own parental role. Entrenched in their mental healthcare infrastructure, the Americans were obligated to navigate a time-consuming system of insurance coverage, scheduling, and waitlists, which may have influenced a sense of personal control that was apparent among this group, including a deep and singular responsibility over the treatment and future of their children. Parents often took on the roles of service provider and public advocate for their child, bringing topics of future education and success to the forefront of the interview. At the point of diagnosis, some parents expressed positive emotions such as relief, as receiving a diagnosis of ASD was perceived as a way of moving forward towards professional care. Unequivocal diagnosis in the US, accompanied by a DSM code, often allows for access to and funding for services that would otherwise be unattainable.

In Senegal, experiences post-diagnosis did not follow the path as described by parents in the US. Due to a lack of services, most Senegalese parents were obliged to provide education for their child in their own home, often in the form of homeschooling or by hiring a private tutor. Access to the internet, books, and toys was rare. Some families accepted treatments from traditional, non-religious healers. Emotional reactions to the diagnosis were mentioned rarely, but were exclusively negative, while religious sentiments about acceptance were occasionally expressed, including relinquishing control to a higher power. From a personal standpoint, the Senegalese

parents seemed to view themselves first and foremost as caregivers within the home and, for those who worked, as economic providers.

Differences in family and community structure may have also affected thematic differences between the U.S. and Senegalese participant groups. In terms of raising a child with autism, the Senegalese norm of living in extended family homes within tight-knit and highly social communities may have protected against the recurring issue of lack of support among American parents. The latter overwhelmingly reported social isolation and loneliness, a lack of exposure to other children, family contentions regarding parenting expectations, and concerns about future housing in the absence of a “safety net” (see Rudy, 2017), which represent parental concerns that went largely unmentioned by the Senegalese families. Social isolation and a lack of social support have been previously reported in North American parent experience studies (e.g., Altieri & von Kluge, 2009; Woodgate, Ateah, & Secco, 2008).

American feelings of loneliness may be compounded by several cultural norms found within individualistic societies (Lykes & Kemmelmeier, 2013), such as small, nuclear households (U.S. Census Bureau, 2012), less frequent family interaction (via looser family obligations) (Fuligni, Tseng, & Lam, 1999; Hofstede, 1980), a preference for scheduled and structured social visits that can limit social opportunities, and an increasingly infrequent interaction with the surrounding neighborhood (A. Smith, 2010; T. W. Smith, Davern, Freese, & Hout, 2018). The daily realities of study participants also included limiting, highly scheduled daily lives and a “scattered community” of distant friends and family. Several participants mentioned extreme lifestyle changes due to a lack of childcare, such as financial and career sacrifices, intensive over-scheduling, and further social isolation (see Cidav, Marcus, & Mandell, 2012; Houser, McCarthy, Lawer, & Mandell, 2014). As a coping strategy, several parents (4 out of 7) reported joining parent support groups, with mixed results. Citing transportation and childcare issues, all parents eventually stopped attending the groups, with one mother continuing participation online.

Within the traditional Senegalese home, which can be polygamous and include several families, the permanent presence of many family members, accompanied by frequent, often unannounced daily visits by neighbors, friends, and extended family creates a natural environment of frequent social interaction. This environment is bolstered by a sociocultural framework of “togetherness” and support for others (as illustrated by the commonly-used phrases *nio far* and *on est ensemble*, in Wolof and French meaning “we’re all together”). These factors, combined with a strong collectivist notion of family obligations, may not only protect

against social isolation and loneliness but may also give ample opportunities for child care, elder and disability care, consistent exposure to other children for comparison, and clear expectations regarding parenting. Research among parents of children with autism in collectivistic cultures shows positive associations between higher levels of family support and a lower number of depression symptoms (Singh, Ghosh, & Nandi, 2017) as well as a greater ability to enjoy life (Al-Kandari et al., 2017).

Thanks to the provision of collective childcare within the Senegalese sample, it was clear that parents were often free to dictate their own daily activities and leave the home when needed, which often rendered their daily schedule highly different from the schedule of their affected child. Among the U.S. mothers, who were often the child’s only caregiver outside the spouse’s support, nearly all parents’ daily routines entirely coincided with the routines and needs of their affected child(ren), as described in other parent experience studies on Americans (Hutton & Caron, 2005; Lutz, Patterson, & Klein, 2012). Although spousal or family tension stemming from raising a child with ASD was present in both country groups, the Senegalese group reported a surprising lack of negative social tension outside the home, which is in stark contrast to previous autism research within Sub-Saharan Africa (de Vries, 2016; Abubakar, Ssewanyana, de Vries, & Newton, 2016). All Americans, by contrast, reported negative reactions from the public and social tension outside the home, including parent blame, ostracization, discrimination, and rudeness. This discrepancy may be due to the widely acknowledged Senegalese cultural norms of keeping the peace and promoting “togetherness” within communities.

## Limitations

Limitations of this study include small sample sizes and a geographically limited Senegalese sample. However, IPA analysis does not necessarily aim for generalizability of findings and instead emphasizes rich and detailed analysis of specific experiences (J. A. Smith et al., 2009). Additionally, the interview process was constrained within the Senegalese home setting, as complete privacy within this setting was often unavailable. This contributed to the unfortunate shortening of the Senegalese interviews. It may have also impacted on rapport and disclosure especially of negative emotions or experiences. More locally informed and indigenously guided cultural research would likely have identified additional relevant themes. Simple cultural immersion of the foreign researcher, praised as an “anti-colonial” measure to maximize understanding of the local environment and its

relationships (Adams, 2014), may not be sufficient to accurately represent and analyze intercultural findings. This method additionally continues to block self-representation in international research by the under-represented populations studied. Future research should include collaboration and participation from Senegalese stakeholders, including co-authorship (Adair, 2009).

## Conclusion

This study identified cultural and contextual variables that may affect parental experience of caring for a child with autism in Senegal and the US. This research has implications for those working with families affected by ASD in Senegal, as well as for future cultural research. Given the finding that the majority of Senegalese participants first sought treatment from local spiritual or traditional healers, there is a need for sensitive and empathetic communication with Senegalese families within clinical practice regarding these topics. Further, there is a need for collaboration with spiritual leaders on the care of families of children with ASD. Withdrawal from spiritual care is not advocated and may prove damaging to those who feel supported by those systems. Additional research also is needed on family and community causal and conceptual beliefs of ASD in Senegal.

The findings also suggested that social support among the Americans may be weak compared to the Senegalese, indicating a need in the United States to address this issue. Though no instances of negative stigma were reported among the Senegalese, future research in this area is needed. Among the urban Senegalese, recent economic and infrastructure developments are bringing about new, individualistic lifestyle habits, including apartment-style living arrangements (Macia, Duboz, Montepare, & Gueye, 2012; Werner, 2008). Fall et al. (2014) argue that this confined living space excludes the extended family, which challenges the authority of elders and can increase familial conflict, reduce in-family support, and augments parental stress. Finally, although internal support within the family and community was strong among the Senegalese, this study revealed a strong need for external services for those affected by ASD in Senegal and their families, such as therapy. While diagnostic assessments are available within Dakar and nearby areas, professional training is minimal and specialized services are rare to non-existent. Research on best practices in Senegal is warranted for treatment of ASD, with a particular focus on community-based and family-delivered care.

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## Supplemental material

Supplemental material for this article is available online.

## ORCID iD

Adair Cardon  <https://orcid.org/0000-0002-7036-2707>

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**Adair Cardon**, M.S., BCBA, is the Director and founder of ABA Senegal. She studied psychology at the University of Washington, Seattle, and earned her master's degree in cross-cultural psychology at Brunel University in London. Her interests include cultural factors affecting treatment delivery and outcomes for children with autism in West Africa. She is currently based in Dakar, Senegal.

**Tara Marshall**, PhD, is the Director of Social Psychology and a professor in the Department of Health, Aging & Society at McMaster University. Previously, she was a Senior Lecturer in the Centre for Culture and Evolution at Brunel University London. Dr. Marshall's research explores the influence of close relationships—their formation, maintenance, and termination—on mental health and well-being, and the ways this influence varies across cultures. Another strand of research examines attachment security and relationship quality as predictors of immigrant couples' acculturative adjustment. She also researches the personality predictors and mental health outcomes of social media use.